

Examining Trends and Coexisting Conditions Among Children Qualifying for SSI Under ADHD, ASD, and ID

Christian D. Pulcini, MD, MEd, MPH; James M. Perrin, MD; Amy J. Houtrow, MD, PhD; John Sargent, MD; Amy Shui, MA; Karen Kuhlthau, PhD

From the Children's Hospital of Pittsburgh of UPMC, Pittsburgh, Pa (Dr Pulcini and Dr Houtrow); Department of Pediatrics, MassGeneral Hospital for Children, Harvard Medical School, Boston, Mass (Dr Perrin, Ms Shui, and Dr Kuhlthau); Tufts Medical Center, Boston, Mass (Dr Sargent); Departments of Physical Medicine and Pediatrics, University of Pittsburgh, Pittsburgh, PA (Dr Houtrow); Department of Pediatrics, Children's Hospital of Pittsburgh of UPMC, Pittsburgh, PA (Dr Pulcini); and Departments of Pediatrics and Psychiatry, Tufts Floating Hospital for Children, Tufts University School of Medicine, Boston, MA (Dr Sargent)

The authors declare that they have no conflict of interest.

Address correspondence to Christian D. Pulcini, MD, MEd, MPH, Children's Hospital of Pittsburgh of UPMC, 4401 Penn Ave, Pittsburgh, PA 15224 (e-mail: Christian.pulcini@chp.edu).

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ABSTRACT

OBJECTIVE: To examine the prevalence trends and coexisting conditions in attention-deficit/hyperactivity disorder (ADHD), autism spectrum disorder (ASD), and intellectual disability (ID) in the pediatric Supplemental Security Income (SSI) population and general population.

METHODS: The Social Security Administration (SSA) provided data on primary and secondary diagnoses of children qualifying for SSI for years 2000 to 2011. We compared SSA data with 2000–2011 National Health Interview Survey data on the prevalence of mental health diagnoses among children in the general population living between 0 and 199% of the federal poverty line. We utilized linear regression analysis to test the statistical significance of differences in the trends of the conditions' prevalence.

RESULTS: Over this time period, the SSI population experienced increases in ADHD (5.8%) and ASD (7.2%) and a decrease in ID (–10.3%). Comparison with change in the general population indicated no significant difference in ADHD but significant differ-

ences in ASD and ID. Relative percentage changes reflect similar changes. The SSI population qualifying for SSI with ADHD (70.8%) had higher rates of coexisting conditions than the general population (66.1%), but lower rates of coexisting conditions for ASD and ID.

CONCLUSIONS: ADHD is on the rise among children receiving SSI and in the general population. This suggests that the rise of ADHD in the SSI population is expected and does not represent a misallocation of resources. Changes described among the SSI population in ASD and ID may allude to diagnostic/coding trends and/or true changes in prevalence. Limitations arise from the comparability of the 2 data sets.

KEYWORDS: ADHD; autism; children; coexisting condition; disability; intellectual disability; mental health impairments; SSI

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WHAT'S NEW

Increases in the Supplemental Security Income (SSI) attention-deficit/hyperactivity disorder population paralleled those in the general population, while autism spectrum disorder increased and intellectual disability decreased in SSI relative to the general population. Shifts in diagnosis, coding, and coexisting conditions may help explain these differences.

THE SUPPLEMENTAL SECURITY Income (SSI) program provides cash and insurance benefits to 1.27 million financially needy children and adolescents who are disabled.¹ When applying for SSI, children undergo a disability determination process that identifies the primary diagnosis that qualifies them for SSI benefits, and at times a secondary code indicating comorbidity is added. In 2011 67.5% of the children who received SSI benefits had a

mental health impairment listed as their primary diagnosis, with attention-deficit/hyperactivity disorder (ADHD) (25.5%), speech and language delays (22.2%), intellectual disability (ID) (15.4%), and autism spectrum disorder (ASD) (12.4%) the largest reported diagnostic categories within the mental health impairment listings.^{2,3} The average monthly cash benefit for children with SSI in 2011 was \$592 for a total annual SSI cash benefit expenditure of approximately \$9 billion.³

