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Dental Homes for Children With Autism:

A Longitudinal Analysis of Iowa Medicaid's I-Smile Program

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Abstract

Introduction—Medicaid-enrolled children with autism spectrum disorder (ASD) encounter significant barriers to dental care. Iowa's I-Smile Program was implemented in 2006 to improve dental use for all children in Medicaid. This study compared dental home and preventive dental utilization rates for Medicaid-enrolled children by ASD status and within three time periods (pre-implementation, initial implementation, maturation) and determined I-Smile's longitudinal influence on ASD-related dental use disparities.

Methods—Data from 2002–2011 were analyzed for newly Medicaid-enrolled children aged 3–17 years (N=30,059), identified each child's ASD status, and assessed whether the child had a dental home or utilized preventive dental care. Log-linear regression models were used to generate rate ratios. Analyses were conducted in 2015.

Results—In 2003–2011, 9.8% of children with ASD had dental homes compared with 8% of children without ASD; 36.3% of children with ASD utilized preventive care compared to 45.7% of children without ASD. There were no significant differences in dental home rates by ASD status during pre-implementation, initial implementation, or maturation. There were no significant differences in preventive dental utilization by ASD status during pre-implementation or initial implementation, but children with ASD were significantly less likely to utilize preventive care during maturation (rate ratio=0.79, $p<0.001$). Longitudinal trends in dental home and preventive dental utilization rates were not significant ($p=0.54$ and $p=0.71$, respectively).

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Conclusions—Among newly Medicaid-enrolled children in Iowa’s I-Smile Program, those with ASDs were not less likely than those without ASD to have dental homes but were significantly less likely to utilize preventive dental care.

Introduction

Autism spectrum disorder (ASD) comprises neurodevelopmental disorders characterized by social communication and interaction deficits, and rigid or repetitive behaviors.^{1,2} Children with ASD are at increased risk for tooth decay secondary to comorbidities like intellectual and developmental disabilities, attention deficit hyperactivity disorder, and anxieties, including dental fears.^{3,4} Parents may use sweets to manage behaviors⁵ and children with ASD frequently have difficulties with toothbrushing and dental visits^{5–10} because of oral sensitivities, which can lead to defensive behaviors.^{11–13} As a result, children with ASD may not receive regular home care and parents may be reluctant to take their child to the dentist.^{13,14} Dental visits can also disrupt the fixed routines of children with ASD.¹⁵ Many dentists have not learned adequate patient behavior management skills and are hesitant to treat children with ASD,^{16,17} which are additional barriers to dental care.

Nearly 50% children with ASD are from low-income families and qualify for publicly financed dental insurance like Medicaid.¹⁸ Medicaid-enrolled children with special healthcare needs, a group that includes children with ASD, are not less likely to utilize preventive dental care than children without, but are more likely to have delayed first dental visits and to undergo oral rehabilitation under general anesthesia.^{19–21}

Medicaid-enrolled children encounter barriers to dental care,²² leading to unmet dental need, poor oral health, and use of the emergency department.^{23–26} Based on promising data from patient navigation programs in medicine,²⁷ states have implemented initiatives to improve dental access for children in Medicaid. One example is Iowa’s I-Smile Program. Implemented in 2006, I-Smile is a community-based patient navigation program in which dental hygienists serve as regional oral health coordinators. Patient navigation includes three main activities. The first is outreach to community agencies serving low-income families. The second is informing families new to Medicaid about the availability of dental services. The third is care coordination to assist families with making dental appointments, transportation, interpreter services, and child care. Care coordinators develop long-term relationships with dental offices and families to ensure ongoing dental care access for children.²⁸ The goal of I-Smile is to help Medicaid-enrolled children establish a dental home.²⁸ Modeled on the medical home concept, the ideal dental home provides care that is accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally competent.^{29,30}

Most parents of children with special healthcare needs recognize the importance of dental homes.³¹ More than 90% of dentists incorporate dental home principles into clinical practice.^{32,33} Despite the importance of dental homes, only two studies have examined dental homes for children in Medicaid. The first, based on claims data, reported that 12.6% of Medicaid-enrolled children in New Hampshire had a dental home (two or more dental checkups/year).³⁴ The second study, based on Child and Adolescent Reporting System data,

reported that among Medicaid-enrolled children with tooth decay, 69.3% had a dental home (a place that maintains the child's dental record and had been utilized in the previous 12 months).³⁵ Both dental home definitions are narrow and indicate limitations associated with measuring the dental home concept using secondary data or short survey questions.

