FOCUS on Health Reform

THE HENRY J. KAISER FAMILY FOUNDATION

September 2009

CHILDREN AND HEALTH CARE REFORM: ASSURING COVERAGE MEETS THEIR HEALTH CARE NEEDS

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EXECUTIVE SUMMARY

As health reform discussions continue, one key topic that will need to be addressed is what will be included in the coverage provided and how well it will meet individuals' health care needs. Because they are growing and developing, children have a distinct set of health care needs that evolve over time and differ from those of adults. Moreover, while as a group children are relatively healthy, one in seven has special health care needs. Given that under reform, many children will be covered through private plans and some children who are currently covered through public programs may be shifted to private plans, it is particularly important to consider how well private plans might meet children's health care needs. A key question for children is what coverage standards will be applied to these private plans under reform.

To examine how well a generous private plan today addresses the varying health needs of children, this brief analyzes the specific health care needs of two children, including:

- Jacob, a 7-year-old boy who is in generally good health but suffers from the relatively common ailments of asthma and allergies; and
- Isabel, a 13-year-old girl who was born prematurely and has cerebral palsy and requires a broad range of acute and long-term services and supports that enable her to function and learn at school.

Profiles of the health care utilization of these children during the last year were developed through interviews with their parents. Their actual utilization was then compared to the benefit coverage and cost-sharing requirements of the Blue Cross Blue Shield Standard Option (BCBSSO) plan to determine which of their services would be covered and what their families would pay both in cost-sharing and for non-covered services. The BCBSSO is the most popular coverage option offered through the Federal Employees Health Benefits Program (FEHBP) and is similar in many respects to coverage offered by other large employers. Overall, it is generous in terms of the benefits covered, but it charges relatively significant cost-sharing. The analysis also considers what coverage these children would receive and the costs their families would pay under Medicaid's EPSDT benefit package, which is specifically designed for children with low incomes and/or high health needs.

Key Findings

A family with a relatively healthy child may still face significant out-of-pocket costs under the BCBSSO plan. Jacob is a relatively healthy child. Like other children, he relies on regular well-child and other preventive care, including dental care, for his healthy development. He also has allergies and mild asthma, which sometimes require acute care as well as regular use of prescription and over-the-counter medications. While most of the services Jacob uses would be covered under the BCBSSO plan, the family would still face significant out-of-pocket costs. It is estimated that Jacob's family would have spent about $2,020 in out-of-pocket costs under the

BCBSSO plan to meet his health care needs in the past year, due to copayments, deductible and coinsurance charges, and the cost of non-covered services, such as over-the-counter medications and much of his dental care.

A child with special health care needs can face significant gaps in coverage and large out-of-pocket costs under the BCBSSO plan. Isabel requires a broad range of services to treat her cerebral palsy and enable her to function and learn at school. In addition to regular visits with her primary care doctor and specialists, she relies on weekly physical and occupational therapy, utilizes several types of medical equipment such as a cane, walker, wheelchair, and voice activated computer, and takes several prescription drugs on an ongoing basis. Further, last year, she had two surgeries to address problems with her back and eyes.

- *Much of Isabel's care would be covered under the BCBSSO plan, but her family would be required to pay significant cost-sharing amounts.* Given the copayment, deductible, and coinsurance requirements that apply to inpatient care, through her two surgeries alone, Isabel would likely reach the plan's $5,000 annual limit on out-of-pocket costs (which could increase to $7,000 if any care is received from non-preferred providers).
- *Further, some of Isabel's health needs extend beyond the coverage limits of the BCBSSO plan*. For example, her physical and occupational therapy needs exceed the plan's yearly limit on visits, and some of the specialized equipment she relies on, such as her computer, would not be covered by the plan. Thus, to receive these services and equipment, the family would have to pay the entire cost out-of-pocket. The total for non-covered care in the past year would likely reach about $4,300, meaning that, overall, Isabel's total costs for cost-sharing charges and non-covered services last year would be in excess of $9,000.