There has been extensive political and media scrutiny of federal benefit programs, including children's SSI.⁴ Lawmakers (among others) are specifically concerned with the increase in the number of children and adolescents with a mental health impairment qualifying for SSI benefits. A Government Accountability Office (GAO) study which evaluated the claim that a general increase in serious chronic health conditions and a rise in poverty among children can be used to explain the increase in the number of

children qualifying for SSI due to a mental health impairment concluded “the relative effects of these and other factors on program growth are not fully known at this time.”⁵ To our knowledge, no studies have examined whether prevalence trends for the SSI population mirrors those for the general population and thus may help explain changes in the SSI population.

The GAO reports noted that 37 out of 50 cases who qualified under the ADHD mental impairment category had a secondary diagnosis that may have contributed to their qualification for SSI funds. The GAO reports did not include coexisting conditions for other mental health impairment categories, most notably ASD and ID. Debate on whether ADHD itself creates substantial disability has persisted over 20 years,⁶ although many speculate that most SSI recipients with ADHD have substantial comorbidity that accounts for much of the disability. No research other than the aforementioned GAO study to our knowledge has evaluated the claim that children qualifying for SSI under mental health impairments, specifically ADHD, ASD, and ID, have multiple coexisting conditions which either in sum or individually qualify them to receive SSI funds.

In this study, we examined whether the mental health SSI prevalence trends are consistent with those of the general population, and furthermore whether trends in coexisting conditions for SSI children with ADHD, ASD, and ID are similar to those in the general population. Although speech and language impairments are one of the most prevalent conditions among children qualifying for SSI under the mental health impairment designation, we will not explore them because no accurate comparison group in the general population is available.

METHODS

We utilized data from the Social Security Administration (SSA) and National Health Interview Survey (NHIS) to explore the trends of primary conditions among children in the SSI population and general population for ADHD, ASD, and ID (from 0 to 199% of the federal poverty level [FPL]); and coexisting conditions also for these populations.

SSI DATA

To evaluate trends in the prevalence and comorbidity among children enrolled in SSI, we used data provided directly by SSA to examine children aged 1 to 18 years for the selected primary condition prevalence and coexisting conditions on the SSI rolls from 2000 to 2011. The data include children ages 1 to 18 years who were awarded SSI for the listed condition in the given year (ie, new enrollees).

SSI disability determination staff record a primary and secondary condition (and no conditions beyond 2) regardless of the number of coexisting conditions. The primary diagnosis is that which qualifies children for the SSI program. Although staff are encouraged to include any secondary diagnosis, they are not required to and have no incentives to do so. Thus, we expect that these data may un-

derestimate the true prevalence of coexisting conditions. We included all available secondary diagnoses, including those other than mental health impairments.

NATIONAL HEALTH INTERVIEW SURVEY

The NHIS is a nationally representative household interview survey that provides estimates of demographic characteristics, health status and health care use, and access for the civilian noninstitutionalized US population.⁷ The sampling plan is a multistage probability design, redesigned after every decennial census. Data are collected by household interview with parents typically serving as respondents for children.⁸ NHIS data specify income of respondents, and we limited respondents to those with incomes of 0 to 199% FPL as a proxy for financial eligibility for SSI. We used the NHIS “sample child” data to search for children ages 1 to 18 who have “ever been told” they had ADHD, ASD, or ID from 2000 to 2011.⁹ For children with these conditions, we determined whether they had an additional condition including all available secondary diagnoses, including ADHD, ASD, ID, developmental delay, down syndrome, cerebral palsy, muscular dystrophy, cystic fibrosis, sickle cell anemia, diabetes, heart disease, other heart condition, arthritis, asthma, seizures, blind/unable to see at all, learning disability, special equipment due to impairment/health problem, and a Mental Health Indicator (MHI) score of 00-08. The MHI has a score of 0 to 100, where a score of 100 represents optimal mental health and lower score indicates higher probability of mental health disease. A score of 00-08 is highly indicative of a mental health disorder (most commonly anxiety and/or depression).^{10,11} Children with ADHD, ASD, ID would not score 00-08 due to these conditions alone.