No studies to date have examined dental home rates or whether patient navigation programs like I-Smile have improved access to dental care specifically for Medicaid-enrolled children with ASD, a population subgroup at risk for disparities in dental care use. Disparities are defined as differences rooted in social inequality. Although I-Smile does not explicitly target children with ASD, an implicit goal of such programs is to reach the most vulnerable child subgroups within Medicaid. There were two study goals: (1) to compare dental home and preventive dental care utilization rates for Medicaid-enrolled children by ASD status; and (2) to determine the extent to which I-Smile influenced ASD-related disparities in dental utilization.

Methods

Study Population and Data

The study focused on newly Medicaid-enrolled children aged 3–17 years. Data from the Iowa Medicaid Program (2002–2011) consisted of enrollment and claims files linked by a unique child identification number. From the enrollment files, nine mutually exclusive cohorts of newly Medicaid-enrolled children aged 3–17 years were drawn (one/calendar year for 2003–2011). Children must have been enrolled for 11–12 months in the cohort year³⁶ to allow for assessment of the outcome measure. Analyses were restricted to children who were newly enrolled, defined as no evidence of enrollment in Iowa Medicaid in the year prior to the child's cohort year, to exclude children who may have recently utilized dental care. The need to create a look-back period for each cohort is why there were 10 years of data required but only nine cohorts. Children aged <3 years were excluded because ASD is typically diagnosed after the child's third birthday even though earlier screening is recommended.³⁷ Across the nine cohorts, there were 30,059 newly Medicaid-enrolled children aged 3–17 years. Analyses were conducted in 2015. The study was approved by the University of Washington IRB.

Measures

The main outcome was whether the child had a dental home in the cohort year (no/yes). Dental home was defined as having received one comprehensive oral evaluation and one periodic oral evaluation or two periodic oral evaluations identified through Current Dental Terminology Codes (D0150+D0120 or D0120+D0120).³⁸ This operationalization does not include all dental home elements (e.g., family-centered, coordinated, compassionate, culturally competent), but is based on a previously published definition³⁴ and is consistent with the way in which dental offices frequently identify active patients of record. A secondary outcome was whether the child used preventive dental care services (no/yes) like dental cleanings, topical fluoride treatment, and pit and fissure sealants (D1110–D1351).³⁹ The secondary measure provided information on the quality of care received.

The predictor variable was whether the child had an ASD diagnosis (no/yes). During the study period, the DSM-IV was used. ASD diagnoses were identified from the medical claims files using the following ICD-9-CM codes: 299, 299.01, 299.10, 299.8, 299.81, and 299.9. Consistent with published methods, diagnoses of autism, childhood disintegrative disorder, Asperger's disorder, and pervasive developmental disorder not otherwise specified were classified as ASD.⁴⁰ Medical claim files up to 1 year beyond each child's cohort year were examined to identify additional ASD diagnosis codes.

Age, sex, and race were modeled as confounders. Age, which is associated with initial diagnosis of ASD⁴¹ and dental care utilization,³⁹ was analyzed as a categorical variable (3–5, 6–12, 13–17 years). These categories reflect the developmental stages of a child's dentition. Sex and race are associated both with ASD diagnosis and dental care use.^{39,42,43} Race was analyzed as a three-category variable (white, non-white, unknown).

