How States Use Medicaid to Fund Community-Based Services to Children With Autism Spectrum Disorders

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Objective: **This study examined the extent to which state Medicaid agencies funded 16 services for children with autism spectrum disorders: individual therapy, physical and occupational therapy, in-home supports, speech therapy, diagnostic assessment, behavior modification, family therapy, case management, targeted case management, respite, day treatment, social skills training, habilitation services, treatment planning, family education and training, and assistive communication devices.** ***Methods:*** **Procedure codes in the Medicaid Analytic eXtract (MAX) "other therapies" file were used to identify community-based services commonly delivered to children with a diagnosis of a primary autism spectrum disorder.** ***Results:*** **Four services are commonly used to address the core deficits of these disorders: physical and occupational therapy, speech therapy, behavior modification, and social skills training. Only six states funded all four services.** ***Conclusions:*** **States varied considerably in use of Medicaid to reimburse these services, indicating that some states may have opportunities to receive federal matching funds.** (***Psychiatric Services*** **64:1051–1055, 2013; doi: 10.1176/appi.ps.201200390)**

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Medicaid represents an important insurer for children with a diagnosis of autism, covering as much as 45% of children in the autism category of special education (1). Because Early and Periodic Screening Detection and Treatment (EPSDT) requires Medicaid to provide children with all federally covered medically necessary services, state Medicaid programs cover more services than do commercial insurance plans, perhaps even more so for children with autism, who often face benefit exclusions or limits under private insurance (2).

This study sought to describe how states use Medicaid funding to treat complex needs of children with autism. It examined specific categories of services by using procedures codes associated with paid Medicaid claims, applying a more specific approach that builds on studies of broad service categories (1,3). Prior national studies of Medicaid-reimbursed mental health services relied on interviews with state Medicaid agency staff and reviews of Medicaid plans, regulations, and managed care contracts (4,5). A challenge to interpreting findings from these studies is that even when a service is included under Medicaid, people with autism may not receive it. In this study, we examined claims associated with Medicaid-reimbursed services for children with autism.

Knowledge of the specific categories of services reimbursed by state Medicaid agencies for children with autism can inform advocates, clinicians, and policy makers, who struggle to use Medicaid to provide a comprehensive array of services to this growing population by educating these groups about what services are Medicaid funded in various states. Community mental health agencies, an important source of services for children with autism, often lack capacity and expertise to meet the specialized service needs of these children (6,7). For states seeking to increase service capacity for children with autism, the development of procedure codes for specialized autism services signals the importance of these services to provider agencies.

Autism spectrum disorders comprise developmental conditions that share deficits in age-appropriate social interaction and communication. Children benefit from service arrays that address autism's core symptoms and co-occurring behavioral challenges and that provide support (8). The most commonly used therapies to address deficits associated with the disorders are speech and language therapy to improve social language and communication; occupational therapy to improve social and daily living skills; physical therapy to improve performance of physical activities and play engagement; and interventions, such

Table 1

Medicaid funding in 48 states of 16 services for children with a primary diagnosis of autism spectrum disorder, 2005[a]

