QUALITY CARE FOR SPECIAL KIDS

Profiles of Children with Chronic Conditions and Disabilities

MATHEMATICA Policy Research, Inc.
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Henry T. Ireys, Shanna Shulman, and Stephanie Peterson

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Who Are Children with Special Health Care Needs?

Twelve percent of the children enrolled in commercial health insurance plans have special health care needs and account for more than 70 percent of every dollar spent on child health. Their conditions range from physical illnesses to developmental, behavioral, and emotional disabilities. Some have relatively common conditions such as asthma, diabetes, and attention deficit hyperactivity disorder, while others have more rare disorders such as cerebral palsy, epilepsy, sickle cell anemia, and hemophilia.

This series is designed to keep commercial plans abreast of critical issues involved in caring for these children. The series was produced by Mathematica Policy Research, Inc., under contract 250-01-0013-004(03) to the Health Resource and Services Administration, U.S. Department of Health and Human Services. For more information, contact Lynda Honberg, Maternal and Child Health Bureau, HRSA, at 301-443-6314 or LHonberg@hrsa.gov, or staff at Mathematica’s DC and Cambridge offices.

About the Data

Many of the findings described in the following updates come from three reports completed for a study of children enrolled in two open-access, managed health care plans in the UnitedHealth Group. The study involved an analysis of administrative and claims data for a sample of approximately 230,000 children in two states from 1999 through 2001. Using the clinical risk group system, we identified 24,807 children with special health care needs in 1999; 28,346 in 2000; and 29,085 in 2001—representing a total of 11 to 12 percent of all enrolled children. The three reports are:


Additional findings reported in these updates come from two other sources:

(1) original tabulations of publicly available data from the 2002 National Survey of Children with Special Health Care Needs, which surveyed 28,489 children—representing the 50 states and the District of Columbia—covered by private insurance (see www.cdc.gov/nchs/about/major/slaits/cshcn.htm) and (2) selected journal articles.

Acknowledgments

In addition to conveying a deep passion for her work, Lynda Honberg, our project officer at the Division of Services for Children with Special Health Care Needs in the Maternal and Child Health Bureau at HRSA, has been a wellspring of practical suggestions that emerged from her experience in both policymaking and parenting. This series of updates benefited enormously from Lynda's generosity in sharing this experience with the project team. We are grateful to have had the opportunity to work with her.

Eileen Peterson, a vice president at UnitedHealth Group, provided valuable advice throughout the development of the series. Her careful review of each update and her continued focus on the “big picture” kept the material relevant to our audience. We appreciate not only her enduring concern for improving services for children with special health care needs but also her willingness to fit our work into her busy schedule.

We are also indebted to three other individuals for their wise guidance at several stages of the project: Holly A. Grason, Associate Professor in the Department of Population, Family, and Reproductive Health at the Johns Hopkins University Bloomberg School of Public Health; Susan G. Epstein, Executive Director of New England SERVE; and John M. Neff, a former director of the Center for Children with Special Health Care Needs at the Children's Hospital and Regional Medical Center in Seattle, Washington. When we were uncertain about our direction, these individuals consistently guided us to the right path.

We appreciate the efforts of several colleagues at Mathematica Policy Research: Carol Irvin's thoughtful review of the updates improved the content substantially. Katherine Bencio's programming skills ensured that we got the facts right. Daryl Hall's essential editing support kept the updates looking and sounding like updates. Sharon Clark prepared numerous PDFs and letters with her usual good cheer. Many thanks also are due Mary Fran Miklitsch, who skillfully designed and produced this series.
Chronic conditions and disabilities are leading cost drivers for commercial health plans. As plans seek innovative and efficient ways to address the needs of members with chronic conditions, children can be easily overlooked. Yet one of every five members with a chronic condition is a child. The ability to identify these children and monitor their service use and cost will help health plans create more efficient care-management programs, evaluate the adequacy of provider networks, and manage benefit packages for their members.