Medicaid fully covers children's acute and long-term care needs with no or very limited cost-sharing requirements. Under Medicaid's EPSDT benefit, all of the needed care for both Jacob and Isabel would be covered. The EPSDT benefit covers all medically necessary care for children, which means it fully covers preventive and primary care, including dental, hearing, and vision care, as well as all acute care needs. Further, Medicaid coverage extends beyond acute care to address long-term care needs. As such, it would cover Isabel's needed therapies, medical equipment, and other support services. Additionally, although some states require modest cost-sharing for families with income above the poverty level, total cost-sharing in a year may not exceed 5% of family income, providing important financial protections for low-income families.

Implications

These findings illustrate that the content of coverage provided under reform will have significant implications for children's access to care and their families' financial security. As policymakers consider standards for coverage provided to children under reform, it will be important for them to consider not only what benefits will be covered, but also the limits that will apply to covered benefits *and* required cost-sharing amounts, including deductible, copayment, and coinsurance charges. Children have a broad and unique range of health care needs. Beyond acute care, children need regular preventive care, including dental, hearing, and vision care, for their healthy development. Further, children with special health care needs often need a larger array of both acute and long-term services and supports. Low- and moderate-income families are very sensitive to cost-sharing amounts and have limited room in their family budgets to pay health care costs. As such, providing children with a benefit package that covers the full range of their

health care needs and offers meaningful financial protections for families will be key to assuring that children can access and obtain necessary and appropriate care.

INTRODUCTION

As Congress and the Obama Administration work to determine the outlines of national health care reform, a key measure of the reform's potential to achieve the end goals of expanded coverage –adequate access to health care and long-term gains in Americans' health – will be whether it provides coverage for children that meets their unique health care needs. The nation has made significant progress in expanding children's coverage, with nine of every ten children in the U.S. now insured. But having an insurance card is not enough to assure that children are able to obtain the care they need; indeed, recent research indicates that children receive recommended care less than half the time.[1] The extent to which children's health coverage translates into access is a reflection of multiple factors, chiefly, the scope of the benefits covered, the cost-sharing requirements that apply, and the adequacy of the provider network available in a health plan.

Today, over one-quarter of children in the U.S. are covered by the nation's public health insurance programs, Medicaid and the Children's Health Insurance Program (CHIP). Medicaid covers comprehensive acute and long-term care services for children through the Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) benefit, and it sharply limits out-of-pocket costs.[2] Depending on the state, children enrolled in CHIP may have EPSDT or, instead, a package of benefits that is somewhat or substantially more limited. Under the major health care reform proposals being debated, millions of children now covered by public insurance, as well as millions who are now uninsured, could receive their health coverage through an "exchange." The reform bills do not specify the full terms of children's coverage under the exchange, but require that insurance offered through it cover an "essential benefits package" similar to coverage generally provided by employers.

The potential implications of such a change for children are great, and they underscore the importance of considering the kinds of care children need and how the structure of their coverage – both benefits and cost-sharing requirements – affects their ability to obtain and afford that care. For children in low-income families and children with extensive health care needs, the risks associated with inadequate coverage are greatest.

In this paper, we begin by reviewing the research literature on children's health needs. We then examine how two children with different health care profiles and utilization histories would fare with an insurance product – the Blue Cross Blue Shield Standard Option (BCBSSO) plan – that is likely to be considered a benchmark for coverage offered under a health insurance exchange.[3] It is a generous plan in terms of the benefits covered, but it charges relatively significant cost-sharing. The analysis also considers what coverage these children would receive and the costs their families would pay under Medicaid's EPSDT benefit package, which is specifically designed for children with low incomes and high health needs.

CHILDREN'S HEALTH CARE NEEDS

Children are a distinct population with unique health care needs. Because children are growing and changing, the health care needed for children includes services to meet their developmental needs as well. For the same reason, health care for children also emphasizes preventive care and early intervention. Appropriate preventive care ensures that, to the maximum extent possible, disease is prevented in children, and children do not experience avoidable health complications. When illnesses or developmental disabilities are not detected and treated early, children may be unable to "catch up" on some developmental losses.[4]

To confer the most benefit, many early detection and preventive services are best provided at specific points in a child's life. Professional guidelines developed by the American Academy of Pediatrics (AAP) establish a schedule for child preventive services, including immunizations and screenings. These guidelines are part of *Bright Futures: Guidelines for Health Supervision of Infants, Children and Adolescents*, which was developed by the Health Resources and Services Administration, in conjunction with providers, consumer representatives, and other experts, to serve as a national standard for quality well-child care.[5]

