Intellectual and Developmental Disabilities

Hospitalizations among Children and Youth with Autism in the United States: Frequency, Characteristics and Costs.

--Manuscript Draft--

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Abstract:	National estimates of hospitalization diagnoses and costs were determined using the 2016 HCUP Kids' Inpatient Database. Children and youth with autism were hospitalized over 45,000 times at over $560 million in costs and 260,000 inpatient days. The most frequent principal diagnoses for hospitalizations of children and youth with autism were epilepsy, mental health conditions, pneumonia, asthma, and gastrointestinal disorders, which resulted in almost $200 million in costs and 150,000 inpatient days. Mental health diagnoses accounted for 24.8% of hospitalizations, an estimated $82 million in costs, and approximately 94,000 inpatient days. Children and youth with autism were more likely hospitalized for epilepsy, mental health diagnoses, and gastrointestinal disorders, and less likely for pneumonia and asthma compared to other children and youth.

Authors' Response to Editor's and Reviewers' Comments

Thank you for the detailed reviews. We appreciate the time and effort the reviewers put into providing constructive feedback. The reviews guided us on restructuring the paper and creating a revision we believe is a more robust version of our work. Our paper has been substantially rewritten and each suggestion from the reviewers addressed. We revised the language in the manuscript to reflect the most recent recommendations for avoiding ableist language in autism research based on the recommendations of Kristen Bottem-Beutal and colleagues in their 2021 article 'Avoiding ableist language in autism research' and included a positionality statement as argued for by Allison Godwin (Bottema-Beutel et al., 2021; Godwin, 2020). Text in the manuscript that addresses a specific comment is highlighted in bold. All other changes are in track changes.

Editor's and Reviewers' comments:
Editor: This paper provides an analysis of administrative data to health service utilization among children with autism using administrative records. In the absence of cohort and longitudinal data collection, the use of administrative records to describe health care utilization (and outcomes) is promising and analyses like these demonstrate what may be possible. As the reviewers have pointed out below, there are methodological concerns and questions which have prompted a request for major revision and resubmission. Thank you for consideration of this thoughtful feedback. We would welcome a resubmission which reflects the formative guidance below in a revision.

Reviewer #1: The health service utilization profile of children and youth with autism is an important area to study on a national level.

1. However, the analytic methods applied in this paper, together with their presentation, are misaligned and contain substantial areas of bias. The authors present the research questions and results as if they are studying utilization across a cohort of children and youth. Instead, they appear to be analyzing individual discharges which do not appear to be linked across the underlying individuals. They conflate describing discharges with describing utilization for children. For example, they state "a cross-sectional descriptive analysis of hospitalized children and youth with and without autism in 2016 with adjusted Wald tests of differences in proportions", but instead of an analysis of a cohort of children/youth, they are appear to be analyzing a series of individual discharges.
    1.1. Authors' Response: This is a function of the nature of the data. The HCUP data is hospital discharge data that in order to preserve patients' confidentiality under the HIPAA Privacy Rule does not include unique patient identifiers; therefore, the unit of analysis is the hospital discharge or encounter. The data also does not contain any information about people who are not hospitalized. As such, we analyzed hospital discharge abstracts that are not linked across individuals, thus making our study a cross-sectional encounter level rather than individual level analysis. It is also cross-sectional rather than cohort data. A cross-sectional design is used for population-based data like

the HCUP KID. While the cross-sectional study is weaker analytically as far as determining cause or effect, it is useful for descriptive studies such as ours (CDC, 2012)

Using encounter-level data from a nation-wide, representative sample allows us to make national estimates of healthcare utilization and costs for particular groups (HCUP Fact Sheet (ahrq.gov)). From the national estimates we can make statements about the number of hospitalizations experienced by a group (in the case of this study, hospitalized autistic children and youth -) and the costs and characteristics of those hospitalizations. But we cannot make any statements about the entire population (those who were hospitalized and those who were not). That is a limitation of the HCUP data.

We made sure to address these issues in our limitations, and we adjusted our paper to make the study design clearer, and ensured our language aligned with the body of literature on health care utilization among autistic children and youth that analyzed HCUP data. We changed the paper to refer to hospitalizations instead of hospitalized children to clarify the sampling unit (hospitalizations) and the cross-sectional nature of the data/study.

2. Additionally, the data does not account for children with multiple episodes of utilization. While this is a sample of utilization, it's still possible that multiple episodes are included for individuals. It is known that children with neurodevelopmental conditions use more health services than children without these diagnoses. This repeat utilization, if not measured, prohibits the accurate estimation of prevalence, as the authors present in the paper.
   2.1. Authors' Response: We are not measuring prevalence in individuals but rather prevalence in hospitalizations. Since we are using HCUP data, our prevalence statistics measure event occurrence and frequency (Fingar et al, 2016). We calculate, for example, the prevalence of pediatric hospital discharges with an ICD 10 code of autism, or the prevalence of hospitalization for mental health conditions among hospital discharges with an ICD code of autism. HCUP is ideal for measuring the prevalence of occurrences among hospitalized patients (Fingar et al, 2016).

3. When examining claims that have an associated code of autism, the authors do not address the important bias that utilization that is more specifically associated with a child's autism is more likely to include a code of autism.
   3.1. Authors' Response: Yes! This is an excellent point. We added the following to our limitations section:

PG 21. Additionally, the identification of children and youth with autism in a hospital setting can have multiple origins (e.g., self-report, parent report, previous medical documentation) and be influenced by multiple factors. For example, utilization that is more specifically associated with a child or youth's autism may be more likely to include a code of autism. While we can be fairly certain that a hospital discharge with a

diagnosis of autism accurately represents a child or youth with a true diagnosis, we are less certain of those discharges without a diagnosis of autism. A study of identifying children and youth with autism using physician billing data in Nova Scotia, Canada found a sensitivity of 62.5% and specificity of 83%, with most of the inaccurate identifications being false negatives (Dodds et al., 2009). Thus, autism may have been underreported in our data, and this may have occurred for a variety of reasons, from low or limited insurance reimbursement policies to inaccurate reporting. Since autism is mostly coded as a secondary diagnosis it may be underreported if autism did not contribute to the reason for the hospitalization (Fingar et al., 2016). While Burke et al. (2014) found reasonably accurate identification of autism in administrative health plan data, we can still assume our data contains an undercount of the true number of hospitalizations associated with children and youth with autism. Should this be the case, our results would underestimate the differences between children and youth with autism and the other children and youth. Given the strong and significant differences we did find between children and youth with autism and other children and youth, we feel confident that our results represent true differences.

4. The authors also only compare demographic factors listed on claims to those in claims without autism codes. This is problematic because it does not account for underlying differences in the subpopulations. The authors state that discharges with autism codes are more likely to be for males, for Whites and for affluent children/youth. But children/youth diagnosed with autism, regardless of utilization, are more likely to be male, white and affluent. The data also appear to exclude children who did not have service utilization in this period.
    4.1. Authors' Response: To account for underlying subpopulation differences, we created comparison groups along the lines of Carbone et al (2015). Carbone et al also analyzed HCUP KID data - but from 2009. They used a since-removed HCUP variable that indicates the presence of a chronic condition to create comparison groups. Since the HCUP variable was removed from HCUP data, we created a chronic condition variable using the Elixhauser comorbidity index. Demographic variables are now compared across two groups: pediatric discharges with a diagnosis of autism; pediatric discharges without a diagnosis of autism but with at least one co-occurring condition from the Elixhauser; and pediatric discharges without a diagnosis of autism and with no chronic condition from the Elixhauser. Table 1 has been updated with the new comparison groups. Text in the paper has been updated to reflect these changes.
    PG 9: The presence of co-occurring conditions that may affect hospitalization costs and length of stay was determined using the Elixhauser comorbidity index and used to create comparison groups (discharges for children and youth with no autism diagnoses but with co-occurring conditions, and discharges for children and youth with no autism diagnoses and no co-occurring conditions). The Elixhauser

comorbidity index identifies co-occurring conditions based on 38 comorbidity measures (*Elixhauser Comorbidity Software Refined for ICD-10-CM*, n.d.)**.**

PG 12: … we calculated the sociodemographic characteristics of hospital discharges for children and youth ages 3-20 with a diagnosis of autism (ICD-10 codes F84.0; F84.5; or F84.9). We also compared these discharges to discharges of children with co-occurring conditions and no autism diagnosis, and children and youth with neither. These comparison groups (autism, only co-occurring conditions, neither) were based on the presence or absence of other co-occurring conditions and created using the Elixhauser comorbidity index.

The current diagnosed population of autistic children is predominantly white, male, and affluent. While we found that hospitalizations fell along demographic lines found in the general population, this may not have been the case and is important to explore, especially considering the potential biases in diagnosis (Begeer et al., 2009; Haney, 2016). If diagnostic criteria change in the future to eliminate this potential bias it will be important to have historical descriptives.

The HCUP data is hospital discharge data, so it only contains information on children and youth who were hospitalized. This is a limitation of the data. We added the following to future research:
PG 21: HCUP data is administrative hospital discharge data, and as such excludes children and youth with autism who did not have service utilization during the study time period and does not account for repeat utilization. This precludes any understanding of the rates of hospitalization among all children and youth with autism and any differences between children and youth with autism who experience hospitalization and those who do not.

Future research should include nationally representative, longitudinal, cohort studies of hospitalizations among children and youth with autism.

5. Authors state that "Neurodevelopmental disorders were also a top reason for hospitalization for children and youth with autism, presumably due to an estimated 3 thousand children and youth with autism having a primary discharge diagnosis of autism (3,214 discharges)". However, it's important to consider that claims are structured for the primary purposes of payment. Therefore, it is likely more accurate that practitioners list autism as the primary diagnosis for those known to have autism in hospitalizations to facilitate enhanced payment rates. It is not clear that the primary reason for hospitalization is necessarily autism, but rather a condition requiring hospital-level treatment that is complicated or requires a higher level of services because of the child's autism.

5.1. Authors' Response: That is a really interesting observation. HCUP data documentation states that the primary diagnosis "is the principal diagnosis defined as the condition established after study to be chiefly responsible for occasioning the admission of the patient to the hospital for care." (see: https://www.hcup-us.ahrq.gov/db/vars/i10_dxn/kidnote.jsp), and the body of literature on hospitalizations using HCUP data typically treats the primary diagnosis as the reason for admission. We searched the literature for any data on the use of autism to facilitate enhanced payment rates and could not find any study of the issue.

6. The paper should be reframed and revised with these considerations prior to the next review.
   6.1. Authors' Response: Thanks again for your comments. We updated the introduction, tables, results, and discussion section in line with these considerations.

Reviewer #2: This study uses the 2016 HCUP Kids Inpatient data to examine aspects of hospitalization among children and youth with autism. The topic is appropriate for the journal, under-researched, and the study is informative. I have a few concerns/suggestions.

1. Provide justification as to why region was used as an individual-level model instead of using multivariate models to nest individuals within their respective regions. I am not saying that this is not justifiable but is not really best practice and should be explained.
   1.1. Authors' Response: In this case, doing regional comparisons or evaluating regional-level variables was not part of the research question, thus we did not contemplate a multilevel model but simply controlled for regional variation in a national study of hospitalizations among children and youth with autism. Additionally, the HCUP KID sampling methods include discharge weights that are used to generate national estimates and appropriate standardized errors. The discharge weights are created by stratifying hospitals on region, urban/rural location, teaching status, bed size, ownership, and children's hospital. Unlike the other two HCUP databases, the National Inpatient and Emergency Department Samples (NIS and NED), the KID data must be weighted, and cannot be analyzed unweighted, and hospital level analysis cannot be performed using KID data (Producing National HCUP Estimates - Accessible Version. Healthcare Cost and Utilization Project (HCUP). December 2018. Agency for Healthcare Research and Quality, Rockville, MD, www.hcup-us.ahrq.gov/tech_assist/nationalestimates/508_course/508course_2018.jsp.). Thus, we cannot run a random effects model using region as a random effect. We cannot run multilevel models using survey final weights, and survey final weights are required to conduct an appropriate discharge-level analysis of the KID data. Analytically, multilevel models require stage-level weight variables rather than the survey final weight, but, doing so would mean not using the discharge weights as specified by HCUP.

   To be certain, we conducted a search of recent literature using HCUP data, a search of IDD papers using HCUP data, and a search of literature focusing on HCUP and autism. We found no instance of analysis using both the appropriate weighting techniques and multilevel modeling with region. In most instances, region is used as a control/independent variable in a logistic regression, as we used it.