Findings

In any given year, about 12 percent of children in commercial plans have special health care needs, an additional 8 percent are at high risk of developing a chronic condition because of a significant acute condition, and 80 percent are healthy (Figure 1). About half of the children with special health care needs have a moderate or severe condition (Figure 2).

As expected, children with chronic conditions use many different kinds of health services, and they tend to use them frequently. For example, more than half of the children with special health care needs see a physician at least five times a year. Most of them (90 percent) take prescription drugs for some aspect of their condition. One in five needs mental health care, and about the same share requires physical, occupational, or speech therapy (Figure 3).

Implications

Many health plans are enrolling their adult members with chronic conditions into special care-management or disease-management programs, and children with chronic conditions could benefit from similar efforts. To date, however, most plans have yet to develop such programs for children.
Like adults, children with chronic conditions vary widely in their treatment needs and must therefore be triaged into different levels of care management. However, care-management procedures must be tailored to children with chronic conditions because, compared with adults, children come in contact with a different set of community institutions and experience different developmental processes.

Effective screening methods that use survey or administrative data can identify which children are moving in and out of the “special needs” category and, for those in this category, who will benefit from intensive care management.

Commercial plans can take the following steps to build a strategy for establishing intensive care-management programs for children with chronic conditions:

- Identify children with chronic conditions by using well-tested tools described in:
  - An overview of the member survey known as the “CSHCN screener” (available at www.chcs.org/usr_doc/CAHMICSHCNscreener.pdf)
  - A previous report in which the clinical risk group system was used to identify children with chronic conditions (see www.mathematica-mpr.com/publications/PDFs/prescription.pdf)

- Build capacity for member stratification by using claims analysis or utilization review to document service use by children with chronic conditions.

- Adapt models of care management used by other health plans for children with chronic conditions. (For descriptions of some models see the Center for Health Care Strategies' website, www.chcs.org.)
**Update 2**

**Prescription Drug Costs for Children with Special Health Care Needs**

The rapid rise in the cost of prescription drugs continues to drive up health care costs across the nation. This trend has affected virtually everyone who needs specialized or continuing medical care. More than 90 percent of children with chronic conditions and disabilities need prescription drugs in a given year, but data on the costs of these drugs are sparse. This update highlights findings from a study showing that costs for prescription drugs for these children are rising seven to eight times faster than use.¹ This information is based on the most comprehensive data available on a large sample of commercially insured children with special needs.

**Findings**

In 2001, annual prescription drug costs for children with special health care needs exceeded $13 million, averaging about $530 per child (Table 1). From 1999 through 2001, the cost of prescription drugs for children with special health care needs was $28.40 in 1999, $33.70 in 2000, and $44.40 in 2001, a jump of 57.1 percent over three years.² In contrast, the number of prescriptions for these children increased by 8.1 percent (from 9,291 prescriptions per 1,000 children in 1999 to 10,043 prescriptions per 1,000 children in 2001).

<table>
<thead>
<tr>
<th>TABLE 1. TRENDS IN PHARMACY COSTS</th>
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<tbody>
<tr>
<td></td>
</tr>
<tr>
<td>1999</td>
</tr>
<tr>
<td>---------</td>
</tr>
<tr>
<td>Total costs in millions</td>
</tr>
<tr>
<td>PMPM cost</td>
</tr>
<tr>
<td>% Change from 1999</td>
</tr>
<tr>
<td>No. prescriptions per 1,000 children</td>
</tr>
<tr>
<td>% Change from 1999</td>
</tr>
</tbody>
</table>

Source: UnitedHealth Group

Prescription drug costs accounted for 14 percent of total costs of care in 2001 (Figure 1). Compared with the cost of other services, the PMPM cost for prescription drugs in 2001 ($44) was exceeded only by the PMPM cost for inpatient care ($91).

For school-aged children, prescription drugs were the single most expensive service in 2001. Specifically, for these children, prescription drug costs accounted for 21.4 percent of the total PMPM cost, exceeding even inpatient costs, which accounted for 15.8 percent of total PMPM costs for that age group in 2001.