ANALYSIS

The project was institutional review board exempt because the study utilized data with no identifiers. Prevalence of ADHD, ASD, and ID were tabulated by year from 2000 to 2011 for the NHIS cohort and compared to those in the SSI cohort. We utilized linear regression analysis to compare the change in prevalence over time of these conditions in the 2 cohorts. A group by time interaction was included in each model to determine the significance of the difference in slopes. Comorbid conditions with each of the 3 primary conditions were also tabulated by year from 2000 to 2011 for the NHIS cohort and compared to those in the SSI cohort. Analyses were performed by SAS 9.4 (SAS Institute, Cary, NC).

RESULTS

Table 1 shows the percentages of SSI new enrollees in 2000 and 2011 with ADHD, ASD, and ID as compared to the SSI total number of new enrollees. It also displays data for ADHD, ASD, and ID for the NHIS in 2000 and 2011. For SSI, there were large increases in the percentages of children with ADHD (+5.8%), ASD (+7.2%), and a large decrease in ID (−10.3%) among the SSI population. The NHIS data in Table 1 indicate increases in the survey respondents who responded “Yes” to “ever been told” they have

Table 1. Rates and Growth of Selected Mental Health Impairments Among New-Enrollee SSI Recipients and NHIS Respondents, 2000–2011

Impairment	2000	2011	Absolute Change	Relative Change
SSI mental health impairment category*				
ADHD	11.1%	16.9%	5.8%	52%
ASD	3.2%	10.4%	7.2%	225%
ID	17.0%	6.7%	−10.3%	−61%
NHIS specified condition†				
ADHD	6.2%	8.2%	2.0%‡	32%
ASD	0.2%	1.0%	0.8%§	400%
ID	1.2%	1.5%	0.3%§	25%

SSI indicates Supplemental Security Income; NHIS, National Health Interview Survey; ADHD, attention-deficit/hyperactivity disorder; ASD, autism spectrum disorder; and ID, intellectual disability.

*Measure represents condition studied divided by total number of SSI recipients for a given year.

†Measure represents condition studied divided by total number of survey respondents from 0 to 199% of the federal poverty level.

‡ $P = .1511$.

§Statistically significant difference ($P < .0001$) compared to SSI.

ADHD (+2.0% points) and ASD (+0.8% points) from 2000 to 2011. There was a small increase in ID (+0.3% points) among the same population. There are statistically significant differences in the absolute percentage trends in these diagnoses for ASD and ID, as indicated in Table 1. Compared to the NHIS population, the SSI population's change in ASD prevalence over time is significantly more positive (difference in slopes = 0.59, $P < .0001$), and its change in ID prevalence over time of is significantly more negative (difference in slopes = −1.00, $P < .0001$). The change in ADHD absolute percentage trend over time does not differ significantly when comparing the 2 cohorts. When comparing relative percentage change, children on SSI with ASD increased at a considerably lower rate (225%) than the general population (400%) from 2000 to 2011. IDs decreased in the SSI population (−61%) while they increased in the general population (25%). Finally, the relative percentage of ADHD increased in both the SSI (52%) and the general population (32%), but at different rates.

Table 2 offers data on secondary conditions of those who qualified in the given year for SSI under the primary impairment categories of ADHD, ASD, and ID. The average percentage of children with a recorded secondary condition over the 12-year time period is 70.8% for ADHD, with a 1.6% point increase from 2000 to 2011. For those children with ASD as a primary impairment from 2000 to 2011, 43.5% had a reported secondary condition, with a 12.9% point increase from 2000 to 2011. In regards to the children with ID as a primary impairment, 56.0% had a secondary condition, with an 11.4% point increase from 2000 to 2011.

The NHIS survey data indicate that the average percentage of children with at least 1 coexisting condition from 2000 to 2011 is 66.1% for ADHD, with a 6.3% point decrease and range of 58.4% to 73.1%. For ASD, 92.1% of children had a reported coexisting condition, with a 16.2% point increase and range of 77.8% to 100% from 2000 to 2011. In regards to the children who indicated an ID from NHIS, 97.0% had a coexisting condition, with a 0.5% point overall decrease and range of 91.7% to 100% from 2000 to 2011.