   Recent Search of HCUP Papers
   Favre, N., Patel, V. A., & Carr, M. M. (2021). Complications in Pediatric Acute Mastoiditis: HCUP KID Analysis. Otolaryngology–Head and Neck Surgery. https://doi.org/10.1177/0194599821989633

Samuels, S., Kimball, R., Hagerty, V., Levene, T., Levene, H. B., & Spader, H. (2021). Association of hospital characteristics with outcomes for pediatric neurosurgical accidental trauma patients. Journal of Neurosurgery: Pediatrics, 1(aop), 1-6.

Rizzo, J. A., Chen, J., Laurich, C., Santos, A., Martinsen, B. J., Ryan, M. P., ... & Gunnarsson, C. (2018). Racial disparities in PAD-related amputation rates among Native Americans and non-Hispanic whites: An HCUP analysis. Journal of health care for the poor and underserved, 29(2), 782-800. (In this paper the authors ran separate models for each region only because they had good practical reason to do so. They knew that Native Americans may be more likely to see Indian Health Authority hospitals in certain regions. They are also using HCUP data that allows for hospital-level analyses).

Search of JAIDD & IDD Papers

Erickson, S.R., Kamdar, N, & Wu, C. (2020). Adverse medication events related to hospitalization in the United States: A comparison between adults with intellectual and developmental disabilities and those without. Am J Intellect Dev Disabil; 125 (1): 37–48. doi: https://doi-org.argo.library.okstate.edu/10.1352/1944-7558-125.1.37

Parish, Susan L et al. (2015). Pregnancy Outcomes Among U.S. Women with Intellectual and Developmental Disabilities." American journal on intellectual and developmental disabilities 120.5 : 433–443.

Search of Literature Focusing on HCUP and Autism

Vohra, R., Madhavan, S., & Sambamoorthi, U. (2016). Emergency department use among adults with autism spectrum disorders (ASD). Journal of autism and developmental disorders, 46(4), 1441-1454.

Carbone, P. S., Young, P. C., Stoddard, G. J., Wilkes, J., & Trasande, L. (2015). A comparison of ambulatory care sensitive hospitalizations among children with and without autism spectrum disorder. Academic Pediatrics, 15(6), 626-635

Kalb, L. G., Stuart, E. A., Freedman, B., Zablotsky, B., & Vasa, R. (2012). Psychiatric-related emergency department visits among children with an autism spectrum disorder. Pediatric Emergency Care, 28(12), 1269-1276.

Lokhandwala, T., Khanna, R., & West-Strum, D. (2012). Hospitalization burden among individuals with autism. Journal of autism and developmental disorders, 42(1), 95-104.

2. Provide clearer specification of the strategy used to groups dx into 'clinically meaningful categories." Per my calculation, in T2 you are reporting on just over half of the dx categories. I am imagining those not included had low prevalence rates. If so, detail cut point. Also,

provide ICD codes for each dx group, especially as you include a good many "related" and "other" descriptors. Also, why only include unspecified (assuming these are R-coded) for mood and GI? Any thought given to including pneumonitis with pneumonia? Why/why not?

2.1. Authors' Response: We used the AHRQ Clinical Classifications Software Refined (CCS-R) to group the diagnosis into clinically meaningful categories. The CCS software has a long history of use for health services research, starting in 1991 with its development based on the needs of public policy researchers. This initial version was modified in 1993 based on clinical homogeneity, frequency of occurrence in inpatient discharge data, and ICD-9-CM coding changes. The CCS was updated again in 1998, and 2008. The 2008 update replaced the mental health section of the CCS , which was created using ICD-9-CM codes, with the CCS-Mental Health and Substance Abuse (MHSA), which used the DSM-IV as the organizing framework. The CCS-R was created in 2018 to reflect the transition from the ICD-9-CM to the ICD-10-CM. To develop the clinically meaningful categories based on the ICD-10-CM, AHRQ used expert opinion on coding and clinical perspectives from a variety of specialties (AHRQ CCSR, 2021).

We updated our text to read:

PG 10: The ICD-10-CM contains over 72,000 diagnostic codes. To reduce the complexity of analytic models using the ICD-10-CM, researchers rely on classification systems that aggregate the diagnostic codes by similar conditions to create a more manageable number of clinical categories. Thus, we aggregated the ICD-10-CM codes into clinically meaningful categories using Clinical Classifications Software Refined (CCSR). The Clinical Classification Software, developed by AHRQ, is well-studied software designed for this purpose. The CCS aggregates the ICD-10-CM diagnostic codes into a limited number of clinically meaningful categories based on expert opinion, clinical homogeneity, and frequency of occurrence in hospital administrative data.

Our goal was to identify the most frequent principal diagnoses in hospital inpatient stays among children and youth with autism. Knowing the most common reasons for hospitalization is important so that advocates and policy makers can plan for and provide resources to address these more frequent conditions, particularly those that are ambulatory care sensitive. The most common reasons for diagnoses were defined a priori as the top ten diagnoses (as in the Pfuntner et al, 2013a and Pfuntner et al, 2013b AHRQ HCUP statistical briefs) if those diagnoses also exceeded 50% of the total diagnoses. If the top ten diagnoses did not exceed 50% of the total diagnosis, then we would expand our criteria out to the top 20 diagnoses . In our analysis the top ten principal diagnoses for hospital inpatient stays among children and youth with autism accounted for 52% of the total inpatient stays. Also, as you correctly surmised, once you get down to the 8th, 9th, and 10th most frequent diagnosis the prevalence rate is low (2%).

References

Pfuntner A (Truven Health Analytics), Wier LM (Truven Health Analytics), Stocks C (AHRQ). Most Frequent Conditions in U.S. Hospitals, 2011. HCUP Statistical Brief #162. September 2013. Agency for Healthcare Research and Quality, Rockville, MD. http://www.hcup-us.ahrq.gov/reports/statbriefs/sb162.pdf.

Pfuntner A, Wier LM, Stocks C. Most Frequent Conditions in U.S. Hospitals, 2010. HCUP Statistical Brief #148. January 2013. Agency for Healthcare Research and Quality, Rockville, MD. http://www.hcup-us.ahrq.gov/reports/statbriefs/sb148.pdf.

Selected other studies focusing on top ten diagnoses

Finley, C. R., Chan, D. S., Garrison, S., Korownyk, C., Kolber, M. R., Campbell, S., Eurich, D. T., Lindblad, A. J., Vandermeer, B., & Allan, G. M. (2018). What are the most common conditions in primary care? Systematic review. Canadian family physician Medecin de famille canadien, 64(11), 832–840.

Caldwell, N., Srebotnjak, T., Wang, T., & Hsia, R. (2013). "How much will I get charged for this?" Patient charges for top ten diagnoses in the emergency department. PLoS One, 8(2), e55491.

Kakande, B., Gumedze, F., Hlela, C., & Khumalo, N. P. (2016). Focus on the top ten diagnoses could reduce pediatric dermatology referrals. Pediatric dermatology, 33(1), 99-102.

Most Common Diagnoses in Hospital Inpatient Stays - HCUP Fast Stats (ahrq.gov)

We provided the ICD codes for each dx group in Appendix 1. Since we are using the CCSR categories to aggregate ICD-10 codes to determine the top diagnoses associated with hospitalizations, we have to consistently use their classification. And it's important to use the CCSR because of the low prevalence rate of individual ICD-10 codes. Also, the CCSR is based on several clinical factors, including frequency of clinical use of the code (meaning they are clinically relevant). Unspecified mood and GI most likely have their own categories because they are frequently used by clinicians as diagnoses. Also, according to the HCUP CCSR documentation: "The number of catch-all categories (those that start with "Other specified") are minimized, because they are of limited value if the ICD-10-CM codes within the category are highly heterogeneous. When a catch-all category is necessary, the number of codes is minimized by separating out clinically relevant groups. This often is a trade-off with the number of overall categories created in the tool."

To illustrate the importance of using the CCSR, we created a table of the top 20 most frequent reasons for hospitalization based on individual ICD-10-CM codes, the related CCSR category, and the frequency of the individual ICD-10-CM codes using the unweighted data. The frequencies of top 20 individual ICD-10-CM codes are low, contain redundant information, and only account for 33% of all inpatient discharges (see below).

We did not include pneumonitis with pneumonia because it is a separate category in the CCSR. Aspiration pneumonitis is the CCSR code RSP010 and includes the ICD-10-CM codes J690, J691, J954, J698, O29011, O29012, O29013, O741, and O8901. It is not included with pneumonia in the CCSR. In total, 110 discharges (0.3%) among youth with autism had a diagnosis of aspiration pneumonitis.

	Principle Diagnosis by ICD-10-CM code	CCSR Category	n(%)	Cumulative (%)
1	F840 Autistic Disorder	MBD014 Neurodevelopmental Disorders	2144 (6.55)	6.55
2	F39 Unspecified mood [affective] disorder	MBD004 Other specified and unspecified mood disorders	998 (3.05)	9.6
3	F329 Major depressive disorder, single episode, unspecified	MBD002 Depressive Disorders		
4	G40909 Epilepsy, unspecified, not intractable, without status epilepticus	NVS009 Epilepsy; convulsions	765 (2.33)	11.93
5	F332 Major depressive disorder, recurrent severe without psychotic features	MBD002 Depressive Disorders	670 (2.04)	13.97
6	F6381 Intermittent explosive disorder	MBD008 Disruptive, impulse-control and conduct disorders	620 (1.89)	15.86
7	R569 Unspecified convulsions	NVS009 Epilepsy; convulsions	612 (1.87)	17.73
8	F319 Bipolar disorder, unspecified	MBD003 Bipolar and related disorders	601 (1.83)	19.56
9	Z5111 Encounter for antineoplastic chemotherapy	FAC006 Encounter for antineoplastic therapies	517 (1.58)	21.14

10	F348 Other persistent mood [affective] disorders	MBD004 Other specified and unspecified mood disorders	508 (1.55)	22.69
11	E860 Dehydration	END011 Fluid and electrolyte disorders	482 (1.47)	24.16
12	J189 Pneumonia, unspecified organism	RSP002 Pneumonia (except that caused by tuberculosis)	451 (1.37)	25.53
13	K5900 Constipation, unspecified	DIG025 Other specified and unspecified gastrointestinal disorders	357 (1.09)	26.62
14	G40409 Other generalized epilepsy	NVS009 Epilepsy; convulsions	354 (1.08)	27.7
15	E1010 Type 1 diabetes mellitus with ketoacidosis without coma	END004 Diabetes mellitus, Type 1	343 (1.04)	28.74
16	A419 Sepsis, unspecified organism	INF002 Septicemia INF003 Bacterial infections	306 (0.93)	29.67
17	F29 Unspecified psychosis not due to a substance or known physiological condition	MBD001 Schizophrenia spectrum and other psychotic disorders	304 (0.92)	30.59
19	F919 Conduct disorder, unspecified	MBD008 Disruptive, impulse-control and conduct disorders	287 (0.87)	31.46
19	F3481 Disruptive mood dysregulation disorder	MBD004 Other specified and unspecified mood disorders	287 (0.87)	32.33
20	K5641 Fecal impaction	DIG012 Intestinal obstruction and ileus	284 (0.86)	33.19

3. LOS was calculated as mean, which is sensitive to outliers. Were results similar when using median. Best to at least check as sensitivity analysis and provide summary if similar.
   3.1. Authors' Response: We present the mean as it is the convention in all the HCUP analyses conducted by AHRQ and most studies in the literature that use the HCUP. We kept the mean to maintain the ability to compare our results with other HCUP results but also added the median in Table 4 for comparison, as LOS tends to be skewed. Our LOS variable is indeed skewed. We added the following to our paper:
   PG 13: Median length of stay was also calculated to control for extreme outliers – children or youth who had unusually long lengths of stay. While length of stay is skewed, we still include the mean to enable comparisons across other studies of hospitalization which most frequently include the mean rather than the median.

4. My major question is why the comparison between those with without ASD is only provided for dx. As I read the study, I really wanted to see the comparisons for cost and LOS as well. Even if not much different, I would include in an appendix. If different, I would imagine trends would be similar. But my burning question is once admitted, is the duration of stay similar or different, and how does this vary by dx.
   4.1. Authors' Response: We updated table 2 and 3 to present this information and updated the text to reflect this addition.

   PG 15: Compared to children and youth with only co-occurring conditions and those with neither, children and youth with autism had higher rates of hospitalizations for each of the most frequent principal diagnoses for hospitalization, with the exception of depressive disorders, pneumonia, and asthma. Children and youth with autism had lower rates of pneumonia-related hospitalizations compared children with only co-occurring conditions but higher rates than children with neither.