For all children with special health care needs, central nervous system/psychiatric drugs accounted for about one-third (32.2 percent) of all prescription drug costs in 2001 (Figure 2). Overall, pediatricians wrote 32 percent of all prescriptions for these drugs in 2001, compared with psychiatrists, who wrote 35 percent.\(^3\)

Implications

The escalating costs of prescription drugs for individuals who have chronic conditions are contributing to the concern that traditional, employer-based health insurance will be increasingly unaffordable for businesses and consumers alike.

Much attention has been given to the implications of rising prescription drug costs for adults with chronic conditions, but families with children who have chronic conditions and disabilities are affected as well. This group of children is often overlooked in the process of developing new strategies for sustaining access to necessary medications. However, because of the heavy use of prescription drugs among these children, it is all the more important to manage their treatment appropriately.

Keeping pediatric providers in a plan’s network abreast of new developments in pharmaceutical treatment is a formidable challenge because the knowledge base is evolving quickly in response to both federal legislation (e.g., the Best Pharmaceuticals for Children Act of 2002) and rapid product development in the pharmaceutical industry.

Health plans can take the following steps to ensure appropriate pharmaceutical treatment for children with special health care needs:

- Develop methods not only to identify children but also to spotlight prescribing and expenditure patterns that signal a need for further review or action.

- Ensure that a plan’s pediatric network has access to information about new prescription drugs (for example, see http://pediatrics.about.com/cs/pharmacology/a/drug_info.htm).

- Track the work of relevant organizations, such as the Committee on Drugs of the American Academy of Pediatrics (www.aap.org/visit/cmte14.htm), and key legislative developments (see for example, http://olpa.od.nih.gov/legislation/107/publiclaws/1best.asp).

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\(^3\)See “Mental Health Services for CSHCN, 1999-2001.” Available at www.mathematica-mpr.com/publications/PDFs/prescription.pdf.
Forty percent of children with special health care needs who are enrolled in commercial health insurance plans need treatment for emotional or behavioral disorders. Health plans have been working to ensure that benefit packages cover effective treatments for these conditions, but over 10 percent of the parents of these children remain dissatisfied with the health benefits their children receive. This rate is twice the rate for parents of children with other chronic conditions and disabilities. As health plans continue to develop products that respond to both the marketplace and their members, they may benefit from taking a closer look at children and adolescents with emotional and behavioral disorders.

Findings

Emotional and behavioral disorders make up a large share of childhood chronic illnesses. Nearly two in five children with special health care needs have an emotional or behavioral disorder—most often ADHD, depression, and acute mental health disorders. In some children, these disorders co-occur with other chronic conditions (Table 1).

Chronic emotional and behavioral disorders can be more debilitating than other chronic conditions. Compared with children with other chronic conditions, children with chronic emotional or behavioral disorders have more severe conditions, need more specialist care, and have more unmet needs, according to their parents (Figure 1). Overall, almost three times as many parents of these children report that their children’s needs are severe and that their children are always affected by their condition.

Findings

Emotional and behavioral disorders make up a large share of childhood chronic illnesses. Nearly two in five children with special health care needs have an emotional or behavioral disorder—most often ADHD, depression, and acute mental health disorders. In some children, these disorders co-occur with other chronic conditions (Table 1).

Chronic emotional and behavioral disorders take a toll on family life as well. Compared with parents of children with other chronic conditions, parents of children with emotional or behavioral disorders say they spend more time providing and coordinating care for their children, miss more hours of work, and are more likely to stop working because of their child’s condition (Figure 1).

Parents believe unmet needs reflect plan characteristics. A large share of the 11 percent of families whose children have unmet needs (Figure 1) believes that the gap in care relates to less-than-adequate benefit packages and provider networks. About half of the parents said they delayed or could not obtain health care for their child because the type of care needed was not covered by their health plan (Figure 2).
Implications

Many parents struggle to find, coordinate, and pay for the mix of services that meet the needs of both the child and the family. However, the number of these children in any single health plan is relatively small, and it may not be appropriate to expand benefit packages to address gaps in their care. Devising systematic ways to address the needs of these families and children on an individual basis might allow plans to better satisfy parents without incurring greater financial risk or establishing unwarranted precedents.

