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

Rafael M. Semansky, M.P.P., Ph.D.,

Health Group, Econometrica, Inc., 7475 Wisconsin Ave., Suite 1000, Bethesda, MD

Ming Xie, M.S.,

Department of Psychiatry, Perleman School of Medicine, University of Pennsylvania, Philadelphia

Lindsay J. Lawer, M.S., and

A. J. Drexel Autism Institute, Drexel University, Philadelphia

David S. Mandell, Sc.D.

Department of Psychiatry, Perleman School of Medicine, University of Pennsylvania, Philadelphia

Rafael M. Semansky: rsemansky@econometricainc.com

Abstract

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.

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).

disclosures

The authors report no competing interests.

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 procedure 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 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.

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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	✓	✓		✓	✓	✓			✓							

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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
Nevada	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓						
New Hampshire	✓	✓	✓	✓	✓		✓	✓	✓	✓						
New Jersey	✓	✓	✓	✓			✓				✓					
New Mexico	✓	✓	✓	✓			✓	✓	✓	✓						
New York	✓	✓	✓	✓	✓			✓		✓			✓			
Ohio	✓	✓	✓	✓	✓						✓					
Oklahoma	✓	✓	✓	✓	✓	✓	✓						✓			
Oregon	✓	✓	✓	✓	✓	✓	✓	✓					✓			✓
Pennsylvania	✓	✓	✓	✓	✓	✓	✓	✓	✓		✓		✓			
Rhode Island	✓	✓	✓	✓	✓	✓	✓	✓					✓			
South Carolina	✓	✓	✓	✓	✓	✓	✓	✓	✓							
South Dakota	✓	✓	✓	✓	✓											
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

^aBecause of poor data quality, no data are presented for Maine, Colorado, and the District of Columbia.