Appropriate health care can help children avoid preventable and serious chronic conditions like obesity, heart disease, and Type II diabetes and promote adequate nutrition and physical activity. It can help a baby born prematurely to grow, thrive, and meet developmental milestones. For children with a serious developmental condition like cerebral palsy, appropriate care means getting the services and supports needed to learn and participate in school. For children with chronic conditions, having access to the services needed to manage the conditions can spare children hospitalizations and avert high costs for families. Vision, hearing, and dental care – often considered "extras" in health coverage for adults – are among the services children need to develop and achieve their full potential. Without glasses, a child with vision problems may not learn to read. Whether a hearing-impaired child develops speech may depend on whether he or she receives a recommended hearing aid or cochlear implant.

Although children are a relatively healthy population, nearly 14% of U.S. children, or approximately 1 in 7, have special health care needs, meaning they have a chronic or serious health problem that requires more intensive health services. These children not only use services like physician visits, specialist care, and prescription drugs more frequently than healthy children do, but they may also require specialized services such as physical, occupational, and speech therapy, or durable medical equipment. In addition, for low-income children, benefits that help their families overcome obstacles to access, such as transportation, interpretation services, and case management, can be crucial, but private insurers generally do not cover these benefits.[6]

Despite broad expert recognition of the distinctive and diverse health needs of children, most commercial health benefit packages are designed for relatively healthy working-age adults, without special provisions for children. The typical employer-sponsored plan does not take into account the fact that recommended comprehensive benefits for children differ in scope from those for adults.[7] In addition to the issue of benefit design is the interlocking issue of the affordability of benefits. Extensive research has shown that cost-sharing can deter patients, particularly those with low income, from seeking needed care.[8] [9] In shaping health coverage that

is adequate to meet the needs of children, both benefits and the structure of cost-sharing, including deductibles, copayments and coinsurance, and caps on families' out-of-pocket expenses, are important dimensions to consider.

STUDY OVERVIEW AND METHODS

Two children with very different health care profiles and needs were selected to assess how well the health care services they need would be covered under the Blue Cross Blue Shield Standard Option (BCBSSO) offered in the Federal Employees Health Benefits Program (FEHBP):

- ***Jacob*** *i*s a 7-year-old boy who is in good general health but suffers from the relatively common ailments of asthma and allergies; and
- ***Isabel*** is a 13-year-old girl who was born prematurely and has cerebral palsy. She needs a broad range of acute and long-term services and supports that enable her to function and learn at school.

To conduct the analysis, BCBSSO benefits and cost-sharing requirements were applied to Jacob's and Isabel's actual utilization of services during the previous year. To obtain the children's utilization history, Georgetown University researchers conducted telephone interviews with each child's mother in May and June of 2009. For comparison, the study also considered how Medicaid's EPSDT benefit, which is specifically designed to meet the full range of children's needs and provides strong financial protections, would cover these children's health needs. The children's utilization profiles were reviewed by Dr. Chen Kenyon, a member of the American Academy of Pediatrics, to validate them for clinical reasonableness.

Overview of Blue Cross Blue Shield Standard Option (BCBSSO) Plan

BCBSSO is the most popular plan in FEHBP, which is the largest employer-sponsored health benefits program in the U.S., covering 8 million federal workers, dependents, and retirees, including Members of Congress. BCBSSO is chosen by roughly half of all FEHBP enrollees. Under the BCBSSO plan, which is a PPO, enrollees who obtain services from "preferred" providers in the plan's network get a higher rate of coverage. That is, they face lower out-of-pocket costs than they would if they obtained the same services from non-preferred providers. The BCBSSO plan designates many, though not all, of its network providers as "preferred."

The list of services covered under the BCBSSO is relatively comprehensive, including hospitalization, physician care, maternity care, mental health care, prescription drugs, and dental care (Table 1). Most covered services are not subject to either annual or lifetime limits, but there are exceptions. Rehabilitative care, such as physical therapy, speech therapy, and occupational therapy, is limited to 75 visits per year. Outpatient mental health care can be limited to 25 visits per year depending on the provider chosen. BCBSSO reimbursement for dental care is very limited: for children up to age 13, the plan pays $22 for a preventive dental visit and $30 for tooth extractions (including local anesthesia).