Plans may wish to consider the following steps to meet the needs of member families with children who have emotional or behavioral disorders:

- Identify children with emotional and behavioral disorders by using the Clinical Risk Group System or other grouping techniques (see, for example, www.mathematica-mpr.com/publications/PDFs/menhltchil.pdf); also understand the characteristics of these children in commercial plans (see Psychiatric Services article by Tami Mark and Jeffrey Beck at http://ps.psychiatryonline.org).

- Use administrative data to examine patterns of denials and complaints for children with emotional and behavioral disorders and to help shape responses that are commensurate with the extent of the problem, such as enhanced care coordination services (see Update 4 on the next page), ensuring continuity of care managers, or benefit exceptions.

- Conduct a targeted survey of member families who have children with emotional and behavioral disorders to learn more about sources of dissatisfaction (see www.ahrq.gov/chttoolbox/measure9.htm#mentalinvent for the most widely used measures of mental health care quality for children).

- Stay current on evidence-based treatments for children with emotional and behavioral disorders (see examples of evidence-based treatments at http://coy.state.va.us/Modalities/refchart.htm and a Health Affairs article by Sherry Glied and Allison Cuellar at http://content.healthaffairs.org/).

<table>
<thead>
<tr>
<th></th>
<th>Percentage</th>
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<tbody>
<tr>
<td>Lack of funds to pay provider</td>
<td>62%</td>
</tr>
<tr>
<td>Care not covered by health plan</td>
<td>49%</td>
</tr>
<tr>
<td>Denied approval for care</td>
<td>40%</td>
</tr>
<tr>
<td>Care unavailable in area</td>
<td>21%</td>
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<tr>
<td>Long wait for appointments</td>
<td>21%</td>
</tr>
<tr>
<td>Provider lacked needed skills</td>
<td>20%</td>
</tr>
</tbody>
</table>

Source: 2002 National Survey of Children with Special Health Care Needs
Note: Percentages refer to parents indicating any unmet need among children.
*Includes developmental disorders

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**Figure 2. Parents’ Reasons for Unmet Needs in Children with Emotional or Behavioral Disorders, Age 6 to 18**

<table>
<thead>
<tr>
<th>Reason</th>
<th>Percentage</th>
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</thead>
<tbody>
<tr>
<td>Long wait for appointments</td>
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</tr>
<tr>
<td>Lack of funds to pay provider</td>
<td>62%</td>
</tr>
</tbody>
</table>

Source: 2002 National Survey of Children with Special Health Care Needs
Note: Percentages refer to parents indicating any unmet need among children.
*Includes developmental disorders

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*Includes developmental disorders*
Many health plans coordinate care for their members with chronic conditions and disabilities to help them use covered services efficiently. Although most models of care coordination have been developed for adults, children who have chronic physical and mental health conditions also benefit from coordinated care. Many public health departments have developed care coordination programs for children with special health care needs, but few such programs have been adopted by commercial health plans despite evidence showing that many parents of these children want more help coordinating care.

One of the reasons commercial plans may have lagged in adopting care coordination for children is that most plans enroll a relatively small number of children with complex conditions. However, these children account for a disproportionate share of a plan’s medical expenditures and typically place a large care-giving burden on their families. Effective care coordination can lead to better health outcomes, lower plan expenditures, reduced parent absenteeism from work, and improved parent satisfaction with plan benefits. Plans may therefore wish to identify opportunities for coordinating care for children with special health care needs without raising administrative costs.

Findings

Most parents of children with special health care needs act as their child’s primary care coordinator. About 43 percent of parents spend an hour or more per week coordinating their child’s care (Figure 1). From scheduling appointments, to facilitating contact between providers, to following up on services, coordinating care can be complex and time-consuming.