   PG 15: Weighted average total costs per most frequent primary diagnosis were higher among admission of children and youth with autism compared to other children, with the exception of epilepsy, pneumonia, and gastrointestinal disorders. Costs associated with a primary discharge diagnosis of pneumonia and gastrointestinal disorders were lower among children and youth with autism ($9,581.86 and $9,065.82)) compared to children with other chronic conditions ($11,638.46 and $13,301.27) but higher than children with no chronic conditions ($5,870.65 and $5,707.17). Costs and length of stay per admission for depressive disorders were higher for children and youth with autism ($6,160.67 and 6.9) compared to children with only co-occurring conditions ($4,893.64 and 5.7), even though their rates were lower (7.2% compared to 11.5%).

   PG 16: After adjusting for sociodemographic characteristics, we find the mean predicted costs associated with the most frequent primary discharge diagnosis for children and youth with autism were generally higher than those for other children. Exceptions occurred among children and youth with other co-occurring conditions and a primary discharge diagnosis of epilepsy, pneumonia, and gastrointestinal disorders – they tended to have higher adjusted mean predicted costs per stay for these diagnoses compared to children and youth with autism.

5. More attention is needed to address the limitation of likely under-reporting of ASD by physicians. While I agree the possibility of under-reporting decreases with severity, there may be more going on - such as instances when the physician does not think ASD is a medical factor, or simply fails to report. Discussion is needed of how this may bias results. Yes, not all are here, but what does that mean for what you found? If we go with the assumption that those with less noticeable or noted ASD are not included, how might this bias results? This obviously involves some conjecture, but you should be able to make a solid description of how who is included may influence the results.
   5.1. Authors' Response: We updated our limitations section to read:

PG 21: Additionally, the identification of children and youth with autism in a hospital setting can have multiple origins (e.g., self-report, parent report, previous medical documentation) and be influenced by multiple factors. For example, utilization that is more specifically associated with a child or youth's autism may be more likely to include a code of autism. While we can be fairly certain that a hospital discharge with a diagnosis of autism accurately represents a child or youth with a true diagnosis, we are less certain of those discharges without a diagnosis of autism. A study of identifying children and youth with autism using physician billing data in Nova Scotia, Canada found a sensitivity of 62.5% and specificity of 83%, with most of the inaccurate identifications being false negatives (Dodds et al., 2009). Thus, autism may have been underreported in our data, and this may have occurred for a variety of reasons, from low or limited insurance reimbursement policies to inaccurate reporting. Since autism is mostly coded as a secondary diagnosis it may be underreported if autism did not contribute to the reason for the hospitalization (Fingar et al., 2016). While Burke et al. (2014) found reasonably accurate identification of autism in administrative health plan data, we can still assume our data contains an undercount of the true number of hospitalizations associated with children and youth with autism. Should this be the case, our results would underestimate the differences between children and youth with autism and the other children and youth. Given the strong and significant differences we did find between children and youth with autism and other children and youth, we feel confident that our results represent true differences.

6. My other major question is about the neurodevelopmental disorders category. What ICD codes were included here, and why were they lumped together? Assuming this category included multiple groups, these are typically quite disparate conditions. As this was the second leading dx, with longer stays, would be interesting to better specify by condition, especially as such a low percentage had this listed as the primary dx.
   6.1. Authors' Response: We created two tables to illustrate the answer. The category neurodevelopmental disorders is a CCSR category that collapses a number of clinically homogeneous ICD-10-CM code into one category. Twenty-eight of those codes are used as primary diagnoses among discharges for children and youth with autism. The following table shows those codes and the frequency of each code among those discharges (unweighted). ICD-10 codes associated with autism and attention-deficit disorder account for 97.43% of the discharges with the CCSR category neurodevelopmental disorders as the primary discharge diagnosis, and 8.35% of the total discharges among children and youth with autism (unweighted). We collapsed those codes to create the second table, which shows the costs and length of stay associated with autism and attention-deficit disorder as a primary discharge diagnosis among hospitalized children and youth with autism, without autism and with at least one

chronic condition, and without autism and without any chronic conditions. We did not add these tables to the paper, but included the second table as Appendix 2.

Diagnoses		Frequency	Percent
ASD (F840,F845, F849)		2,360	81.92%
ADHD (F900, F901, F902, F908, F909)		447	15.52%
	Total	2,807	97.43%

Diagnosis group & primary discharge diagnosis	Weighted prevalence n(%)	Total mean costs	Length of stay	
			mean	median
Autism				
Autism	3214 (7.14)	7524.55	9.03	6
ADD	622 (1.38)	7254.95	8.71	6
Co-occurring condition				
ADD	2323 (0.24)	6700.70	8.12	6
No co-occurring condition				
ADD	2658 (0.37)	5978.78	7.14	6

Hospitalizations among Children and Youth with Autism in the United States: Frequency, Characteristics and Costs.

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This manuscript has not been presented

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Abstract

National estimates of hospitalization diagnoses and costs were determined using the 2016 HCUP Kids' Inpatient Database. Children and youth with autism were hospitalized over 45,000 times at over $560 million in costs and 260,000 inpatient days. The most frequent principal diagnoses for hospitalizations of children and youth with autism were epilepsy, mental health conditions, pneumonia, asthma, and gastrointestinal disorders, which resulted in almost $200 million in costs and 150,000 inpatient days. Mental health diagnoses accounted for 24.8% of hospitalizations, an estimated $82 million in costs, and approximately 94,000 inpatient days. Children and youth with autism were more likely hospitalized for epilepsy, mental health diagnoses, and gastrointestinal disorders, and less likely for pneumonia and asthma compared to other children and youth.

Keywords: hospitalization, HCUP, autism, mental health, inpatient costs

Hospitalizations among Children and Youth with Autism in the United States: Frequency, Characteristics and Costs.

Autism is increasingly recognized and diagnosed in the United States. From 2000 to 2016 rates of autism diagnoses rose nearly 175 percent. Currently, an estimated 1 in 54 children in the United States have a diagnosis of autism (Maenner et al., 2020). Children and youth with autism experience several co-occurring conditions that increase the likelihood of emergency department visits and inpatient care utilization (Carbone et al., 2015; Iannuzzi et al., 2015). Seizures, gastrointestinal issues, mental health diagnoses, and sleep disturbances are all example of common conditions among children and youth with autism that are associated with emergent and inpatient care (Carbone et al., 2015; Kohane et al., 2012; Righi et al., 2018; Simonoff et al., 2008). Hospitalizations are of particular concern as inpatient care can represent a gap in community care (Gao et al., 2014; Stulz et al., 2015), be traumatic (Detsky & Krumholz, 2014; Krumholz, 2013), be stressful for youth with autism (Muskat et al., 2015; Siegel & Gabriels, 2014) and increase the risk of suicide (Doupnik et al., 2018). Once admitted, children and youth with autism experience longer lengths of stay compared to children and youth without autism (Lokhandwala et al., 2012). Even though children and youth with autism spend a disproportionate amount of time in the hospital, hospital staff may be ill-equipped to provide supportive and appropriate care (Muskat et al., 2015; Zerbo et al., 2015). Furthermore, hospitalizations (in this instance, psychiatric hospitalizations) are associated with police interactions and school disciplinary actions, which are also traumatic for children and youth with autism (Turcotte et al., 2018).

Rates of Hospitalizations

The rate of hospitalizations among children and youth with autism is concerning, considering that hospitalizations are distressing, disrupt family, work and school functioning, and can have negative developmental effects on youth with chronic conditions (Lapillonne et al., 2012; Van Horn & Kautz, 2007). Hospitalizations can cause a significant amount of stress which may lead to readmissions (Krumholz, 2013) and be traumatic (Detsky & Krumholz, 2014). Children and youth with autism may be particularly sensitive to features of hospitalizations, which in the words of Detsky & Krumholz (2014) include "incessant loud noises, a lack of privacy, awakenings in the middle of the night, and examinations by strangers."

Children and youth with autism tend to be hospitalized more frequently than their neurotypical peers. Estimates of hospitalizations among children and youth with autism vary widely, from 2% to 20 %, with this wide range depending on differences in the population of children studied, the reason for hospitalization, and the specification of the analytic model (Croen et al., 2006; Cummings et al., 2016; Mandell, 2008a; Mandell et al., 2012; Schlenz et al., 2015; Siegel & Gabriels, 2014). For example, in their study of data from five health care systems, Cummings and colleagues (2016) controlled for co-occurring conditions, which resulted in a narrowed gap in the rates of hospitalizations between children and youth with autism and those without. In children, youth, and emerging adults with autism enrolled in Medicaid, Mandel and colleagues (2012) found that 2.3% experienced a psychiatric hospitalization in 2004. An earlier study of children and youth enrolled in the Kaiser Permanente Medical Care Program in California found slightly higher rates, with 5% of children with autism hospitalized from 2003 to 2004, compared to 2% of children without autism (Croen et al., 2006). Analyzing data from a community survey of 760 caregivers of children with autism, Mandell et al. (2008) found even higher rates for psychiatric hospitalizations, with 11% of autistic youth experiencing

hospitalizations for mental health conditions. In a longitudinal study in South Carolina, Schlenz and colleagues (2015) reported that children with autism between the ages of 9 to 12 had higher rates of inpatient visits (16.5%) compared to children and youth without autism (9.24%). The rate of hospitalizations was 20.24% among all children and youth with autism in the sample (ages 9 to 18).

Trends in current research indicate that hospitalization rates of children and youth with autism may be rising. Nayfack et al. (2014) conducted a longitudinal study of pediatric hospitalizations in California and concluded that hospitalizations among children with autism increased ten-fold over a ten-year period, from 770 in 1999 to 2400 in 2009. They argue that this increase may be due to the rise in autism recognition and diagnosis which resulted in a diminished ratio of public funding for community-based services per child diagnosed. Supporting this argument that hospitalizations may be linked to the provision of community-based care, Carbone and colleagues found that among a nationwide sample of hospitalized children in the United States, children with autism were more likely to be hospitalized for ambulatory care sensitive conditions (i.e., conditions that can be treated in an outpatient or community-based setting, like dehydration) compared to children with other chronic conditions and neurotypical children (Carbone et al., 2015). Similarly, Spark et al (2018) reported higher rates of hospital admissions for constipation, an ambulatory care sensitive condition, in children and youth with autism compared to other children (Sparks et al., 2018). In a smaller, regional sample, Hand et al also found higher rates of ambulatory care sensitive admissions among children and youth with autism and a co-occurring intellectual and developmental disability compared to those without autism (Hand et al., 2019). Mandel et al (2012) associated community-based respite care for caregivers with reductions in hospitalizations. A later study by

Mandell and colleagues suggests that preventative community-based services, that aren't simply a reaction to self-injury or externalizing behaviors, may reduce the risk of psychiatric hospitalizations (Mandell et al., 2019).

Costs of Hospitalizations

In general, inpatient expenditures of children and youth with autism are greater than those of youth without autism (Carbone et al., 2015; Lokhandwala et al., 2012; Peacock et al., 2012). Charges for all-cause hospitalizations among autistic people was $24,862 per discharge in 2007, which was significantly higher than charges among people without autism and mainly driven by younger ages (children, youth, and emerging adults) (Lokhandwala et al., 2012). Looking at charges for ambulatory care sensitive conditions, Carbone and colleagues noted that spending on inpatient care among children with autism was higher than spending for children without any chronic conditions, particularly for psychiatric hospitalizations. Psychiatric hospitalization charges among children with autism grossed an estimated $97 million in 2009, with an average weighted total charges per stay of $17,015, which was higher than children with other chronic conditions ($14, 962) and children with no chronic conditions ($13, 959) (Carbone et al., 2015). Sparks et al also noted higher total charges for ambulatory care sensitive hospitalizations – in this case, for constipation – among children with autism compared to children with no chronic conditions (Sparks et al., 2018).

Similar to the rise in hospitalization rates, Leslie and Martin (2007) found that inflation-adjusted health care expenditures for children with autism increased 20.4% over four years, from $4965 per child in 2000 to $5979 per child in 2004. Focusing on claims data from several private insurers during 2008-2012, Mandell et al. (2019) concluded that psychiatric hospitalizations

alone resulted in $4,000 in spending per week among children, youth, and emerging adults with autism.