Statistical Analysis

The 9 cohort years were divided into three I-Smile periods: 2003–2005 (pre-implementation), 2006–2008 (initial implementation), and 2009–2011 (maturation). The main hypotheses were that newly Medicaid-enrolled children with ASD would be less likely to have dental homes and less likely to utilize preventive dental care than newly Medicaid-enrolled children without ASD. These hypotheses were evaluated for all years (2003–2011) and specifically within three time I-Smile periods. It was also hypothesized that I-Smile influenced potential ASD-related disparities in dental home and preventive dental care utilization over time. To evaluate the main hypotheses for all years, log-linear regression models were used to estimate crude dental home and preventive dental utilization rates by ASD status and rate ratios (RRs) of ASD to non-ASD with 95% CIs ($\alpha=0.05$). Covariate-adjusted log-linear regression models with empirical SE estimates were used to estimate RR adjusted for age, sex, race, and time period.⁴⁴ Generalized estimating equations were used to fit the log-linear models and estimate SEs.⁴⁵ Similar procedures were used to test the hypotheses within the three time periods except that time period was included in the models as a main effects variable. To examine the longitudinal influence of I-Smile on ASD-related disparities over time, an interaction term between ASD status and time period was included in the log-linear regression models. All statistical analyses were completed using SAS, version 9.3.

Results

Of the 30,059 children in the study, 408 were identified with ASD (1.4%). The mean age was 10.1 (4.5) years and 50.5% were male. About 47.4% of children were white, 16.9% were non-white, and 35.7% had missing race data. Most children with ASD were male (84.8%). Children with ASD were younger than children without ASD (9.5 [3.8] years and 10.1 [4.5] years, respectively, $p<0.01$). A larger proportion of children without ASD were white than children with ASD (47.5% and 41.4%, respectively, $p<0.0001$).

Eight percent of study children had a dental home. Across all years (2003–2011), 9.8% of children with ASD had a dental home (95% CI=7.3%, 14.1%) and 8.0% children without ASD had a dental home (95% CI=7.8%, 8.3%). Forty-six percent of all children utilized

preventive dental care. Across all years, 36.3% of children with ASD utilized preventive dental care (95% CI=31.8%, 41.3%) compared with 45.7% of children without ASD (95% CI=45.1%, 46.3%). Comparative preventive dental utilization rates for children with and without ASD across the three I-Smile time periods were: 32% and 44% (pre-implementation), 36% and 42% (initial implementation), and 37% and 50% (maturation).

Across all years (2003–2011), children with ASD were more likely to have a dental home, but this difference was not statistically significant (RR=1.23, 95% CI=0.91, 1.65, $p=0.17$) (Table 1). In the crude regression models, children with ASD were less likely to have a dental home during the earlier periods (pre-implementation and initial implementation) but more likely to have a dental home in the most recent period (maturation). No differences were statistically significant. Findings were similar in the covariate-adjusted regression models. Dental home trends were not significantly different across the three time periods ($p=0.54$).

Across all years, children with ASD were significantly less likely to use preventive dental care (RR=0.79, 95% CI=0.70, 0.91, $p<0.001$) (Table 2). In the pre-implementation and initial implementation periods, there were no significant differences in preventive dental care use by ASD status. In the maturation period, children with ASD were significantly less likely to utilize preventive dental care (RR=0.74, 95% CI=0.63, 0.86, $p<0.001$). Results from the covariate-adjusted regression models were similar. Trends in preventive dental care disparities were not significant across the three time periods ($p=0.71$).

Discussion

This study evaluated Iowa's I-Smile Program, a patient navigation program for children in Medicaid, and examined dental home and preventive dental care utilization rates for new enrollees with ASD. During the overall study period (2003–2011), there was no significant difference in dental home rates by ASD status, but children with ASD were significantly less likely to utilize preventive dental care. There were no significant differences in dental home rates by ASD status during I-Smile pre-implementation, initial implementation, or maturation. In the I-Smile maturation period (2009–2011), children with ASD were significantly less likely to use preventive dental care than children without ASD. Over time, ASD-related disparities in dental home and preventive dental care rates did not change. Collectively, these findings suggest newly Medicaid-enrolled children with ASD are not less likely to have dental homes, but are significantly less likely to use preventive care under the I-Smile Program.