In addition to parents, many health and social service professionals may be involved in coordinating care. About half (53 percent) of professional care coordination services for children with special health care needs are delivered through a primary care physician’s office, although specialty providers (11 percent), insurance plans (5 percent), and other agencies (31 percent) also provide services. However, nearly three-quarters of parents who need professional care coordination services for their child say they do not get enough help—if they get any at all (Figure 2). Moreover, one-third of those who do get help are not fully satisfied with the quality of the services they receive (Figure 3).
Care coordination responsibilities can lead parents to reduce their work hours, resulting in greater financial challenges for families. The 2002 National Survey of Children with Special Health Care Needs indicates that about 25 percent of parents of children with special health care needs sacrifice time at work to attend to their child’s medical needs, and about 10 percent have stopped working because of their child’s condition. The resulting financial burden becomes even greater for many parents who are forced to work less just as they are facing higher out-of-pocket costs for care. Families of children with emotional or behavioral disorders have particular challenges providing and coordinating care for their children (see Update 3 on page 5).

Implications

Commercial health plans face a difficult trade-off in coordinating care for children with special health care needs. On the one hand, these children make up a relatively small part of a plan’s enrollment, so total expenditures for their care are low relative to expenditures for other groups (for example, older adults with diabetes). As a result, a separate care coordination program for them may not be administratively feasible. On the other hand, care coordination services targeted to a carefully selected group of children—such as children with the most complex or expensive chronic conditions—could significantly improve child health outcomes, thereby reducing a plan’s health care expenditures at a relatively modest administrative cost.

Health plans interested in learning more about how to improve care coordination services for child members with chronic conditions can take the following steps:

- Assign children with chronic conditions to risk-based groups by using standard groupers or algorithms based on ICD codes and utilization history (for examples, see www.mathematica-mpr.com/publications/PDFs/childrenspecial.pdf).
- Explore strategies for extending existing care coordination programs to children with chronic conditions.
- Consult with experts who have developed and evaluated care coordination models for children with chronic conditions in commercial health insurance plans:
  - One model, Partners in Chronic Care, was developed at Dartmouth and is being used for commercially insured children with chronic conditions in several New England states. Contact Dr. Ardis L. Olson or Beth Pearson at (603) 653-1442 for more information.
  - The Center for Children with Special Needs at the Children’s Hospital & Regional Medical Center in Seattle has developed methods to identify children with chronic conditions and provide them with cost-effective care coordination. Contact Dr. John Neff at (206) 987-5275 (see also www.cshcn.org).
About 60 percent of children have health insurance through their parent’s employer. However, the extent to which this insurance covers services for children with special health care needs depends on a variety of factors, including how employers resolve the trade-off between the advantages of a generous benefits package and the cost of that coverage. Typically, the more comprehensive the benefit package, the larger the share of health care costs assumed by employees. This burden will be greater for families of children with special health care needs because these children use more services and see providers more often than other children. Financial stress can increase even more for parents who curtail their work hours or forgo a job altogether in order to manage their child’s care.

Commercial health insurance plans are limited in their ability to influence the economic forces that shape employers’ decisions about health coverage. However, health plans can work with employers to provide coverage for the services needed by this small, but vulnerable, group of member families.

Findings

Out-of-pocket expenses add up. Families generally pay 10 percent of the total cost of services for a child with a chronic condition (Table 1). In 2001, that translated to an average of $34 per month in out-of-pocket costs for a child with any chronic condition and $103 per month for a child with a severe condition (data not shown). Cost-sharing by families is highest for mental health services and prescription drugs; families paid 31 percent of the total cost of the former and 26 percent of the total cost of the latter in 2001.

Many families find out-of-pocket costs difficult to manage, according to a survey of families of children with chronic conditions enrolled in commercial plans. Nearly one-fifth of families reported that their child’s condition led to financial problems (Figure 1), and 15 percent said that their current income would not cover their child’s medical expenses. The same survey found that more than one-quarter of families believe that their health plan’s out-of-pocket charges are “unreasonable” (data not shown).

Home care demands can be significant. Nearly one-quarter of families spend at least one hour a week arranging or otherwise providing care for their child; six percent spend at least one hour a day (Figure 2). Health plan benefits, such as respite services, can alleviate these demands, but nearly one-quarter of families who need respite services reported that the level of care does not meet their needs (data not shown).