Gaps in the literature

These and other studies of hospitalizations among children and youth with autism provide important information but are limited to a) regional hospitalizations (Croen et al., 2006; Cummings et al., 2016; Hand et al., 2019; Mandell et al., 2006; Nayfack et al., 2014), b) specific conditions (Carbone et al., 2015; Mandell, 2008b; Sparks et al., 2018), c) particular payers (Leslie & Martin, 2007), d) charges rather than costs (Carbone et al., 2015; Lokhandwala et al., 2012; Sparks et al., 2018), and e) healthcare systems outside the United States (Wu et al., 2015). Similar studies of national healthcare administration data also aggregated children and youth with autism into the adult population of people with autism (Lokhandwala et al., 2012). These studies have been key in helping us understand hospitalizations among children and youth with autism, however, there is still limited information on the most common reasons for hospitalization among children and youth with autism and the costs associated with these hospitalizations using nationwide, all-payer data in the United States. Thus, there is a knowledge gap in our understanding of the most frequent principal diagnoses for inpatient stays among children and youth with autism, the costs associated with these hospitalizations, and time burden (in length of hospital stay) that children and youth with autism experience through hospitalization. Without an understanding of these factors, we cannot develop appropriate community-based support services to reduce hospitalizations. In the absence of this knowledge, rates of hospitalizations and associated costs among children and youth with autism may continue to climb in the United States.

Research Questions

To address this gap in knowledge and provide direction for health policy and supportive services for children and youth with autism, we used nationally representative discharge data of pediatric hospitalizations in 2016 to answer the following research questions:

1. What are the characteristics of hospitalized children and youth with autism?
2. What are the most frequent principal diagnoses for hospitalizations among children and youth with autism?
3. What are the costs associated with the most frequent principal diagnoses for hospitalizations among children and youth with autism?
4. Are children and youth with autism more likely to be hospitalized for the most frequent principal diagnoses compared to other children and youth?

Positionality

This study was conceived and conducted by a team of researchers with a wide range of vested interests in the health and well-being of children and youth with autism. Two of the researchers are autistic, and three of the researchers are caregivers for people with autism or an intellectual and developmental disability who have been hospitalized as youth or are at risk of hospitalization. These experiences led us to want to know more about the current state of evidence and gaps in understanding around the hospitalization of children and youth with autism.

Research Methods

Data Source

We conducted a cross-sectional analysis of the 2016 Kids´ Inpatient Database (KID), Healthcare Cost and Utilization Project (HCUP), Agency for Healthcare Research and Quality. The HCUP suite of databases is created through federal, state, and industry partnerships and

sponsored by the Agency for Healthcare Research and Quality (AHRQ). The KID is the only publicly available all-payer database of pediatric hospitalizations in the United States. It includes discharge data from 4,200 community hospitals (a 20% stratified sample) from 46 states (plus the District of Columbia) in the United States. The KID yields national estimates of hospital inpatient stays for patients younger than 21 years of age, making it ideal for the study of hospital service utilization and hospitalization costs among children and youth with autism. Each hospital discharge abstract provides demographic data on the child or youth, ICD-10 diagnoses up to 30 levels, procedure codes, and associated charges. HCUP databases conform to the definition of a limited data specified by the privacy rule, thus Institutional Review Board approval was not required for the study (in compliance with federal regulations; CFR Title 45 Section 46.101 subparagraph (b) (4)). More information about the KID and the other healthcare databases that form part of the HCUP is available on-line (https://www.hcup-us.ahrq.gov).

Population

Our study population consisted of children and youth ages 3 to 20 who were hospitalized in 2016. In line with previous studies, we excluded discharges of children and infants under the age of three years (Carbone et al., 2015). While autism can be reliably diagnosed as early as age 2 (Johnson et al., 2007), many children do not receive a formal diagnosis until they begin attending school (Mandell et al., 2005; Shattuck et al., 2009).

Variables

Identifying Discharges of Children and Youth with Autism

Children and youth with autism were identified in the data using the most recent diagnostic criteria for autism brought about by the DSM V (APA, 2013). Discharge abstracts with a diagnosis of autism (ICD-10 F84.0), Asperger's (ICD-10 F84.5) or pervasive

developmental disorders (ICD-10 F84.9) among any of the 30 diagnosis levels captured in the HCUP KID hospital discharge abstract were coded as a child or youth with autism.

Patient Characteristics

Age, gender, race and ethnicity, geographic location, median household income, emergency department use, primary payer, and co-occurring conditions were included in the analysis as person-level variables or, in the case of co-occurring conditions, to create comparison groups. For descriptive statistics, we used age groupings of five years starting at age three (3–5, 6–10, 11–15, and 16–20 years). Race and ethnicity included six primary groups of people: White, Black, Hispanic, Asian or Pacific Islander, Native American, or other. Geographic location was based on the child or youth's residential zip code and categorized into rural and urban. Median household income described the income quartiles ($1-42,999; $43,000-53,999; $54,000-70,999; and $71,000 and up) for the child or youth's zip code. Emergency department use indicated whether the discharge abstract had any indicator of emergency department service use, such as an emergency department revenue code; emergency department charge, point of origin from the emergency department, or admission source from the emergency department. Emergency department use was coded yes for any evidence of use, or no for no evidence of use. The primary payer was either Medicaid, Medicare, private, or other (which included self-pay, no charge, and primary payers that didn't fall into any of the categories). **The presence of co-occurring conditions that may affect hospitalization costs and length of stay was determined using the Elixhauser comorbidity index and used to create comparison groups (discharges for children and youth with no autism diagnoses but with co-occurring conditions, and discharges for children and youth with no autism diagnoses and no co-occurring conditions). The Elixhauser comorbidity index identifies co-occurring conditions**

based on 38 comorbidity measures (*Elixhauser Comorbidity Software Refined for ICD-10-CM*, n.d.)**.**

Hospital Characteristics

Hospital characteristics included census region, ownership, and bed size of the hospital. Each hospital could be situation in the Northeast, Midwest, South, and West regions. Hospitals were either government owned (but non-federal), not-for-profit, or for profit. The size of the hospital could be small, medium, or large. Size determination was based on the number of staffed, short-term acute care beds in the hospital, while considering the hospital's location and teaching status.

Principal Diagnoses for Hospitalizations

Principal diagnoses for hospitalization were taken from ICD-10-CM codes in the primary discharge diagnosis field in the HCUP data. This diagnosis is listed first and is considered the condition or diagnosis primarily responsible for the child or youth being admitted to the hospital for care. **The ICD-10-CM contains over 72,000 diagnostic codes. To reduce the complexity of analytic models using the ICD-10-CM, researchers rely on classification systems that aggregate the diagnostic codes by similar conditions to create a more manageable number of clinical categories. Thus, we aggregated the ICD-10-CM codes into clinically meaningful categories using Clinical Classifications Software Refined (CCSR). The Clinical Classification Software, developed by AHRQ, is well-studied software designed for this purpose. The CCS aggregates the ICD-10-CM diagnostic codes into a limited number of clinically meaningful categories based on expert opinion, clinical homogeneity, and frequency of occurrence in hospital administrative data.**

Hospitalization Costs

The HCUP KID contains information on total charges per hospital discharge. These charges are the amount hospitals billed for services related to inpatient care for a particular hospital discharge and are not the actual expenses or costs. For example, HCUP total charges exclude physician fees whereas the cost estimates should contain those fees. Thus, total hospitalization costs were calculated from hospital charges using the HCUP Cost-to-Charge Ratio (CCR) file, which converts total charges to estimated costs using hospital-specific cost-to-charge ratios based on all-payer inpatient cost information from the Centers for Medicare & Medicaid Services (CMS) hospital accounting reports.

Average Length of Stay

Average length of stay was determined by averaging the length of stay across all occurrences of interest. This variable is calculated by subtracting the admission date from the discharge date for each encounter. Same-day stays (stays that do not extend overnight) are coded as 0.

Statistical Analyses

The statistical analyses for this study consisted of: a cross-sectional descriptive analysis of **hospital admissions among** children and youth with and without autism in 2016 with adjusted Wald tests of differences in proportions, unadjusted weighted total mean costs and length of stay, and adjusted gamma general linearized cost analysis of the costs for the most frequent principal diagnoses associated with hospitalizations among children and youth with autism, and a logistic regression model of the likelihood of hospitalization for the most frequent principal diagnoses among children and youth with autism compared to other children and youth.

To obtain national estimates and calculate appropriate standard errors, all analyses accounted for survey design and sampling weights using the svy command in Stata 15 (StataCorp, 2017).

To answer the first research question: '*What are the characteristics of hospitalized children and youth with autism*?*'*, **we calculated the sociodemographic characteristics of hospital discharges for children and youth ages 3-20 with a diagnosis of autism (ICD-10 codes F84.0; F84.5; or F84.9). We also compared these discharges to discharges of children with co-occurring conditions and no autism diagnosis, and children and youth with neither. These comparison groups (autism, only co-occurring conditions, neither) were based on the presence or absence of other co-occurring conditions and created using the Elixhauser comorbidity index.** Adjusted Wald tests were used to test for differences between proportions in the weighted analysis of demographic characteristics. These tests determined if discharges for children and youth with autism were significantly different from discharges for other children and youth along key person and hospital characteristics.

To answer the second and third research questions: *'What are the most frequent principal diagnoses for hospitalizations among children and youth with autism?'* and *'What are the costs associated with the most frequent principal diagnoses for hospitalizations among children and youth with autism?* we calculated then sorted CCSR codes in the primary diagnosis field in order of descending frequency. CCSR codes that explained at least fifty percent of all hospitalizations based on weighted estimates were considered the most frequent principal diagnoses. We then developed unadjusted and adjusted models of costs using mean costs and length of stay for the unadjusted models and general linearized models (GLM) with gamma distribution and log link for adjusted models to account for the positive skewness of the cost data. In our gamma model, those discharges with very high, or 'outlier' predicted hospital charges were downweighted in

the analysis (Barber & Thompson, 2004). Costs of the most frequent diagnoses associated with hospitalizations for children and youth with autism were adjusted using patient and hospital characteristics to develop estimates of mean costs while holding cost influences outside the presenting diagnosis constant. Mean length of stay was calculated using weighted estimates of length of stay. **Median length of stay was also calculated to control for extreme outliers – children or youth who had unusually long lengths of stay. While length of stay is skewed, we still include the mean to enable comparisons across other studies of hospitalization which most frequently include the mean rather than the median.**

To answer the fourth research question: *'Are children and youth with autism more likely to be hospitalized for the most frequent principal diagnoses compared to other children and youth?'*, we developed multivariate logistic regression models to determine the odds of hospitalization for each of the most frequent principal diagnoses for children and youth with autism compared to others while controlling for co-occurring conditions. Child, youth, and hospital characteristics were included in the analysis to determine the likelihood of children and youth with autism being hospitalized for a particular condition compared to their peers while holding all other characteristics constant.

Results

Characteristics of Hospitalized Children and Youth with Autism

Since the dataset contained population weights, charges, costs to charges ratios, and length of stay we could make national estimates on prevalence and costs of the most frequent hospital discharge diagnoses and the burden of the inpatient care (in average length of stay) for children and youth with autism. Children and youth with autism were hospitalized over 45,000 times in the United States in 2016 (Table 1). Mean costs per stay was $12, 457.55 with an

average length of stay of 5.87 days, for an estimated total of $561,200,169.95 in costs and 264,427.63 days spent in the hospital. In line with population trends in autism diagnoses, children and youth with autism who were hospitalized were predominantly White (64.1%), male (75.8%), and living in urban areas (80.5%), more so than other hospitalized children and youth ($p<0.000$ for each comparison). Children and youth with autism also tended to be younger and more affluent than their hospitalized peers ($p<0.000$ for each comparison). Half of the hospitalized children and youth with autism had health insurance through state Medicaid programs (52.3%), and a third were hospitalized in the Southern region of the United States (33.2%).

[INSERT TABLE 1 ABOUT HERE]

Most Frequent Principal Diagnoses for Hospitalizations

Table 2 presents the most frequent principal diagnoses for hospitalizations. Children and youth with autism were most frequently hospitalized for epilepsy, neurodevelopmental disorders, mental health conditions, asthma, pneumonia, and gastrointestinal disorders. These conditions accounted for over half (52.9%, or 23,768 discharges) of the hospitalizations among children and youth with autism aged 3 to 20 in 2016 (see Appendix 1 for a detailed breakout of the ICD-10-CM diagnoses by CCR code). Mental health conditions accounted for nearly a quarter of all hospitalizations (24.8%, or 11,192 discharges) among children and youth with autism. Neurodevelopmental disorders were also a top reason for hospitalization for children and youth with autism, presumably due to 3,214 hospital admissions among children and youth with autism having a primary discharge diagnosis of autism (see Appendix 2 for a detailed breakout of the diagnoses associated with neurodevelopmental disorders).

