



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

Study of Health Outcomes in Children with Autism and Their Families

Task C: Health Care Utilization and Costs

Final Report - Executive Summary

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Executive Summary

Introduction and Study Objectives

The National Institute of Mental Health (NIMH) contracted with The Lewin Group to conduct a two-year study from September 2010 to September 2012 entitled “The Study of Health Outcomes in Children with Autism and their Families.” This study seeks to address a significant gap in the empirical knowledge base about the trajectories of health conditions and utilization of health care services among children with autism spectrum disorders (ASD), their siblings, and their parents. The ability to study a very large and heterogeneous group of children with ASD using claims data and the ability to link to information about family members is unprecedented and holds promise to advance clinical and health services knowledge about ASD substantially.

The objective of Task C was to describe the use of health care services by children with ASD and their families and compare their use to children without ASD and their families. To meet this overarching objective, Task C was designed to have two components. This study first examined the use and costs of a broad set of health care services and then addressed two areas of particular interest in the literature and to NIMH and our External Advisory Committee (EAC) – psychotropic polypharmacy and adherence to MMR vaccination.

The goals of the psychotropic polypharmacy and MMR vaccination analyses were to:

- Measure the prevalence and extent of polypharmacy among children with ASD;
- Determine the individual and provider characteristics related to psychotropic medication use and psychotropic polypharmacy among children with ASD;
- Compare the rates of MMR vaccination among children with ASD and their siblings relative to children without ASD and their siblings;
- Compare the rates of MMR vaccination among children with ASD vs. children without ASD and ASD younger siblings vs. comparison younger siblings; and
- Determine if there was a difference in MMR vaccination rates between children with ASD and their younger siblings and between children without ASD and their younger siblings.

Study Design and Analytic Strategy

This retrospective claims data study used medical data, pharmacy data, and enrollment information from the OptumInsight research database containing claims from the large health plan affiliated with OptumInsight. Claims data for the period 01 January 2001 to 31 December 2009 were linked to a consumer database for select socioeconomic information. All study subjects were identified among commercial enrollees who have medical, pharmacy, and behavioral health coverage. Six main samples were selected: children with ASD, a comparison group of children without ASD, parents of children with and without ASD, and siblings of children with and without ASD.

Based on the results of the Task A: Chart Study, children with at least 2 ASD claims were defined as having ASD and were included in the Task C study. In the Chart Study, the positive predictive value increased from 74.2% to 87.4% when children with only 1 ASD claim were excluded from

the case definition, increasing our confidence that the children with ASD in Task C are true cases. However, exclusion of children with only 1 ASD claim from both the case and comparison groups likely increases the differences between children with ASD and their family members when compared to controls.

To address the research questions concerning the use and costs of health care services by children with ASD and their family members relative to children without ASD and their family members, descriptive techniques that account for length of enrollment time were used; annualized health care visits, counts of medications and medication dispensings and per member per month (PMPM) health care costs were calculated. Additionally, for the binary variable indicating whether a study subject had evidence of psychotropic medication use, we utilized logistic regression to produce enrollment-adjusted proportions and odds ratios. The odds of having a psychotropic medication fill for each medication class of interest at any point during enrollment were estimated. All results are stratified by case sample (children with ASD, parents of children with ASD, and siblings of children with ASD) and the respective comparison group. Further, select results were produced for each sample by gender and age groups at index date (See Appendix C).

Psychotropic Polypharmacy

The analytic approach to measuring psychotropic polypharmacy included a clear definition of polypharmacy and appropriate modeling techniques. Measures of psychotropic polypharmacy variables were determined for children with ASD based on pharmacy claims for prescriptions filled during the child's total enrollment time during the study. An episode of single-class psychotropic polypharmacy was defined as overlapping fills of two or more psychotropic medications within the same class for at least 30 days. Two definitions were created – one that captured episodes of *specific* within-class medication combinations lasting 30 days or more and a broader definition that captured episodes of *any* within-class combination(s) lasting 30 days or more. An episode of multi-class psychotropic polypharmacy was defined as overlapping fills of medications across two or more classes for at least 30 days. As with single-class polypharmacy, two definitions were created – one that captured episodes of *specific* class combinations lasting 30 days or more and an overall definition that captured episodes of *any* multi-class combination(s) lasting 30 days or more. In measuring multi-class polypharmacy, no single medication within a class needed to overlap by 30 days with a particular medication in another class. We were only interested in unique combinations of *classes* of at least 30 days.