State	Individual therapy	Physical and occupational therapy	In-home supports	Speech therapy	Diagnostic assessment	Behavior modification	Family therapy	Case management	Targeted case management	Respite	Day treatment	Social skills training	Habilitation services	Treatment planning	Family education and training	Assistive communication device
Alabama	√	√		√	√	√	√				√			√		
Alaska	√	√	√	√		√		√		√	√	√				√
Arizona	√	√	√	√	√	√		√		√			√		√	
Arkansas	√	√	√	√	√	√	√	√				√				
California	√	√	√	√		√		√		√	√		√		√	
Connecticut	√		√													
Delaware	√	√	√	√												
Florida	√	√	√	√		√										
Georgia	√	√		√		√	√	√					√			√
Hawaii	√	√	√				√			√						
Idaho	√	√		√	√	√		√								
Illinois	√	√	√	√		√		√								
Indiana	√	√	√	√	√	√	√	√			√	√				
Iowa		√	√	√		√										
Kansas	√		√		√	√	√		√						√	
Kentucky	√	√	√	√			√	√	√							
Louisiana	√	√	√	√	√			√								
Maryland	√	√	√	√	√	√	√	√		√			√		√	
Massachusetts	√	√	√	√		√	√									
Michigan	√	√	√	√	√	√			√	√						
Minnesota	√	√	√	√	√	√	√	√	√			√				
Mississippi	√	√	√	√		√	√		√		√			√		
Missouri	√	√	√	√	√	√	√	√	√	√			√			
Montana	√	√	√	√		√	√	√		√	√					
North Carolina	√	√	√	√	√			√	√	√					√	
North Dakota		√	√	√	√		√	√	√							
Nebraska	√	√		√	√		√									
Nevada	√	√	√	√	√	√	√		√							
New Hampshire	√	√	√	√	√		√	√	√	√						
New Jersey	√	√	√	√			√				√					
New Mexico	√	√	√	√			√		√	√		√				
New York	√	√	√		√			√		√			√			
Ohio	√	√	√		√						√					
Oklahoma	√	√	√		√	√	√							√		
Oregon	√	√	√	√	√		√	√						√		√
Pennsylvania	√	√	√		√	√	√	√	√		√			√		
Rhode Island	√		√		√	√		√						√		
South Carolina	√	√	√	√	√	√	√	√	√							
South Dakota	√		√		√											

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Table 1

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State	Individual therapy	Physical and occupational therapy	In-home supports	Speech therapy	Diagnostic assessment	Behavior modification	Family therapy	Case management	Targeted case management	Respite	Day treatment	Social skills training	Habilitation services	Treatment planning	Family education and training	Assistive communication device
Tennessee	✓	✓		✓	✓		✓	✓								✓
Texas	✓	✓	✓	✓	✓	✓	✓	✓					✓			
Utah	✓		✓			✓		✓	✓	✓					✓	
Vermont	✓		✓		✓	✓	✓		✓		✓	✓			✓	
Virginia	✓	✓	✓	✓	✓		✓		✓	✓	✓	✓				
Washington	✓	✓		✓		✓						✓				
Wisconsin	✓	✓	✓	✓	✓	✓					✓					
West Virginia		✓	✓	✓	✓			✓	✓	✓			✓	✓		
Wyoming	✓	✓	✓	✓	✓	✓			✓			✓				
Total states providing service	45	42	42	37	31	29	27	26	18	15	11	9	8	7	7	4
Percentage of all states	96	89	89	79	66	62	57	55	38	32	23	19	17	15	15	9

[a] Because of poor data quality, no data are presented for Maine, Colorado, and the District of Columbia.

as behavior modification and social skills training based on the principles of applied behavior analysis (ABA), to increase desired behaviors and improve interactions with family and peers. Assistive communication devices also are commonly recommended for children lacking speech to express needs and thoughts (9). Service intensity is a distinguishing characteristic of therapies for children with these disorders; expert consensus holds that maximum benefit occurs in one-to-one settings and involves frequent and consistent reinforcement by families and care providers (10).

State Medicaid programs vary in definitions of and reimbursement practices for services for children with autism. The policy of the Centers for Medicare and Medicaid Services has been inconsistent on whether habilitation services, including ABA and other services that teach individuals new behaviors, can be covered under Medicaid state plans, which adds to state variability (11).

Methods

The 2005 Medicaid Analytic eXtract (MAX) "other therapies" file, the most recent year available to us, was the data source. It comprises paid Medicaid fee-for-service claims and data on managed care encounters for outpatient services in 48 states. Poor data quality prevented inclusion of Maine, Colorado, and the District of Columbia. Claims for children age three to 17 associated with primary *ICD-9* codes for autistic disorder (299.00) or Asperger's disorder or pervasive developmental disorder not otherwise specified (299.8) were identified (12). The study received institutional review board approval at the University of Pennsylvania.