Compared to children and youth with only co-occurring conditions and those with neither, children and youth with autism had higher rates of hospitalizations for each of the most frequent principal diagnoses for hospitalization, except for depressive disorders, pneumonia, and asthma. Children and youth with autism had lower rates of pneumonia-related hospitalizations compared children with only co-occurring conditions but higher rates than children with neither.

[INSERT TABLE 2 ABOUT HERE]

Costs Associated with the Most Frequent Principal Diagnoses

The weighted average total costs are depicted in Table 3 and the length of stay associated with the most frequent principal diagnoses are depicted in Table 4. Total costs and length of stay across the hospital admissions of children and youth with autism were calculated by summing the product of the weighted average total costs or length of stay and the weighted frequency. The most frequent principal diagnoses among hospital admissions of children and youth with autism resulted in almost $200 million in hospital costs ($189,082,175) and an estimated 150,000 days spent in the hospital (154,186.39) in 2016. Mental health conditions showed some of the highest unadjusted average hospitalization costs, ranging from just over $6,000 to just under $10,000 per inpatient stay, with an average of $7342.04 in hospital costs per stay and an average length of stay of 8.4 days. Just over an estimated $82,172,111.7 in costs and 94,012.8 days of inpatient stays over the course of 2016 were attributed to mental health conditions. Diagnoses associated with neurodevelopmental disorders accounted for an estimated $30 million in hospital costs, and 35,000 days of inpatient stays among children and youth with autism in 2016. **Weighted average total costs per most frequent primary diagnosis were higher among admission of children and youth with autism compared to other children, with the exception of epilepsy,**

pneumonia, and gastrointestinal disorders. Costs associated with a primary discharge diagnosis of pneumonia and gastrointestinal disorders were lower among children and youth with autism ($9,581.86 and $9,065.82)) compared to children with other chronic conditions ($11,638.46 and $13,301.27) but higher than children with no chronic conditions ($5,870.65 and $5,707.17). Costs and length of stay per admission for depressive disorders were higher for children and youth with autism ($6,160.67 and 6.9) compared to children with only co-occurring conditions ($4,893.64 and 5.7), even though their rates were lower (7.2% compared to 11.5%).

[INSERT TABLE 3 & 4 ABOUT HERE]

The adjusted mean predicted costs associated with the most frequent principal diagnoses are presented in Table 5. Mental health conditions were the main drivers of costs of inpatient care, accounting for the top five highest adjusted predicted mean costs per stay. Bipolar and related disorders were associated with the highest costs at an estimated $12,316.46 adjusted mean costs per stay. **After adjusting for sociodemographic characteristics, we find the mean predicted costs associated with the most frequent primary discharge diagnosis for children and youth with autism were generally higher than those for other children. Exceptions occurred among children and youth with other co-occurring conditions and a primary discharge diagnosis of epilepsy, pneumonia, and gastrointestinal disorders – they tended to have higher adjusted mean predicted costs per stay for these diagnoses compared to children and youth with autism.**

[INSERT TABLE 5 ABOUT HERE]

Likelihood of hospitalization for the most frequent principal diagnoses

The likelihood of hospitalization for the most frequent principal diagnoses are presented in Table 6. After controlling for sociodemographic characteristics and co-occurring conditions, children and youth with autism were more likely to be hospitalized for the more expensive and lengthier (in terms of days spent in hospital) diagnoses, like mental health conditions, epilepsy, and gastrointestinal disorders compared to children and youth without autism (Table 4). The odds of children and youth with autism being admitted for any mental health condition were 2.5 times greater than the odds for other children and youth. However, the odds of hospitalization for pneumonia and asthma were lower among children and youth with autism compared to other children and youth while controlling for chronic conditions.

[INSERT TABLE 6 ABOUT HERE]

Discussion

Our study explored the most frequent principal diagnosis for hospitalization among children and youth with autism using the only nationally representative dataset of all-payer pediatric hospital discharges in the United States. Over half of the discharges for hospitalized children and youth with autism were for epilepsy, neurodevelopmental disorders, mental health conditions, asthma, pneumonia, and gastrointestinal disorders. Looking at each diagnosis separately, hospitalized children and youth with autism were more likely to have a principal hospitalization diagnosis for mental health conditions, epilepsy, and gastrointestinal disorders but less likely for asthma and pneumonia. The current study also confirm previous findings: that mental health diagnoses still rank among the leading causes of hospitalizations among children and youth with autism (Carbone et al., 2015; Kalb et al., 2019; Nayfack et al., 2014). This is concerning, as hospitalizations are the most intensive and costly way to address mental health issues, and effective community-based services may decrease hospitalization frequency, thus

leading to a decrease in medical costs and an increase in continuity of care (Chen, Bloodworth, et al., 2018; Chen, Novak, et al., 2018).

Unlike some previous research using the HCUP KID we included children and youth with a primary diagnosis of autism. Carbone et al. (2015) convincingly argue against including autism as a principle diagnosis since autism is not typically considered an admitting condition (Carbone et al., 2015). HCUP defines the primary diagnosis in the KID as the condition responsible for the hospital admission, potentially precluding discharges with autism in that field. Our research team decided to follow the lead of other researchers, such as Lokhandwala et al. (2012) who identified people with autism in HCUP databases using all diagnostic positions to include the primary position (Lokhandwala et al., 2012). Whether or not autism *should* be included as an admitting condition does not mean that it *is not* documented as such, and in our view does not justify excluding the ICD-10 codes associated with an autism diagnosis, which accounted for 7% of all the hospitalizations for children and youth with autism and a substantial burden in terms of costs ($7524.55 average mean cost per stay for an estimated total of $24,182,136 in 2016) and time spent in the hospital (9.03 mean length of stay for 29,0122.42 total days in 2016). However, we agree with Carbone et al. (2015) in speculating that those discharges with a principal discharge diagnosis of autism may actually represent a hospitalization for a mental health condition, which would strengthen our findings around psychiatric hospitalizations.

Policy and Practice Implications

The rates of children and youth with autism increased by 10% since the Nayfack et al. (2014) and Carbone et al. (2015) studies, from 1 in 68 children to 1 in 54 (Carbone et al., 2015; Maenner et al., 2020; Nayfack et al., 2014). In addition, in the time since Lokhandwala et al.

(2012) and Carbone et al. (2015) analyzed data collected in 2009, several policies and clinical guidelines were developed and implemented in an effort to address some of the disparities among children and youth with autism that historically lead to inpatient stays (Carbone et al., 2015; Lokhandwala et al., 2012). Furthermore, since 2009, 33 states have enacted new legislation or expanded existing legislation requiring health insurance providers to cover services for people with autism (*States With Specific Autism Mandates*, n.d.). Thus, this updated look at hospitalizations among children and youth with autism was necessary to help understand the possible effect of these policy changes and direct further efforts to ensure appropriate care for children and youth with autism. While it may be too early to tell, the new or expanding legislation targeting insurance coverage of therapies and treatments may have fallen short, as the rates of hospitalizations for mental health conditions in our study based on 2016 data are identical to the rates found by Carbone et al. (2015) using 2009 data (Carbone et al., 2015). If we use the same population as Carbone (excluding autism as a primary diagnosis and excluding diagnoses of Asperger's and pervasive developmental disorder), our rates of hospitalization for mental health conditions are 23% compared to Carbone et al. (2015) at 23.5%. Given that roughly half of the children and youth who were hospitalized in 2016 were Medicaid enrollees (52%), state-level efforts to provide supportive community-based services for mental health conditions could assist in state cost containment efforts. However, these services must be developed and implemented with the autism community (Benevides et al., 2020; den Houting et al., 2021; Nicolaidis, 2012; Nicolaidis et al., 2019) and improving well-being, not cost-offset, should be the primary goal (Sturm, 2001). Focusing solely on cost-offset can result in ineffective and harmful policies and practices.

Our results concur with previous research suggesting that community-based care may not be providing children and youth with autism with the care they need (L. Brookman-Frazee, Baker-Ericzén, et al., 2012; L. Brookman-Frazee, Drahota, et al., 2012; L. I. Brookman-Frazee et al., 2010; Cantor et al., 2020; Dingfelder & Mandell, 2011) or affecting inpatient services (Candon et al., 2018). This mismatch between need and provision may be due, in part, to the lack of involvement of the autism community in autism research (den Houting et al., 2021; Nicolaidis, 2012; Pellicano et al., 2014). The current study further suggests that the policies and clinical guidelines currently in place would better serve children and youth with autism by specifically targeting mental health conditions and societal factors that precipitate mental health conditions, like adverse childhood events. Children and youth with autism have higher rates of adverse childhood events, and experiencing more adverse childhood events is associated and increased risk of mental health issues among children and youth with autism (Hoover & Kaufman, 2018; Rigles, 2017). This is especially important considering the lack of behavioral health care services for children and youth with autism (Cantor et al., 2020), the need for additional resources for child psychiatrists who care for children and youth with autism in mental health crises (Kalb et al., 2017) and the relatively modest effect of Medicaid expansion on the growth of the number of child psychiatrists (McBain et al., 2021).

It is also important to note that the development of policies, clinical guidelines, and support services should not place the onus on children and youth with autism to ‘get better’ and avoid hospitalizations. A large body of literature points to contextual and societal issues that affect the health of children and youth with autism that are external to the child or youth. Bullying (Rodriguez et al., 2021), lack of acceptance (Cage et al., 2018), poorly-trained care providers (Carbone et al., 2013), police violence (Treisman, 2020), and promotion of therapies

deemed damaging and traumatic by the autism rights advocates are all social issues associated with poor outcomes among children and youth with autism. Widespread community use of one of the most common and controversial therapies for children and youth with autism – applied behavioral analysis (ABA) – has been called into question. Recent studies suggest that research on the effectiveness of ABA is potentially fraught with biases (Bottema-Beutel & Crowley, 2021; Tincani & Travers, 2019), and ABA is considered a dangerous and traumatic approach by some members of the autism community (Devita-Raeburn, 2016; McGill & Robinson, 2020; Ram, 2020; Sandoval-Norton & Shkedy, 2019). However, ABA supporters maintain the effectiveness of the therapy (Leaf et al., 2021). Regardless, appropriate support services must include community-based initiatives that address this and the aforementioned issues.

Limitations

HCUP data is administrative hospital discharge data, and as such excludes children and youth with autism who did not have service utilization during the study period and does not account for repeat utilization. This precludes any understanding of the rates of hospitalization among all children and youth with autism and any differences between children and youth with autism who experience hospitalization and those who do not.

Additionally, the identification of children and youth with autism in a hospital setting can have multiple origins (e.g., self-report, parent report, previous medical documentation) and be influenced by multiple factors. For example, utilization that is more specifically associated with a child or youth's autism may be more likely to include a code of autism. While we can be fairly certain that a hospital discharge with a diagnosis of autism accurately represents a child or youth with a true diagnosis, we are less certain of those discharges without a diagnosis of autism. A study of identifying children and youth

with autism using physician billing data in Nova Scotia, Canada found a sensitivity of 62.5% and specificity of 83%, with most of the inaccurate identifications being false negatives (Dodds et al., 2009). Thus, autism may have been underreported in our data, and this may have occurred for a variety of reasons, from low or limited insurance reimbursement policies to inaccurate reporting. Since autism is mostly coded as a secondary diagnosis it may be underreported if autism did not contribute to the reason for the hospitalization (Fingar et al., 2016). While Burke et al. (2014) found reasonably accurate identification of autism in administrative health plan data, we can still assume our data contains an undercount of the true number of hospitalizations associated with children and youth with autism. Should this be the case, our results would underestimate the differences between children and youth with autism and the other children and youth. Given the strong and significant differences we did find between children and youth with autism and other children and youth, we feel confident that our results represent true differences.

Future Research

Future research should include nationally representative, longitudinal, cohort studies of hospitalizations among children and youth with autism. Additionally, we do not fully understand the causes of mental health related hospitalizations among children and youth with autism, and what community services most effectively reduce hospitalization rates. Thus, there is a critical need to develop a conceptual model of factors associated mental health related hospitalizations among children and youth with autism and use this model to develop community interventions. This is especially critical considering the trauma children and youth with autism may experience around hospitalizations (Detsky & Krumholz, 2014; Krumholz, 2013; Muskat et

al., 2015; Siegel & Gabriels, 2014), and the association between 'safety' hospitalizations for mental health conditions and subsequent deaths by suicide (Olfson, 2017; Olfson et al., 2016).