The highest 3 documented coexisting conditions for those awarded SSI in 2011 for ADHD were oppositional/defiant

disorder (19.3%), affective mood disorders (10.3%), and speech and language delays (8.7%). For ASD, they were speech and language delays (20.4%), ADHD (11.7%), and ID (4.5%). For ID, they were speech and language disorders (17.1%), ADHD (16.6%), and ASD (6.3%).

DISCUSSION

We showed similar trends in ADHD between the SSI and general population, and significant differences between ASD and ID in regards to changes in prevalence among the SSI and general population. We also showed differences in comorbidity trends for ASD and ID from 2000 to 2011. Children receiving SSI for ADHD had higher rates of comorbid conditions, but lower rates for ASD and ID compared to children in the general population.

Table 2. Coexisting Conditions Among SSI New Enrollees and NHIS Survey Respondents With ADHD, ASD, and ID Aged 1 to 18 Years From 2000 to 2011

Condition	2000	2011	Change
SSI			
ADHD			
Total	15,975	34,039	18,064
Comorbidity	71.9%	73.5%	1.6%
ASD			
Total	4660	21,006	16,346
Comorbidity	38.2%	51.1%	12.9%
ID			
Total	24,466	13,501	−10,965
Comorbidity	52.6%	64.0%	11.4%
NHIS			
ADHD			
Total	224	392	168
Comorbidity	64.7%	58.4%	−6.3%
ASD			
Total	9	50	41
Comorbidity	77.8%	94.0%	16.2%
ID			
Total	48	76	28
Comorbidity	97.9%	97.4%	−0.5%

SSI indicates Supplemental Security Income; NHIS, National Health Interview Survey; ADHD, attention-deficit/hyperactivity disorder; ASD, autism spectrum disorder; and ID, intellectual disability.

Growth in the SSI population has been described extensively, and mainly reflects 1) new rules that defined and expanded eligible children's mental health conditions in 1990, 2) a Supreme Court decision (also in 1990) requiring systematic assessment of functioning and disability in childhood applicants,³ 3) a general rise in serious chronic health conditions among children and adolescents,¹² 4) limited number of continuing disability reviews by SSA in recent years (these allow the SSA to review the persistence or loss of disability in a child),¹³ and 5) an increase in child poverty.^{14,15}

Our data suggest that the rise of ADHD as a primary impairment qualifying children for SSI reflects secular trends in diagnosis of ADHD, as opposed to changes in the eligibility determination process of SSA. Recent research further supports this claim, which suggests an overall increase in ADHD in a similar time period, especially among those from economically disadvantaged backgrounds.¹⁶⁻¹⁹

In regards to ASD and ID, we speculate that the methodology used to code these disorders by SSI Disability Determination Offices may have changed from 2000 to 2011 for these conditions. In general, disability determination for these conditions is easier than for ADHD, with clear and specific requirements. This is further evidenced by the rate of recorded denials for these conditions, with ADHD being much higher than ASD and IDs.^{2,3} With the growth of ASD in general, it may have become easier to use this diagnosis for children who exhibit both ID and autistic characteristics. Thus, the significant decrease in ID in the SSI population may reflect a diagnostic shift leading to the large increases in ASD. Other studies have characterized similar diagnostic shifts in ASD in the general population, which supports our claim.^{8,20,21} We would expect these shifts to appear also in the NHIS data, although our findings do not support this expectation.

Children who qualify for SSI with ADHD as a primary impairment have higher rates of coexisting conditions than children with ADHD in the general population. These results could reflect more SSI adjudicator scrutiny to determine disability for ADHD because of the less specific SSI requirements as well as the policy and media attention to ADHD among children receiving SSI. Children with ADHD on SSI may of course have more functional impairment and qualify for SSI due to multiple coexisting conditions rather than ADHD alone. In contrast, children with autism and ID on SSI have lower rates recorded than the general population. ASD and ID have high rates of allowance for SSI benefits, and disability determination staff have less reason to seek coexisting conditions that could cause disability. Our NHIS findings confirm previously research by Houtrow et al,¹⁶ which found that approximately two-thirds of children with ADHD in the general population had at least 1 comorbid condition.