Descriptive analyses were conducted to examine the prevalence and extent of psychotropic polypharmacy among children with ASD and summarize the characteristics of their psychotropic polypharmacy episodes. To determine the individual and provider characteristics related to psychotropic use and psychotropic polypharmacy, four multivariate models were run based on the sample of children with ASD. In the first two analyses, binary measures of any psychotropic use and any combination-specific multi-class polypharmacy, respectively, were modeled using a logistic regression model. The third model, a multinomial logistic regression, modeled psychotropic use and combination-specific multi-class polypharmacy. The dependent variable for this model categorized children with ASD into five mutually-exclusive groups: 0) no psychotropic use, 1) at least one psychotropic medication without multi-class polypharmacy, 2) multi-class polypharmacy with a maximum of 2 classes, 3) multi-class polypharmacy with a maximum of 3 classes, and 4) multi-class polypharmacy with a maximum of 4 or more classes.

Finally, a generalized linear model with gamma distribution and log link was used to model length of polypharmacy among the subset of children with ASD with evidence of combination-specific multi-class polypharmacy.

Adherence to MMR Vaccination

Adherence to recommended MMR vaccinations was determined for children with and without ASD and their siblings. Specifically, whether or not a child had a claim for MMR between the ages of 12 and 24 months and between the ages of 4 and 6 years was determined.

To compare how children with ASD and their siblings compare to children without ASD and their siblings in terms of recommended MMR vaccination, the proportion of children with evidence of MMR vaccination between the age periods of 12 and 24 months and 4 and 6 years was calculated. To compare whether having a child with ASD is related to adherence to recommended MMR vaccinations among younger siblings, logistic regression analyses modeling vaccination were conducted, one model for the period of 12 to 24 months of age and another for the period of 4 to 6 years of age. The analyses were based on a matched pair sample, including children with and without ASD with enrollment during the entire age period who also had a *younger* sibling with enrollment during the entire same age period. Comparisons examined within the models were children with ASD vs. children without ASD and ASD younger siblings vs. comparison younger siblings. We also tested whether there was a difference between children with ASD and their younger siblings and between children without ASD and their younger siblings.

Results

We found the following results about health care utilization and costs, psychotropic polypharmacy, and adherence to recommended MMR vaccinations:

- Overall, children with ASD had higher utilization than children without ASD. Children with ASD had more inpatient and emergency department visits, total office visits, total outpatient facility visits, behavioral health care visits, preventive care visits, ancillary therapy visits, and medication dispensings than children without ASD. In addition, children with ASD were more likely to have psychotropic medication fills.
- Similarly, with the exception of parent use of inpatient services, family members of children with ASD had higher health care utilization than their comparison groups. For example, parents of children with ASD had a median of 6.2 ambulatory visits per year, compared to 4.5 for comparison parents. Siblings of children with ASD had a median of 4.6 total ambulatory visits per year, compared to 3.0 for comparison siblings. The median number of medication dispensings was 6.3 and 4.0 for ASD and comparison parents respectively, and 2.2 and 1.4 for and ASD and comparison siblings, respectively.
- Greater utilization of health care services translated into higher health care costs for children with ASD as well as for their family members. For example, median monthly costs for children with ASD exceeded those for children without ASD for total medical care (\$202.28 vs. \$39.53), behavioral health care (\$72.26 vs. \$0.00), and medications (\$46.22 vs. \$3.86).
- Just under 40% of all children with ASD had either single-class or multi-class polypharmacy. Approximately 20% of the 33,565 children with ASD had evidence of

single-class polypharmacy, and 35% of the sample had evidence of multi-class polypharmacy. The most common type of single-class polypharmacy was among ADD medications (11.6%).