Conclusion

Our study is the first study to explore the most frequent principal diagnoses for hospitalizations among children and youth with autism using the 2016 HCUP KID, ICD-10 diagnostic codes, costs instead of charges, and the updated clinical classification of autism. Given the relatively high rates of principal diagnoses for mental health conditions we found among hospitalized children and youth with autism, our results underscore the need for community-based supports and services addressing mental health for people with autism. Services provided in the community, if properly tailored to the needs of children and youth with autism, stand to prevent these expensive and potentially traumatic hospitalizations. A focus on contextual and social factors that lead to mental health issues among children with autism, like lack of autism acceptance in communities, is needed to shift the focus away from 'fixing' people with autism. Without an understanding of the factors surrounding mental health related hospitalizations among children and youth with autism, we cannot identify and implement effective and efficient community services to reduce hospitalizations. Consequently, rates of mental health related hospitalizations, associated costs, and exacerbation of other conditions may continue to climb.

References

Benevides, T. W., Shore, S. M., Palmer, K., Duncan, P., Plank, A., Andresen, M.-L., Caplan, R., Cook, B., Gassner, D., Hector, B. L., Morgan, L., Nebeker, L., Purkis, Y., Rankowski, B., Wittig, K., & Coughlin, S. S. (2020). Listening to the Autistic Voice: Mental Health Priorities to Guide Research and Practice in Autism from a Stakeholder-Driven Project. *Autism*, *24*(4), 822–833. https://doi.org/10.1177/1362361320908410

Bottema-Beutel, K., & Crowley, S. (2021). Pervasive Undisclosed Conflicts of Interest in Applied Behavior Analysis Autism Literature. *Frontiers in Psychology*, *12*. https://doi.org/10.3389/fpsyg.2021.676303

Brookman-Frazee, L., Baker-Ericzén, M., Stadnick, N., & Taylor, R. (2012). Parent Perspectives on Community Mental Health Services for Children with Autism Spectrum Disorders. *Journal of Child and Family Studies*, *21*(4), 533–544. https://doi.org/10.1007/s10826-011-9506-8

Brookman-Frazee, L., Drahota, A., Stadnick, N., & Palinkas, L. A. (2012). Therapist Perspectives on Community Mental Health Services for Children with Autism Spectrum Disorders. *Administration and Policy in Mental Health and Mental Health Services Research*, *39*(5), 365–373. https://doi.org/10.1007/s10488-011-0355-y

Brookman-Frazee, L. I., Taylor, R., & Garland, A. F. (2010). Characterizing Community-Based Mental Health Services for Children with Autism Spectrum Disorders and Disruptive Behavior Problems. *Journal of Autism and Developmental Disorders*, *40*(10), 1188–1201. https://doi.org/10.1007/s10803-010-0976-0

Burke, J., Jain, A., Yang, W., Kelly, J., Kaiser, M., Becker, L., Lawer, L., & Newschaffer, C. (2014). Does a claims diagnosis of autism mean a true case? *Autism*, *18*(3). https://doi.org/10.1177/1362361312467709

Cage, E., Di Monaco, J., & Newell, V. (2018). Experiences of Autism Acceptance and Mental Health in Autistic Adults. *Journal of Autism and Developmental Disorders*, *48*(2), 473–484. https://doi.org/10.1007/s10803-017-3342-7

Candon, M. K., Barry, C. L., Epstein, A. J., Marcus, S. C., Kennedy-Hendricks, A., Xie, M., & Mandell, D. S. (2018). The Differential Effects of Insurance Mandates on Health Care Spending for Children's Autism Spectrum Disorder. *Medical Care*, *56*(3), 228–232. Embase. https://doi.org/10.1097/MLR.0000000000000863

Cantor, J., McBain, R. K., Kofner, A., Stein, B. D., & Yu, H. (2020). Fewer Than Half Of US Mental Health Treatment Facilities Provide Services For Children With Autism Spectrum Disorder. *Health Affairs*, *39*(6), 968–974. https://doi.org/10.1377/hlthaff.2019.01557

Carbone, P. S., Murphy, N. A., Norlin, C., Azor, V., Sheng, X., & Young, P. C. (2013). Parent and Pediatrician Perspectives Regarding the Primary Care of Children with Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders*, *43*(4), 964–972. https://doi.org/10.1007/s10803-012-1640-7

Carbone, P. S., Young, P. C., Stoddard, G. J., Wilkes, J., & Trasande, L. (2015). A Comparison of Ambulatory Care Sensitive Hospitalizations Among Children with and Without Autism Spectrum Disorder. *Academic Pediatrics*, *15*(6), 626–635. Scopus. https://doi.org/10.1016/j.acap.2015.07.006

Chen, J., Bloodworth, R., Novak, P., Cook, B. L., Goldman, H. H., Rendall, M. S., Thomas, S. B., & Reynolds, C. F. (2018). Reducing Preventable Hospitalization and Disparity: Association with Local Health Department Mental Health Promotion Activities. *American Journal of Preventive Medicine*, *54*(1), 103–112. https://doi.org/10.1016/j.amepre.2017.10.011

Chen, J., Novak, P., & Goldman, H. (2018). Public Health System-Delivered Mental Health Preventive Care Links to Significant Reduction of Health Care Costs. *Population Health Management*, *21*(6), 462–468. https://doi.org/10.1089/pop.2018.0010

Croen, L. A., Najjar, D. V., Ray, G. T., Lotspeich, L., & Bernal, P. (2006). A Comparison of Health Care Utilization and Costs of Children with and Without Autism Spectrum Disorders in a Large Group-Model Health Plan. *Pediatrics*, *118*(4), e1203–e1211. Scopus. https://doi.org/10.1542/peds.2006-0127

Cummings, J. R., Lynch, F. L., Rust, K. C., Coleman, K. J., Madden, J. M., Owen-Smith, A. A., Yau, V. M., Qian, Y., Pearson, K. A., Crawford, P. M., Massolo, M. L., Quinn, V. P., & Croen, L. A. (2016). Health Services Utilization Among Children With and Without Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders*, *46*(3), 910–920. https://doi.org/10.1007/s10803-015-2634-z

den Houting, J., Higgins, J., Isaacs, K., Mahony, J., & Pellicano, E. (2021). 'I'm Not Just a Guinea Pig': Academic and Community Perceptions of Participatory Autism Research. *Autism*, *25*(1), 148–163. https://doi.org/10.1177/1362361320951696

Detsky, A. S., & Krumholz, H. M. (2014). Reducing the Trauma of Hospitalization. *JAMA*, *311*(21), 2169–2170. https://doi.org/10.1001/jama.2014.3695

Devita-Raeburn, E. (2016, August 11). *Is the Most Common Therapy for Autism Cruel?* The Atlantic. https://www.theatlantic.com/health/archive/2016/08/aba-autism-controversy/495272/

Dingfelder, H. E., & Mandell, D. S. (2011). Bridging the Research-to-Practice Gap in Autism Intervention: An Application of Diffusion of Innovation Theory. *Journal of Autism and Developmental Disorders, 41*(5), 597–609. https://doi.org/10.1007/s10803-010-1081-0

Dodds, L., Spencer, A., Shea, S., Fell, D., Armson, B. A., Allen, A. C., & Bryson, S. (2009). Validity of autism diagnoses using administrative health data. *Chronic Diseases in Canada*, *29*(3), 102–107.

Doupnik, S., Rodean, J., Zima, B. T., Coker, T. R., Worsley, D., Rehm, K. P., Gay, J. C., Hall, M., & Marcus, S. (2018). Readmissions After Pediatric Hospitalization for Suicide Ideation and Suicide Attempt. *Journal of Hospital Medicine, 13*(11), 743–751. Scopus. https://doi.org/10.12788/jhm.3070

Elixhauser, A., Steiner, C., Harris, D. R., & Coffey, R. M. (1998). Comorbidity Measures for Use with Administrative Data. *Medical Care*, *36*(1), 8–27.

Elixhauser Comorbidity Software Refined for ICD-10-CM. (n.d.). Retrieved July 8, 2021, from https://www.hcup-us.ahrq.gov/toolssoftware/comorbidityicd10/comorbidity_icd10.jsp

Fingar, K., Owens, P., Barrett, M., & Steiner, C. (2016). *Using the HCUP databases to study incidence and prevalence.* (No. 2016–06; HCUP Methods Series). U.S. Agency for Healthcare Research and Quality. : http://www.hcup-us.ahrq.gov/reports/methods/methods.jsp

Gao, J., Moran, E., Li, Y.-F., & Almenoff, P. L. (2014). Predicting Potentially Avoidable Hospitalizations. *Medical Care*, *52*(2), 164–171.

Hand, B. N., Boan, A. D., Bradley, C. C., Charles, J. M., & Carpenter, L. A. (2019). Ambulatory Care Sensitive Admissions in Individuals with Autism Spectrum Disorder, Intellectual Disability, and Population Controls. *Autism Research*, *12*(2), 295–302. APA PsycInfo®. https://doi.org/10.1002/aur.2050

Hoover, D. W., & Kaufman, J. (2018). Adverse Childhood Experiences in Children with Autism Spectrum Disorder. *Current Opinion in Psychiatry*, *31*(2), 128–132. https://doi.org/10.1097/YCO.0000000000000390

Iannuzzi, D. A., Cheng, E. R., Broder-Fingert, S., & Bauman, M. L. (2015). Brief Report: Emergency Department Utilization by Individuals with Autism. *Journal of Autism and Developmental Disorders*, *45*(4), 1096–1102. Scopus. https://doi.org/10.1007/s10803-014-2251-2

Kalb, L. G., Stuart, E. A., Mandell, D. S., & Olfson, M. (2017). Management of Mental Health Crises Among Youths with and Without ASD: A National Survey of Child Psychiatrists. *Psychiatric …*, *68*(Query date: 2021-06-14 16:14:42), 1039–1045. https://doi.org/10.1176/appi.ps.201600332

Kalb, L. G., Stuart, E. A., & Vasa, R. A. (2019). Characteristics of Psychiatric Emergency Department Use Among Privately Insured Adolescents with Autism Spectrum Disorder. *Autism*, *23*(3), 566–573. Scopus. https://doi.org/10.1177/1362361317749951

Kohane, I. S., McMurry, A., Weber, G., MacFadden, D., Rappaport, L., Kunkel, L., Bickel, J., Wattanasin, N., Spence, S., Murphy, S., & Churchill, S. (2012). The co-morbidity burden of children and young adults with autism spectrum disorders. *PloS One*, *7*(4). Scopus. https://doi.org/10.1371/journal.pone.0033224

Krumholz, H. M. (2013, January 9). *Post-Hospital Syndrome—An Acquired, Transient Condition of Generalized Risk* (world) [N-perspective]. Https://Doi.Org/10.1056/NEJMp1212324; Massachusetts Medical Society. https://doi.org/10.1056/NEJMp1212324

Lapillonne, A., Regnault, A., Gournay, V., Gouyon, J.-B., Gilet, H., Anghelescu, D., Miloradovich, T., Arnould, B., & Moriette, G. (2012). Impact on Parents of Bronchiolitis Hospitalization of Full-Term, Preterm and Congenital Heart Disease Infants. *BMC Pediatrics*, *12*(1), 171. https://doi.org/10.1186/1471-2431-12-171

Leaf, J. B., Cihon, J. H., Leaf, R., McEachin, J., Liu, N., Russell, N., Unumb, L., Shapiro, S., & Khosrowshahi, D. (2021). Concerns About ABA-Based Intervention: An Evaluation and Recommendations. *Journal of Autism and Developmental Disorders*. https://doi.org/10.1007/s10803-021-05137-y

Leslie, D. L., & Martin, A. (2007). Health Care Expenditures Associated with Autism Spectrum Disorders. *Archives of Pediatrics and Adolescent Medicine*, *161*(4), 350–355. Scopus. https://doi.org/10.1001/archpedi.161.4.350

Lokhandwala, T., Khanna, R., & West-Strum, D. (2012). Hospitalization burden among individuals with autism. *Journal of Autism and Developmental Disorders*, *42*(1), 95–104. Scopus. https://doi.org/10.1007/s10803-011-1217-x

Maenner, M. J., Shaw, K. A., Baio, J., Washington, A., Patrick, M., DiRienzo, M., Christensen, D. L., Wiggins, L. D., Pettygrove, S., Andrews, J. G., Lopez, M., Hudson, A., Baroud, T., Schwenk, Y., White, T., Rosenberg, C. R., Lee, L.-C., Harrington, R. A., Huston, M., … Dietz, P. M. (2020). Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years—Autism and Developmental Disabilities Monitoring Network, 11 Sites, United