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### Table 1. Average Monthly Out-of-Pocket Costs for Families of Children with Chronic Conditions, Selected Services, 2001

<table>
<thead>
<tr>
<th>Service</th>
<th>Average cost per month to family</th>
<th>Percent of total cost shared by family</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total cost</td>
<td>$34</td>
<td>10%</td>
</tr>
<tr>
<td>Prescription drugs</td>
<td>11</td>
<td>26%</td>
</tr>
<tr>
<td>Primary care</td>
<td>5</td>
<td>17%</td>
</tr>
<tr>
<td>Mental health</td>
<td>3</td>
<td>31%</td>
</tr>
<tr>
<td>Specialist</td>
<td>3</td>
<td>8%</td>
</tr>
<tr>
<td>Inpatient</td>
<td>3</td>
<td>3%</td>
</tr>
</tbody>
</table>

Source: UnitedHealth Group

### Figure 1. Burden of a Child’s Chronic Condition on Family and Work Life

- Caused financial problems for family: 18%
- Needed additional income to pay for medical expenses: 15%
- Cut work hours to care for child: 24%
- Stopped working to care for child: 10%
- Required family counseling related to child’s condition: 12%

Source: 2002 National Survey of Children with Special Health Care Needs
Caring for children with chronic conditions may prevent parents from working outside the home. In one-quarter of the families surveyed, a parent reduced his or her work hours to care for a child (Figure 1). In 10 percent of families, a parent stopped working altogether to care for a child with a chronic condition.

Chronic conditions take an emotional toll on other family members. Twelve percent of family members—parents and other children—require counseling for issues related to a child’s chronic condition (Figure 1), according to a survey of such families. The survey also found that families who need such counseling are more likely to shoulder a significant financial and work-related burden stemming from their child's condition (data not shown).

Implications

Although health plans cannot directly lighten the financial and emotional burden on families of children with chronic conditions, they can take the following steps:

- Stay up to date on information about reducing the burden on working parents of children with chronic conditions. For example, see the “Employee Benefits Study for Children with Special Health Care Needs” (www.massgeneral.org/children/professionals/ccahp/empl_benefit_study/ccahp_empl_benefits_study_about.aspx).

- Seek appropriate ways to work with employers and families to customize benefits for families of children with chronic conditions. New England SERVE provides several examples in its “Working Together: Family-Professional Partners Institute” (www.neserve.org/neserve/pdf/NES%20Publications/Working_Together-Institute_Brochure.pdf), which includes specialized training for service representatives on questions related to caring for children with special health care needs.

- Analyze the out-of-pocket costs for families of children with chronic conditions to identify families that are at high financial risk. For example, see the analysis in “Family Cost-Sharing for Children with Special Health Care Needs in Employer-Based Managed Care Plans 1999-2001” (www.mathematica-mpr.com/publications/PDFs/familycost.pdf).
Along with childhood obesity and asthma, attention deficit hyperactivity disorder (ADHD) is one of the most common chronic conditions among children. Approximately two million children in the United States have ADHD, and prevalence rates continue to rise. The disorder is usually quite stressful for families, and some parents choose to work fewer hours to meet the needs of a child with ADHD. A higher incidence of injuries and behavioral problems as well as greater use of prescription drugs push medical costs for these children beyond the costs for children without special health care needs.

Children with ADHD receive most of their care from primary care clinicians, who make the initial diagnosis, manage a child’s care, and supervise treatment. Effective management of ADHD is multifaceted and typically involves working with parents and schools. As a result, treatment may fall short of recommended national guidelines. As commercial health plans continue to refine current products and develop new ones, they may benefit from taking a closer look at the role of primary care physicians in the diagnosis and treatment of children with ADHD.