To limit the analysis to commonly used services in each state, a service category minimum of 100 claims or 1% of all autism-related claims per state—whichever represented fewer claims—was set. The threshold for assessment services was lowered to 50 because these services usually are conducted annually. Service descriptions associated with specific procedure codes were identified through software developed by the Agency for

Healthcare Research and Quality and supplemented with searches on state Medicaid Web sites and communications with state agencies providing services for children with intellectual and developmental disabilities (13). Many states have developed their own terminology for comparable services. Therefore, we created broad categories of similar services for cross-state comparisons. Development of broad service categories began with a review of literature on evidence-based and effective services for children with autism spectrum disorders and children with other special health needs (7,14). We then created final categories by revising initial categories in light of empirical findings from the claims-based analysis and conversations with clinicians and experts. Funding of services in 16 categories was examined: individual therapy, physical and occupational therapy, in-home supports, speech therapy, diagnostic assessment, behavior modification, family therapy, case management, targeted case management, respite, day treatment, social skills training, habilitation services, treatment planning, family education and training, and assistive communication devices. A list of the specific procedure codes by state is available under "Tools for Researchers" on the Web site of the Center for Mental Health Policy and Services Research, University of Pennsylvania (www.med.upenn.edu/cmhpsr/resources.html).

Results

In 2005, the number of services for children with primary autism spectrum disorders that were paid for by state Medicaid agencies ranged from a low of two in Connecticut to a high of 11 in Maryland and Missouri (Table 1). States paid for an average of seven services. The five most commonly reimbursed services for autism spectrum disorders were individual therapy (45 states); occupational and physical therapy (42 states); in-home supports (42 states), including medical and nonmedical supports such as nursing, one-to-one assistance, and supported-living services to help children remain in communities; speech therapy (37 states); and diagnostic assessment (31 states). Between 20 and 30 states reimbursed for the following services: behavior modification, including ABA (29 states); family therapy (27 states); and case management (26 states). Between ten and 20 states provided the following services: targeted case management (18 states), which provides staff who interact with the child and his or her family to coordinate and find services; respite (15 states); and day treatment (11 states). Ten states or fewer provided the following services: social skills training (nine states); habilitation services (eight states) to improve self-help, socialization, and adaptive skills; treatment planning (seven states); family education and training (seven states); and assistive communication devices (four states).

Discussion

This study highlights the types of services that state Medicaid agencies reimburse for children with a primary diagnosis of autism. No state Medicaid agency paid for services in all 16 categories described here. Only six states funded all four commonly used services to address core deficits of autism: physical and occupational therapy, speech therapy, behavior modification, and social skills training.

Some study limitations should be noted. First, some services may have been missed; our methods did not examine services billed with broad EPSDT service codes because no specific service was identified. Second, states may use other funding sources to deliver services to children with autism. For example, the finding that less than half of states paid for diagnostic assessment may be explained, in part, by the fact that children receive a diagnosis of autism during the process of applying for Supplemental Security Income before Medicaid enrollment (1). This variation may reflect a state's intention to fund other services or may result from a Medicaid policy decision not to fund or provide these services to children with autism. In other words, the variation does not mean that a state lacks knowledge about what is covered by Medicaid and about the services that would therefore receive a federal match.

Conclusions

Our study revealed considerable differences in state use of Medicaid to reimburse services for children with autism, indicating that some states may have opportunities to receive the federal Medicaid match for funding autism services. Few states funded social skills training, habilitation services, family education and training, and assistive communication devices. States have been slow to add services needed by children with autism spectrum disorders to address the growing increase in prevalence of these disorders among children.