States, 2016. *MMWR Surveillance Summaries*, *69*(4), 1–12. https://doi.org/10.15585/mmwr.ss6904a1

Mandell, D. S. (2008a). Psychiatric Hospitalization Among Children with Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders*, *38*(6), 1059–1065. Scopus. https://doi.org/10.1007/s10803-007-0481-2

Mandell, D. S. (2008b). Psychiatric Hospitalization Among Children with Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders*, *38*(6), 1059–1065. APA PsycInfo®. https://doi.org/10.1007/s10803-007-0481-2

Mandell, D. S., Candon, M. K., Xie, M., Marcus, S. C., Kennedy-Hendricks, A., Epstein, A. J., & Barry, C. L. (2019). Effect of outpatient service utilization on hospitalizations and emergency visits among youths with autism spectrum disorder. *Psychiatric Services*, *70*(10), 888–893. APA PsycInfo®. https://doi.org/10.1176/appi.ps.201800290

Mandell, D. S., Cao, J., Ittenbach, R., & Pinto-Martin, J. (2006). Medicaid Expenditures for Children with Autistic Spectrum Disorders: 1994 to 1999. *Journal of Autism and Developmental Disorders*, *36*(4), 475–485. APA PsycInfo®. https://doi.org/10.1007/s10803-006-0088-z

Mandell, D. S., Xie, M., Morales, K. H., Lawer, L., McCarthy, M., & Marcus, S. C. (2012). The Interplay of Outpatient Services and Psychiatric Hospitalization Among Medicaid-Enrolled Children with Autism Spectrum Disorders. *Archives of Pediatrics and Adolescent Medicine*, *166*(1), 68–73. Embase. https://doi.org/10.1001/archpediatrics.2011.714

McBain, R. K., Cantor, J. H., Kofner, A., Stein, B. D., & Yu, H. (2021). Brief Report: Medicaid Expansion and Growth in the Workforce for Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*. https://doi.org/10.1007/s10803-021-05044-2

McGill, O., & Robinson, A. (2020). "Recalling hidden harms": Autistic experiences of childhood applied behavioural analysis (ABA). *Advances in Autism*, *ahead-of-print*(ahead-of-print). https://doi.org/10.1108/AIA-04-2020-0025

Muskat, B., Riosa, P. B., Nicholas, D. B., Roberts, W., Stoddart, K. P., & Zwaigenbaum, L. (2015). Autism comes to the hospital: The experiences of patients with autism spectrum disorder, their parents and health-care providers at two Canadian paediatric hospitals. *Autism*, *19*(4), 482–490. APA PsycInfo®. https://doi.org/10.1177/1362361314531341

Nayfack, A. M., Huffman, L. C., Feldman, H. M., Chan, J., Saynina, O., & Wise, P. H. (2014). Hospitalizations of Children with Autism Increased from 1999 to 2009. *Journal of Autism and Developmental Disorders*, *44*(5), 1087–1094. Scopus. https://doi.org/10.1007/s10803-013-1965-x

Nicolaidis, C. (2012). What Can Physicians Learn from the Neurodiversity Movement? *AMA Journal of Ethics*, *14*(6), 503–510. https://doi.org/10.1001/virtualmentor.2012.14.6.oped1-1206

Nicolaidis, C., Raymaker, D., Kapp, S. K., Baggs, A., Ashkenazy, E., McDonald, K., Weiner, M., Maslak, J., Hunter, M., & Joyce, A. (2019). The AASPIRE Practice-Based Guidelines for the Inclusion of Autistic Adults in Research as Co-Researchers and Study Participants. *Autism*, *23*(8), 2007–2019. https://doi.org/10.1177/1362361319830523

Olfson, M. (2017). Suicide Risk After Psychiatric Hospital Discharge. *JAMA Psychiatry*, *74*(7), 669–670. https://doi.org/10.1001/jamapsychiatry.2017.1043

Olfson, M., Wall, M., Wang, S., Crystal, S., Liu, S.-M., Gerhard, T., & Blanco, C. (2016). Short-term Suicide Risk After Psychiatric Hospital Discharge. *JAMA Psychiatry*, *73*(11), 1119–1126. https://doi.org/10.1001/jamapsychiatry.2016.2035

Peacock, G., Amendah, D., Ouyang, L., & Grosse, S. D. (2012). Autism Spectrum Disorders and Health Care Expenditures: The Effects of Co-Occurring Conditions. *Journal of Developmental and Behavioral Pediatrics*, *33*(1), 2–8. APA PsycInfo®. https://doi.org/10.1097/DBP.0b013e31823969de

Pellicano, E., Dinsmore, A., & Charman, T. (2014). What Should Autism Research Focus Upon? Community Views and Priorities from the United Kingdom. *Autism*, *18*(7), 756–770. https://doi.org/10.1177/1362361314529627

Ram, J. (2020, June 2). *I am a disillusioned BCBA: Autistics are right about ABA*. NeuroClastic. https://neuroclastic.com/2020/06/02/i-am-a-disillusioned-bcba-autistics-are-right-about-aba/

Righi, G., Benevides, J., Mazefsky, C., Siegel, M., Sheinkopf, S. J., & Morrow, E. M. (2018). Predictors of Inpatient Psychiatric Hospitalization for Children and Adolescents with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, *48*(11), 3647–3657. APA PsycInfo®. https://doi.org/10.1007/s10803-017-3154-9

Rigles, B. (2017). The Relationship Between Adverse Childhood Events, Resiliency and Health Among Children with Autism. *Journal of Autism and Developmental Disorders*, *47*(1), 187–202. https://doi.org/10.1007/s10803-016-2905-3

Rodriguez, G., Drastal, K., & Hartley, S. L. (2021). Cross-lagged model of bullying victimization and mental health problems in children with autism in middle to older childhood. *Autism*, *25*(1), 90–101. https://doi.org/10.1177/1362361320947513

Sandoval-Norton, A. H., & Shkedy, G. (2019). How much compliance is too much compliance: Is long-term ABA therapy abuse? *Cogent Psychology*, *6*(1), 1641258. https://doi.org/10.1080/23311908.2019.1641258

Schlenz, A. M., Carpenter, L. A., Bradley, C., Charles, J., & Boan, A. (2015). Age Differences in Emergency Department Visits and Inpatient Hospitalizations in Preadolescent and Adolescent Youth with Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders*, *45*(8), 2382–2391. Scopus. https://doi.org/10.1007/s10803-015-2405-x

Siegel, M., & Gabriels, R. L. (2014). Psychiatric hospital treatment of children with autism and serious behavioral disturbance. *Child and Adolescent Psychiatric Clinics of North America*, *23*(1), 125–142. APA PsycInfo®. https://doi.org/10.1016/j.chc.2013.07.004

Simonoff, E., Pickles, A., Charman, T., Chandler, S., Loucas, T., & Baird, G. (2008). Psychiatric Disorders in Children with Autism Spectrum Disorders: Prevalence, Comorbidity, and Associated Factors in a Population-Derived Sample. *Journal of the American Academy of Child & Adolescent Psychiatry*, *47*(8), 921–929. https://doi.org/10.1097/CHI.0b013e318179964f

Sparks, B., Cooper, J., Hayes, C., & Williams, K. (2018). Constipation in Children with Autism Spectrum Disorder Associated with Increased Emergency Department Visits and Inpatient Admissions. *Journal of Pediatrics*, *202*((Sparks B., brandon.sparks@nationwidechildrens.org; Hayes C.; Williams K.) Division of Gastroenterology, Hepatology, and Nutrition, Nationwide Children's Hospital, Columbus, OH, United States), 194–198. Embase. https://doi.org/10.1016/j.jpeds.2018.05.004

States With Specific Autism Mandates. (n.d.). American Speech-Language-Hearing Association; American Speech-Language-Hearing Association. Retrieved July 13, 2021, from https://www.asha.org/advocacy/state/states-specific-autism-mandates/

Stulz, N., Nevely, A., Hilpert, M., Bielinski, D., Spisla, C., Maeck, L., & Hepp, U. (2015). Referral to Inpatient Treatment Does not Necessarily Imply a Need for Inpatient Treatment. *Administration and Policy in Mental Health and Mental Health Services Research*, *42*(4), 474–483. https://doi.org/10.1007/s10488-014-0561-5

Sturm, R. (2001). Economic Grand Rounds: The Myth of Medical Cost Offset. *Psychiatric Services*, *52*(6), 738–740. https://doi.org/10.1176/appi.ps.52.6.738

Tincani, M., & Travers, J. (2019). Replication Research, Publication Bias, and Applied Behavior Analysis. *Perspectives on Behavior Science*, *42*(1), 59–75. https://doi.org/10.1007/s40614-019-00191-5

Treisman, R. (2020). *13-Year-Old Boy With Autism Disorder Shot By Salt Lake City Police*. NPR.Org. https://www.npr.org/2020/09/09/910975499/autistic-13-year-old-boy-shot-by-salt-lake-city-police

Turcotte, P., Shea, L. L., & Mandell, D. (2018). School discipline, hospitalization, and police contact overlap among individuals with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *48*(3), 883–891. APA PsycInfo®. https://doi.org/10.1007/s10803-017-3359-y

Van Horn, E. R., & Kautz, D. (2007). Promotion of Family Integrity in the Acute Care Setting: A Review of the Literature. *Dimensions of Critical Care Nursing*, *26*(3), 101–107. https://doi.org/10.1097/01.DCC.0000267803.64734.c1

Wu, C.-M., Kung, P.-T., Li, C.-I., & Tsai, W.-C. (2015). The Difference in Medical Utilization and Associated Factors Between Children and Adolescents with and Without Autism Spectrum Disorders. *Research in Developmental Disabilities*, *36*, 78–86. APA PsycInfo®. https://doi.org/10.1016/j.ridd.2014.09.019

Zerbo, O., Massolo, M. L., Qian, Y., & Croen, L. A. (2015). A Study of Physician Knowledge and Experience with Autism in Adults in a Large Integrated Healthcare System. *Journal of Autism and Developmental Disorders*, *45*(12), 4002–4014. https://doi.org/10.1007/s10803-015-2579-2

- HCUP Kids' Inpatient Database (KID). Healthcare Cost and Utilization Project (HCUP). 2006 and 2009. Agency for Healthcare Research and Quality, Rockville, MD. www.hcup-us.ahrq.gov/kidoverview.jsp
- HCUP Clinical Classifications Software Refined (CCSR) for ICD-10-CM diagnoses, v2021.2. Healthcare Cost and Utilization Project (HCUP). Agency for Healthcare Research and Quality, Rockville, MD. www.hcup-us.ahrq.gov/toolssoftware/ccsr/dxccsr.jsp. Accessed August 10, 2020.
- HCUP Cost-to-Charge Ratio (CCR) for the Kids' Inpatient Database (KID). Healthcare Cost and Utilization Project (HCUP). 2016. Agency for Healthcare Research and Quality, Rockville, MD. www.hcup-us.ahrq.gov/db/ccr/ip-ccr/ip-ccr.jsp. Accessed May 16, 2020

Table 1. Weighted discharge and hospital characteristics of children and youth ages 3-20, HCUP KID, 2016