Findings

Children who have ADHD use significantly more health care services than do children who do not have ADHD. The former have more primary care visits, more mental health visits, and more pharmaceutical use compared with other children. One study of children with ADHD in commercial plans found that their overall annual medical costs were double the costs for children who do not have ADHD ($1,465 versus $690; Figure 1).¹

¹National Institutes of Health (www.nimh.nih.gov/publicat/adhd.cfm); Centers for Disease Control and Prevention (www.cdc.gov/ncbddd/adhd/publichealth.htm); Agency for Healthcare Research and Quality (www.ahrq.gov/clinic/epcsums/adhdsutr.htm).

Pediatricians, family doctors, and other primary care physicians play a critical role in the treatment of children with ADHD. Primary care physicians are often involved in the initial diagnosis of ADHD, finding mental health specialists for further counseling and coordinating care with other providers and schools. In addition, primary care physicians prescribe and manage the most common forms of ADHD medication. In fact, more than two-thirds of the providers who prescribe stimulants for ADHD in school-age children (6 to 12 years old) are pediatricians or other primary care physicians (Figure 2).


Standard treatment for ADHD now includes a mix of approaches, such as medication therapy, psychosocial/behavioral treatment, supportive services offered in school, and various combinations of the three. However, about half of the children identified as having ADHD do not receive appropriate care, as defined by guidelines of the American Academy of Child and Adolescent Psychiatry. According to primary care physicians, major barriers to care—the same for ADHD and other childhood emotional and behavioral chronic conditions—include a shortage of pediatric specialists, delays in getting appointments, and coverage issues such as physician panel restrictions and a complex appeals process for the use of out-of-plan specialists (see Table 1).⁴

### Implications

Because primary care physicians provide a substantial amount of care for children with ADHD, health plans can use several newly developed tools to help ensure that treatment is delivered efficiently and appropriately in primary care offices.

- The National Center for Quality Assurance has a HEDIS measure of adequate follow-up care for children on medication for ADHD. The measure, which reflects care delivered in the first 30 days of treatment and within the next nine months, is intended to guard against adverse side effects of medication (www.ncqa.org/main/sponsors/hedis_measureimplementation.pdf).

- Surveys of member families who have children with ADHD can help plans learn more about satisfaction with services. The ECHO component of the Consumer Assessment of Healthcare Providers and Systems provides questions on children receiving treatment for ADHD through commercial health plans (www.cahps.ahrq.gov/content/cahpskit/files/255_echo_mbho_v3_eng_child.pdf).

- The American Academy of Pediatrics’ toolkit recommends that private payers recognize the complexity involved in making the initial diagnosis and ensure that providers are properly reimbursed (see Perrin et al., *Principles for Improving the Fiscal Environment for the Provision of ADHD Services.* Elk Grove, IL: American Academy of Pediatrics, March 2004).

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### TABLE 1. PERCENT OF PRIMARY CARE PHYSICIANS REPORTING SELECTED BARRIERS TO CARE FOR CHILDREN WITH EMOTIONAL AND BEHAVIORAL CHRONIC CONDITIONS

<table>
<thead>
<tr>
<th>Barriers</th>
<th>Percent</th>
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<tbody>
<tr>
<td>Lack of pediatric specialists</td>
<td>64</td>
</tr>
<tr>
<td>Difficulty/delay in getting appointment</td>
<td>64</td>
</tr>
<tr>
<td>Physician panel restrictions</td>
<td>48</td>
</tr>
<tr>
<td>Complex appeals process for utilization of out-of-plan specialists</td>
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</tr>
<tr>
<td>Authorization procedures</td>
<td>39</td>
</tr>
<tr>
<td>Financial disincentives</td>
<td>35</td>
</tr>
<tr>
<td>Burdensome paperwork</td>
<td>29</td>
</tr>
</tbody>
</table>

About Mathematica

Mathematica, a nonpartisan policy research firm, conducts research and surveys for federal and state governments, foundations, and private sector clients. The employee-owned company has conducted some of the most important evaluations of health care, education, nutrition, welfare, employment, and early childhood policies and programs in the United States. Mathematica strives to improve public well-being by bringing the highest standards of quality, objectivity, and excellence to bear on the provision of information collection and analysis to its clients.
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