The main finding was no significant difference in dental home rates for newly Medicaid-enrolled children by ASD status. This was in contrast to the original hypothesis that children with ASD would be less likely to have dental homes than those without ASD. The overall dental home rate of 8% was lower than previously reported rates of 12.6% (claims-based) and 69.3% (survey-based).^{34,35} One reason for lower overall dental homes rates for children in the present study is strict inclusion criteria, which included new Medicaid enrollees who were in Medicaid for 11 months of the year. There are two possible explanations of why Medicaid-enrolled children with ASD were not less likely to have dental homes. First,

families of Medicaid-enrolled children with ASD in Iowa may dedicate extra effort to find dental care for their children compared with other families. These efforts may help children with ASD overcome some but not all of the previously documented barriers to dental care.^{13,46} Providing families of children with ASD with additional resources, like respite care, could help more caretakers establish and maintain dental homes for children with ASD.^{47,48} Second, in contrast to dental provider reluctance to treat children with ASD identified in prior studies,^{16,17} Iowa dentists may be increasingly likely to treat Medicaid-enrolled children with ASD as they are Medicaid-enrolled children without ASD, with 58% of Iowa dentists accepting new Medicaid patients.⁴⁹ One concern is that despite being equally as likely to have dental homes, Medicaid-enrolled children with ASD may continue to have unmet dental needs because of factors that increase their caries risk, consistent with the finding that Medicaid-enrolled children with ASD are significantly less likely to use preventive dental care.³ Future studies should examine parent experiences associated with establishing and maintaining dental homes for Medicaid-enrolled children with ASD and determine the extent to which equivalent dental home rates translate to similar outcomes, including dental disease rates and parent satisfaction with care.

There were no significant differences in dental home rates for children with ASD within each of the three periods (pre-implementation, initial implementation, maturation) or longitudinally across the three periods. Though not statistically significant in the current study, an apparent reversal in the dental home RRs favoring children with ASD (i.e., change in RR from <1 to >1) from pre-implementation and early implementation to maturation could indicate clinically meaningful improvements associated with I-Smile. Additional years of program maturation may lead to further improvements in dental home rates for Medicaid-enrolled children with ASD, making these differences more evident. Studies should continue to evaluate I-Smile to help policymakers implement programmatic improvements.

There were no longitudinal changes in preventive dental care use across time periods for newly Medicaid-enrolled children with ASD, but children with ASD in the I-Smile maturation period (2009–2011) were significantly less likely to utilize preventive dental care than newly Medicaid-enrolled children without ASD. This is consistent with similar studies on children in foster care and children with neurologic conditions.^{50–52} There may be important differences between families with children with ASD that influence the likelihood of their child utilizing preventive dental care. A possible explanation is parental refusal of preventive dental care, including topical fluoride,⁵³ which may be of particular concern for parents of children with ASD.⁵⁴ Based on the importance of preventive care for high-risk children, there is a need for additional theory-driven behavior change research that will inform the development of chairside interventions. These interventions could help parents make well-informed decisions that optimize the oral health of their children. In addition, community-based interventions might be incorporated as part of I-Smile. Primary care physician offices and community health centers could be recruited to provide families with consistent anticipatory guidance and dentist referrals and high-risk children with preventive care like fluoride varnish. Post-hoc analyses indicated twice as many Medicaid-enrolled children with dental homes utilized preventive dental care as children without dental homes (84% and 42%, respectively, data not shown). However, among all Medicaid-enrolled children with dental homes, there was no difference in the proportion of children with and

without ASD who utilized preventive dental care (95% and 83.6%, respectively, $p=0.10$). These findings need to be confirmed through longitudinal analyses, but underscore the potential role of dental homes in promoting preventive dental care use for Medicaid-enrolled children.

The broader significance of the current study is that fewer than 10% of children had a dental home. For Medicaid-enrolled children with ASD, this is extremely low and does not help to mitigate the multiple risk factors for poor oral health. These findings underscore the importance of training dentists to treat children with ASD using appropriate behavior management strategies. Families of children with ASD should also be linked to dentists, a process that could be facilitated through incorporation of dental programs within health facilities that treat patients with ASD and stronger interprofessional ties among dentistry and medicine, nursing, pharmacy, and social work.