- The mean number of multi-class episodes per child was 5.6, totaling a median of approximately 346 days of polypharmacy. Approximately 38% of the children with multiclass polypharmacy had at least one episode involving an antidepressant and ADD medication, and just over a quarter had at least one episode with an antipsychotic and ADD medication. About 20% of the children with multi-class polypharmacy had at least one episode with an antipsychotic and antidepressant or an antipsychotic, antidepressant and ADD medication.
- Our results suggest that seizures, ADD, bipolar disorder, and anxiety are all significant predictors of psychotropic use and, along with depression, of multi-class polypharmacy among children with ASD. Furthermore, children with ASD who also had seizures, ADD, or bipolar disorder had the highest odds of more complicated multi-class polypharmacy (as measured by a higher number of medication classes involved). Additionally, among children with multi-class polypharmacy, these three conditions were associated with a 15%-30% longer duration on polypharmacy.
- Older age at index and having had a psychiatrist visit were consistently related to higher odds across all psychotropic medication use outcomes (psychotropic use, polypharmacy and polypharmacy use involving many classes of medications) relative to no psychotropic use. Additionally, among children with multi-class polypharmacy, older age at index and having had a psychiatrist visit were associated with longer duration on polypharmacy.
- After controlling for demographic characteristics and the presence of allergies or seizures, we found that children with ASD were just as likely as comparison children to be vaccinated with MMR between the ages of 12 and 24 months and between the ages of 4 and 6 years. In contrast, younger siblings of children with ASD were less likely to have received the MMR vaccination than younger siblings of comparison children during both age periods. Most importantly, we found that between 12 and 24 months of age, while younger siblings of the comparison sample did not differ from their older sibling without ASD, younger siblings of children with ASD were less likely to be vaccinated than the child with ASD. Our interpretation of this finding is that in spite of an increase in the rate of vaccination over time, parents of children with ASD may continue to harbor some apprehension about a potential causal link between the MMR vaccine and ASD and, as a result, fewer younger siblings of children with ASD were vaccinated.

Implications and Recommendations

In summary, we found that children with ASD and their families used more health care services than children without ASD and their families. Our psychotropic polypharmacy analysis found that 40% of children with ASD had psychotropic polypharmacy and the presence of co-occurring conditions was associated with more complicated psychotropic polypharmacy use. We also found that younger siblings of children with ASD were less likely to have received the MMR

vaccination than their older sibling with ASD between 12 and 24 months of age. Specifically, our results lead to the following implications:

- Considering the morbidity of ASD itself and the high rates of co-occurring conditions, it is somewhat reassuring to see that these children are making use of health care services substantially more than comparison children without ASD. Still unanswered, however, are questions regarding whether they are receiving appropriate or enough care for ASD and co-occurring conditions as well child care that all children should receive.
- Our findings demonstrate that the medical use and cost patterns of the entire family may be influenced by having a child with ASD. Supportive interventions for the family as a whole rather than each individual separately are therefore necessary in order to improve the health care experience and quality of life of children with ASD and their families.
- When comparing our psychotropic medication use results to results in the literature for children with ASD covered by Medicaid, our results suggest more unity than discord. Both populations have a prevalent use of psychotropic medications, a high rate of polypharmacy, and age, race, and co-occurring conditions are all statistically significant on psychotropic use.
- The high use of concomitant pharmacotherapy with powerful psychotropic medications merits concern and further investigation about the safety and effectiveness of such practices on developing children. Our estimates of the prevalence of polypharmacy among children with ASD emphasize the need for additional evidence on the appropriateness, effectiveness and safety of psychotropic medications in this population. Moreover, further research into the sociodemographic and geographic variation in the practice of polypharmacy and whether the variation is driven by clinical need or other factors may provide a better understanding of differences in treatment patterns across the country.
- Our finding that younger siblings of children with ASD are less likely to have received the MMR vaccination than the child with ASD, underscores the need for continued public education on the topic of vaccination safety, especially among families caring for children with ASD.

Because we have the ability to include a large and heterogeneous group of children with ASD and to compare to children and families without ASD, our estimates may be more precise and objective than previously available. Our findings on general utilization are in line with previous studies but are based on a larger and likely more heterogeneous population of privately insured children with ASD with great ability to conduct in-depth analysis of important variables and subgroups in the future. Our analyses of polypharmacy and MMR vaccinations provide new insights about challenges in care for children with ASD and their siblings.