It is also important to note the magnitude of change in each given condition studied, especially for ASD. Although we compared absolute percentages in our statistical analysis and found a statistically significant increase in ASD as compared to the general population, it is inter-

esting that ASD had a 3-fold increase (relative change of 225%) in the SSI population and a 5-fold increase in the general population (relative change of 400%). This alternate method of comparison further supports that ASD have increased greatly in both the SSI and general population from 2000 to 2011, and contextualizes some important limitations of our analysis.

POTENTIAL BARRIERS/LIMITATIONS

This study has several limitations. Most importantly, these diagnostic indicators are collected for very different purposes: SSA to determine eligibility, NHIS to determine rates of parent-reported conditions. The SSI diagnoses come from codes determined by the disability determination staff from data included on the SSI application. The primary diagnosis must be a condition that addresses the child's eligibility. Secondary diagnoses are noted, but there is no incentive for SSI reviewers to record multiple conditions if a child is deemed eligible according to the primary condition. As noted above, children with ASD and ID rarely require a secondary condition to qualify for SSI given their level of disability, while children on SSI with ADHD may have more extensive evaluation to ensure they meet the standard of disability necessary for SSI eligibility. Little information helps to verify the accuracy of primary and secondary impairments in the SSA data.

Our study does not account for potential migration of children on and off the SSI rolls because we were unable to obtain and analyze individual-level data. We do know that chronic conditions change over time in any given population, however,¹¹ and this further complicates the analysis.

SSA does not record beyond primary and secondary impairment, while NHIS may record multiple coexisting conditions based on a parent checking a predefined list of conditions for an individual child. These processes make difficult comparative assessments of comorbidity. Second, the comparison of SSA and NHIS overall is problematic because the method in which they are collected and determined is very different. SSI requires extensive documentation of condition and disability by medical and nonmedical professionals, and the NHIS does not have information on the level of disability for children with these diagnoses. Further, the time frame differs. For the SSI data, we utilized new enrollee data indicating that the children identified have the given condition at the point in time of enrollment. The NHIS survey indicates those "who have or who have ever had" the given condition, all the children studied may not have the selected condition at the time of the study.

Lastly, our estimate of financial eligibility among the NHIS population does not exactly mirror the SSI requirements; ie, the FPL 0 to 199% is not an ideal proxy for SSI financial standard for enrollment. Nonetheless, children in households with incomes up to 200% FPL can receive SSI. Poverty has increased among children over time³ and children with special health care needs often pose complex financial burdens for their families,²² and this rise in poverty may have also contributed to the rise in children with ADHD and ASD receiving SSI from 2000 to 2011. We were unable to measure in our study

how increasing rates of poverty may have contributed to children receiving SSI for mental health impairments.

This study reflects the first effort to compare growth in mental health conditions among the SSI population with growth in the general pediatric population. To our knowledge, no previous literature compares trends in mental health diagnoses in the US population to mental health impairment in the SSI population, nor that explores coexisting conditions among the SSI population.

CONCLUSIONS

Growth in ADHD in the SSI population in large part mirrors that in the general population. This study does not support the notion that the rise in ADHD among children receiving SSI reflects inappropriate evaluation by SSA. The findings regarding ASD and ID may reflect the relative ease of SSI determinations for these conditions. This study provides some information to help answer questions raised in the GAO report.¹⁸ There is ample evidence that more children are being diagnosed with mental health problems; therefore, it is not surprising that there is a rise in mental health disability cases among children with SSI. Our data provide a new comparison of national prevalence trends for mental health conditions among children living in or near poverty with SSI mental health disability trends. This study sets the stage for additional research, such as variations among states in these comparisons, and such comparisons could help to explain variations in growth.

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