Characteristic	Autism (n=45,049; 2.5%) n (%)	Co-occurring conditions (n=983,639; 56.0%) n (%)	No co-occurring conditions (n=737,898; 42.0%) n (%)
Cost, mean (SD)	Mean= 12,457.55 (41,811.52)	Mean= 13,476.59 (49,009.74)	Mean= 8,174.30 (16,710.29)
Length of Stay, mean (SD)	Mean=5.87 (14.02)	Mean=4.87 (10.20)	Mean=3.01 (5.44)
Age (years), mean (SD)	Mean=12.43 (5.7)	Mean=13.73 (6.43)	Mean=14.80 (6.43)
3-5	4,654 (10.3)	114,029 (11.6)	64,372 (8.9)
6-10	10,804 (23.9)	157,249 (15.9)	100,996 (14.0)
11-15	15,327 (34.0)	231,705 (23.5)	124,048 (17.1)
16-20	14,264 (31.6)	480,655 (48.8)	435,624 (60.0)
Gender			
Female	10,939 (24.2)	550,288 (55.9)	498,094 (68.6)
Race			
White	26,522 (64.1)	459,852 (50.7)	32,3477 (47.6)
Black	5,627 (13.6)	188,171 (20.7)	122,580 (18.0)
Hispanic	6,028 (14.5)	180,684 (19.9)	177,146(26.1)
Asian or Pacific Islander	964 (2.3)	24,864 (2.7)	17,216 (2.5)
Native American	197 (0.05)	8,819 (0.9)	6,316 (0.9)
Other	1,994 (4.8)	43,477 (4.8)	32,130 (4.7)
Median household income			
$1-42,999	11,613 (26.1)	312,551 (32.3)	255,983 (35.8)
$43,000-53,999	11,025 (24.8)	236,494 (24.4)	184,508 (25.8)
$54,000-70,999	11,039 (24.8)	225,735 (23.3)	158,230 (22.1)
$71,000+	10,764 (24.2)	192,995 (19.9)	116,424 (16.3)
Primary Payer			
Medicare	418 (0.93)	7,206 (0.73)	2,621 (0.36)
Medicaid	23,191 (52.3)	494,754 (50.3)	407,815 (56.4)
Private	18,716 (41.5)	401,297 (40.8)	261,430 (36.1)
Other[1]	2,679.6 (5.9)	79,053 (8.0)	51,746 (7.1)
Location of patient: Rural	8,819 (19.5)	214,204 (21.7)	184,038 (25.4)
Evidence of ED service use	22,092 (49.0)	512,913 (52.1)	292,196 (40.2)
Region of hospital			
Northeast	10,438 (23.1)	182,020 (18.5)	109,027 (15.0)
Midwest	11,292 (25.0)	231,754 (23.5)	148,018 (20.4)
South	14,994 (33.2)	366,733 (37.2)	304,316 (42.0)
West	8,325 (18.4)	203,133 (20.6)	164,039 (22.6)
Hospital bed size			
Small	3,986 (8.85)	110,740 (11.2)	102,316 (14.1)
Medium	10,494 (23.3)	238,102 (24.2)	185,217 (25.5)
Large	30,569 (67.8)	634,797 (64.5)	437,868 (60.4)
Hospital ownership			
Government[2]	5,661(12.5)	127,735 (12.9)	101,492 (14.0)
Private	36,005 (79.9)	752,948 (76.5)	512,282 (70.6)
Private	3,383 (7.51)	102,957 (10.4)	111,626 (15.4)

Note. Adjusted Wald test of differences in proportions where Prob>f = 0.000 and is considered significant. Every difference in proportions was significantly different.

[1]Includes the HCUP categories 'self-pay', 'no charge', and 'other' [2]Non-federal

Table 2. Weighted prevalence of most frequent primary discharge diagnoses in 1,754,089 discharges of children and youth ages 3-20, HCUP KID 2016

Diagnoses[+]	Autism (n=45,049) n (%) (95% CI)	Co-occurring conditions (n=983,639) n (%) (95% CI)	No co-occurring conditions (n=737,898) n (%) (95% CI)
Epilepsy: Convulsions	5,670 (12.5%) (4876- 6464)	46,203 (4.7%) (40885- 51522)	N/A
Neurodevelopmental disorders [*]	3,938 (8.7%) (3224-4652)	2,584 (0.26%) (2012-3156)	5,042 (0.68%) (4020- 6064)
Depressive disorders	3,264 (7.2%) (2838-3689)	113,996 (11.5%) (101231- 126761)	N/A
Other specified and unspecified mood disorders	2,480 (5.5%) (1905- 3056)	12,266 (1.2%) (10051- 14480)	13,575 (1.8%) (10277- 16872)
Disruptive, impulse control, and conduct disorders	2,236 (4.9%) (1501- 2971)	6,018 (0.61%) (4601- 7435)	5,967 (0.81%) (5967- 4544)
Bipolar and related disorders	1,896 (4.2%) (1584-2208)	21,023 (2.1%) (18617-23430)	9,122 (1.2%) (7738-10505)
Schizophrenia spectrum and other psychotic disorders	1,316 (2.9%) (1153- 1479)	18,971 (1.9%) (17361-20581)	N/A
Pneumonia (except that caused by tuberculosis)	1,034 (2.3%) (908-1160)	33,308 (3.3%) (30640-35977)	14,172 (1.9%) (13096-15248)
Asthma	964 (2.1%) (825-1102)	65,761 (6.6) (59533-71990)	N/A
Other specified and unspecified gastrointestinal disorders	925 (2.0%) (784-1065)	5,663 (0.58%) (4970-6356)	5,991 (0.81%) (5289-6692)

Note: N/A denotes very small or zero cell count. [*]7.1% of discharges with a diagnosis of ASD had a primary discharge diagnosis of ASD [+]the ten most common primary discharge diagnoses group by clinical classifications account for 52.9% of all primary discharge diagnoses

Table 3. Weighted average total costs in 2016 dollars of most frequent primary discharge diagnoses for discharges of children and youth 3-20, HCUP KID, 2016

	Total Costs, *SE* (95% CI)		
Diagnosis	Autism	Co-occurring condition	No co-occurring condition
Epilepsy: Convulsions	$9485.14, *518.80* (8467.80-10502.48)	$9672.12, *421.84* (8845.07-10499.17)	N/A
Neurodevelopmental disorders	$7451.99, *442.17* (6584.98-8319)	$6810.41, *524.43* (5782.03-7838.80)	$6222.55, *427.00* (5385.26-7059.84)
Depressive Disorders	$6160.67, *264.25* (5642.53-6678.816)	$4893.64, *178.12* (4544.41-5242.87)	N/A
Other specified and unspecified mood disorders	$6089.58, *506.35* (5096.65-7082.52)	$5472.15, *328.55* (4827.91-6116.38)	$5150.57, *403.82* (4358.74-5942.41)
Disruptive, impulse control, and conduct disorders	$9367.02, *1018.11* (7370.54-11363.51)	$6449.45, *401.35* (5662.48-7236.41)	$6448.33, *605.78* (5260.53-7636.13)
Bipolar and related disorders	$6976.95, *451.6307* (6091.39-7862.51)	$6181.29, *234.22* (5722.07-6640.52)	$5904.90, *310.20* (5296.71-6513.09)
Schizophrenia spectrum and other psychotic disorders	$9714.56, *666.49* (8407.67-11021.45)	$8811.67, *292.83* (8237.54-9385.80)	N/A
Pneumonia (except that caused by tuberculosis)	$9581.86, *906.88* (7803.63-11360.09)	$11638.46, *519.52* (10619.91-12657)	$5870.65, *249.91* (5380.68-6360.62)
Asthma	$5699.24, *635.7996* (4452.49- 6946)	$5189.83, *118.10* (4958.29-5421.37)	N/A
Other specified and unspecified gastrointestinal disorders	$9,065.82, *1041.18* (7023.90-11107.75)	$13,301.27, *754.75* (11821.5-14781.04)	$5,707.17, *269.58* (5178.61-6235.74)

Note: N/A denotes very small/zero cell count.

Table 4. Length of stay of most frequent primary discharge diagnoses for discharges of children and youth ages 3-20, HCUP KID, 2016

	LOS in days mean, *SE* (95% CI)			LOS in days median (25^{th}, 75^{th} pct)		
Diagnosis	Autism	Co-occurring conditions	No co-occurring conditions	Autism	Co-occurring conditions	No co-occurring conditions
Epilepsy: Convulsions	2.8, *0.10* (2.6-3.0)	2.69, *0.05* (2.58-2.80)	N/A	2 (1-3)	2 (1-3)	N/A
Neurodevelopmental disorders	8.83, *0.73* (7.40-10.27)	7.80, *0.64* (6.53-9.06)	7.04, *0.40* (6.14-7.84)	6 (3-9)	6 (3-8)	5 (3-8)
Depressive Disorders	6.9, *0.23* (6.5-7.4)	5.7, *0.14* (5.51-6.06)	N/A	6 (4-8)	5 (3-7)	N/A
Other specified and unspecified mood disorders	7.1, *0.39* (6.3-7.8)	6.6, 0.36 (5.92-7.34)	6.7, *0.70* (5.39-8.17)	5 (3-8)	5 (3-7)	5 (3-7)
Disruptive, impulse control, and conduct disorders	9.5, *0.89* (77-11.2)	7.4, *0.40* (6.65-8.23)	7.2, *0.38* (6.5-8.05)	6 (4-10)	5 (3-8)	5 (3-8)
Bipolar and related disorders	9.6, *1.01* (7.7-11.6)	7.5, *0.24* (7.08-8.06)	7.6, *0.48* (6.73-8.62)	6 (4-9)	6 (4-8)	6 (4-8)
Schizophrenia spectrum and other psychotic disorders	11.1, *0.75* (9.6-12.6)	10.0, *0.24* (9.5-10.4)	N/A	6 (4-11)	7 (4-11)	N/A
Pneumonia (except that caused by tuberculosis)	3.7, *0.18* (3.3-4.0)	4.0, *0.10* (3.88-4.29)	2.8, *0.06* (2.7-2.9)	3 (2-4)	3 (2-4)	2 (1-3)
Asthma	2.1, *0.95* (1.9-2.2)	2.0, *0.27* (2.0-2.1)	N/A	2 (1-2)	2 (1-3)	N/A
Other specified and unspecified gastrointestinal disorders	3.8, *0.32* (3.2-4.5)	4.7, *0.19* (4.36-5.11)	2.4, *0.06* (2.28-2.54)	2 (2-4)	3 (3-5)	2 (1-3)

Note: N/A denotes zero cell count.

Table 5.
Adjusted mean predicted costs of most frequent primary discharge diagnosis for discharges of children and youth ages 3-20, HCUP KID 2016

	Adjusted mean costs in 2016 dollars, *SE*		
Primary discharge diagnosis	Autism	Co-occurring conditions	No co-occurring condition
Epilepsy: Convulsions	$9,198.77, *612.23*	$9,408.21, *559.94*	N/A
Neurodevelopmental disorders	$6,516.97, *577.41*	$6,142.24, *571.84*	$5,228.65, *467.00*
Depressive disorders	$11,002.21, *1283.294*	$8,770.918, *993.40*	N/A
Other specified and unspecified mood disorders	$9,796.47, *1558.74*	$9450.22, *1348.58*	$7877.28, *1090.41*
Disruptive, impulse control, and conduct disorders	$11,642.81, *1797.02*	$7,832.22, *1054.43*	$7196.44, *1062.09*
Bipolar and related disorders	$12,316.46, *2259.96*	$11,706.64, *2112.36*	$10,284.75, *1879.60*
Schizophrenia spectrum and other psychotic disorders	$11,540.12, *1627.86*	$10,506.04, *1325.49*	N/A
Pneumonia (except that caused by tuberculosis)	$7,923.312, *757.20*	$9,993.20, *480.44*	$5,589.95, *267.38*
Asthma	$5455.60, *618.25*	$4878.15, *161.35*	N/A
Other specified and unspecified gastrointestinal disorders	$8,420.669, *1199.71*	$11,909.58, *1038.06*	$5305.16, *372.20*

Note: Adjusted for race, gender, age, primary payor, patient location (rural vs, urban), average quartile income of patient (based on zip code), emergency department use, hospital location (region), hospital bed size, and hospital ownership and skewness using gamma GLM modeling. N/A denotes zero cell count.

Table 6.Adjusted likelihood of most frequent primary diagnoses among discharges of children and youth ages 3-20 with autism, HCUP KID, 2016

Diagnosis	Adjusted odd ratio* (CI)
Epilepsy: Convulsions	4.06 (3.78-4.36)
Depressive disorders	1.15 (1.05-1.26)
Other specified and unspecified mood disorders	3.06 (2.63-3.57)
Disruptive, impulse control, and conduct disorders	5.46 (4.55-6.56)
Bipolar and related disorders	2.50 (2.27-2.76)
Schizophrenia spectrum and other psychotic disorders	2.47 (2.22-2.74)
Pneumonia (except that caused by tuberculosis)	0.69 (0.63-0.76)
Asthma	0.40 (0.36-0.41)
Other specified and unspecified gastrointestinal disorders	2.68 (2.42 -2.98)
Any mental health condition[1]	2.47 (2.29-2.66)

Note: Adjusted for co-occurring conditions, race, gender, age, primary payor, patient location (rural vs, urban), average quartile income of patient (based on zip code), emergency department use, hospital location (region), hospital bed size, and hospital ownership.
** All odds ratios are significant at p=0.000 [1]Depressive disorders; other specified and unspecified mood disorders; disruptive, impulse control, and conduct disorders; bipolar and related disorders; and schizophrenia spectrum and other psychotic disorders*

Appendix 1

Appendix 2