Limitations

There were five main study limitations. First, the operationalization of dental home was based on claims data. Only 8% of children, regardless of ASD status, had two or more dental checkups within a year. This is likely to be a conservative estimate because not all children visit a dentist every 6 months.⁵⁵ It is possible children who had their first dental checkup in the latter half of the cohort year could have had their second checkup in the first half of the subsequent year. As a sensitivity analysis, dental home identification period was extended 6 months into the subsequent year and the results did not change. Second, the definition of dental home does not assume the care received by children was easily accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally competent. Additional studies based on a comprehensive primary data collection protocol are needed to further refine measurement of the dental home concept and compare the quality of and satisfaction with dental homes by ASD status. Third, the ASD identification protocol used diagnostic codes from the child's medical claims files, which assumes coding accuracy by the health provider. Failure to code ASD diagnoses could have resulted in misclassification bias. However, the estimated prevalence of ASD (1.4%) is similar to previous estimates.⁴² Fourth, the benefits associated with dental homes have not been empirically assessed, warranting additional research on a topic of increasing interest to policymakers and legislators, particularly in an era of value-based health care and calls for evidence-based dental care. Fifth, although regular dental visits have an important role in dental caries prevention, dental visits are not a panacea. A comprehensive caries prevention strategy includes promotion of a diet low in fermentable carbohydrates and twice daily toothbrushing with fluoridated toothpaste, behaviors that may be difficult for families to reinforce in children with ASD.

Conclusions

Study findings suggest that having ASD does not affect whether Medicaid-enrolled children have a dental home and that establishment of dental homes for children with ASD was not impacted by the implementation of the I-Smile Program. Although not statistically significant, ASD-related disparities in dental home rates appeared to have improved in recent years in favor of children with ASD, which could indicate clinically meaningful

improvements associated with the I-Smile Program. However, in the most recent years, use of preventive dental care was lower for Medicaid-enrolled children with ASD than those without ASD. Future efforts should evaluate longitudinal outcomes associated with having a dental home by ASD status and determine the reasons why children with ASD in Medicaid are less likely to use preventive dental care.

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Table 1

Dental Homes for Medicaid-Enrolled Children by Autism Spectrum Disorder Status (N=30,059)

Time period	Crude regression models			Covariate-adjusted regression models ^d		
	Rate ratio ^b for children with ASD	95% CI	p- value	Rate ratio ^b for children with ASD	95% CI	p- value
All ^c	1.23	0.91 1.65	0.17	1.10	0.81 1.47	0.55
I-Smile pre-implementation (2003–2005)	0.79	0.26 2.40	0.68	0.85	0.28 2.59	0.77
I-Smile initial implementation (2006–2008)	0.69	0.23 2.09	0.52	0.72	0.24 2.18	0.56
I-Smile maturation (2009–2011)	1.19	0.86 1.63	0.30	1.25	0.91 1.73	0.17

ASD, Autism Spectrum Disorder

^a Adjusted for child's age, sex, and race

^b Reference group is children without autism spectrum disorders

^c Adjusted for time period

Table 2

Preventive Dental Care Use for Medicaid-Enrolled Children by Autism Spectrum Disorder Status (N=30,059)

Time period	Crude regression models			Covariate-adjusted regression models ^d				
	Rate ratio ^b for children with ASD	95% CI	p-value	Rate ratio ^b for children with ASD	95% CI	p-value		
All ^c	0.79	0.70	0.91	<0.001	0.74	0.65	0.84	<0.001
I-Smile pre-implementation (2003–2005)	0.72	0.49	1.05	0.09	0.73	0.50	1.07	0.10
I-Smile initial implementation (2006–2008)	0.86	0.62	1.21	0.39	0.86	0.62	1.20	0.37
I-Smile maturation (2009–2011)	0.74	0.63	0.86	<0.001	0.74	0.63	0.86	<0.001

ASD, Autism Spectrum Disorder

Note: Boldface indicates statistical significance ($p < 0.05$).

^a Adjusted for child's age, sex, and race

^b Reference group is children without autism spectrum disorders

^c Adjusted for time period