Acknowledgments and disclosures

This study was funded by grant MH077000-01 from the National Institute of Mental Health (NIMH) ("Interstate Variation in Health Care and Utilization among Children with Autism Spectrum Disorders"). The authors thank Michele DeFelice Haverly, M.S., Deb Dunn, J.D., Maureen Davey, Ph.D., Steve Eiken, B.A., M.P.A., Chris Koyanagi, Debra Langer, M.P.A., M.Sc., and Gail Stein, M.S.W., M.Ed., for helpful suggestions and comments on earlier drafts. All views expressed are those of the authors and do not necessarily reflect the views of NIMH.

The authors report no competing interests.

References

1. Semansky RM, Xie M, Mandell DS: Medicaid's increasing role in treating youths with autism spectrum disorders. Psychiatric Services 62:588, 2011
2. Peele PB, Lave JR, Kelleher KJ: Exclusions and limitations in children's behavioral health care coverage. Psychiatric Services 53:591–594, 2002
3. Peng CZ, Hatlestad P, Klug MG, et al: Health care costs and utilization rates for children with pervasive developmental disorders in North Dakota from 1998 to 2004: impact on Medicaid. Journal of Child Neurology 24:140–147, 2009
4. Following the Rules: A Report on Federal Rules and State Actions to Cover Community Mental Health Under Medicaid. Washington, DC, Bazelon Center, 2008
5. Ridgely MS, Maglione MA: Managing Medicaid behavioral health care: findings of a national survey in the year 2000. Psychiatric Services 57:1000–1006, 2006
6. Mandell DS, Walrath CM, Manteuffel B, et al: The prevalence and correlates of abuse among children with autism served in comprehensive community-based mental health settings. Child Abuse and Neglect 29:1359–1372, 2005
7. Brookman-Frazee L, Drahota A, Stadnick N, et al: 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: 365–373, 2012

8. Myers SM, Johnson CP: Management of children with autism spectrum disorders. Pediatrics 120:1162–1182, 2007

9. Rispoli MJ, Franco JH, van der Meer L, et al: The use of speech generating devices in communication interventions for individuals with developmental disabilities: a review of the literature. Developmental Neurorehabilitation 13:276–293, 2010

10. Lord C, McGee J: Educating Children With Autism. Washington, DC, National Academies Press, 2001

11. Medicaid Program: Coverage For Rehabilitative Services: Proposed Rule. CMS 2261-P. Section 42 CRF Parts 440 and 441, (2007)

12. International Classification of Diseases, Ninth Rev. Salt Lake City, Utah, Medi-Index, 1987

13. Health Care Cost and Utilization Project: Clinical Classification Software for Services and Procedures. Rockville, Md, Agency for Healthcare Research and Quality, 2010

14. Burns T, Knapp M, Catty J, et al: Home treatment for mental health problems: a systematic review. Health Technology Assessment 5:1–139, 2001

Submissions Invited for New *Psychiatric Services* Column on Integrated Care

The integration of primary care and behavioral health care is a growing research and policy focus. Many people with mental and substance use disorders die decades earlier than other Americans, mostly from preventable chronic medical illnesses. In addition, primary care settings are now the gateway to treatment for behavioral disorders, and primary care providers need to provide screening, treatment, and referral for patients with general medical and behavioral health needs.

To stimulate research and discussion in this critical area, *Psychiatric Services* is launching a new column on integrated care. The column will focus on service delivery and policy issues encountered on the general medical–psychiatric interface. Submissions are welcomed on topics related to the identification and treatment of (a) common mental disorders in primary care settings in the public and private sectors and (b) general medical problems in public mental health settings. Reviews of policy issues related to the care of comorbid general medical and psychiatric conditions are also welcomed, as are descriptions of current integration efforts at the local, state, or federal level. Submissions that address care integration in settings outside the United States are also encouraged.

Benjamin G. Druss, M.D., M.P.H., is the editor of the Integrated Care column. Prospective authors should contact Dr. Druss to discuss possible submissions (bdruss@emory.edu). Column submissions, including a 100-word abstract and references, should be no more than 2,500 words.