Table 1:
Covered Services and Cost-Sharing Requirements under BCBSSO Plan

Item/Service	Subject to Deductible?	Additional Cost-Sharing When Care is Rendered by Preferred Provider		Additional Cost-sharing When Care is Rendered by Non-Preferred Provider or Out-of-Network*		Benefit Limits
		Copay	Coinsu-rance	Copay	Coinsu-rance	
Hospital inpatient	No	$200	-	$300	-	
Hospital outpatient	Yes	-	15%	-	30%	
Ambulance (medical condition)	No	$100	-	$100	-	
Ambulance (accidental injury)	No	$0		-	$0	
Emergency care (medical)	Yes	-	15%	-	30%	
Emergency care (accidental injury)	No	-	-	-	-	
Physician, professional care, inpatient	Yes	-	15%	-	30%**	
Physician, professional care, outpatient office visits	No	$20	-	-	30%	
Outpatient mental health	No	$20	-	-	40%	Limited to 25 visits/year; may seek waiver of limit if treated by preferred provider
Lab, x-ray	Yes	-	15%	-	30%	
Durable medical equipment	Yes	-	15%	-	30%	
Home health care	Yes	-	15%	-	30%	Limited to 25 visits/year, no more than 2 hours per visit/day
Hospice care (outpatient)	No	-	-	-	-	
Physical, occupational, speech therapy	No	$20	-	-	30%	Limited to 75 visits/year, combined
Eye exam	No	$20	-	-	30%	Not covered unless related to a specific medical condition
Eyeglasses	Yes	-	15%	-	30%	Not covered unless related to specified mental conditions
Nutritional formula, feeding tube equipment and supplies	Yes		15%		30%	
Prescription drugs – generic	No	-	20%	-	45%	
Prescription drugs – brand	No	-	30%	-	45%	
Dental	No	Limited reimbursement		Limited reimbursement		Reimbursement capped, e.g., $22 for pediatric hygienist visit; patient pays remainder
Case management services	n/a					Not covered
Personal assistance care	n/a					Not covered
Transportation services/equipment	n/a					Not covered
Annual deductible	$300 ($600 family)					
Annual out-of-pocket (OOP) maximum	$7,000 (individual or family); $5,000 if all care is received from preferred providers					

* Patients who receive care from non-network providers may be subject to balance-billing in addition to otherwise applicable cost-sharing.

** Coinsurance for non-preferred radiologists, pathologists, and surgical assistants is limited to 15% when patient care is received in a preferred hospital. Such coinsurance counts toward the $7,000 annual out-of-pocket cap.

Cost-sharing requirements apply to most covered services. The plan imposes an annual deductible of $300 for an individual ($600 for a family), which is somewhat lower than the deductible under most other employer-sponsored PPO plans.[10] A $20 copayment is required for many outpatient physician visits, while coinsurance of 15% applies to lab tests, medical equipment, and inpatient medical care. A higher coinsurance rate of 30% applies when this care is received from non-preferred providers, and also when patients receive care from providers outside the plan network. In the latter case, patients are also subject to "balance billing" – charges in excess of the BCBSSO allowance that patients may be required to pay.[11] Finally, prescription drugs are subject to coinsurance – 20% for generics and 30% for brand-name medicines.[12]

Cost-sharing for covered services, whether deductibles, copayments, or coinsurance, is limited by an annual out-of-pocket cap of $7,000. Within the overall cap of $7,000, a lower cap of $5,000 applies if all care is received from "preferred providers" in the BCBSSO plan network. If patients receive care from both preferred and non-preferred providers, cost-sharing for covered services might accumulate to more than $5,000 but cannot exceed $7,000 for the calendar year.

Overview of Medicaid's EPSDT Benefit

Medicaid's EPSDT benefit entitles all children in Medicaid to comprehensive screening, prevention, diagnosis, and treatment services through age 21. To foster early identification of children's physical, mental, and developmental conditions, EPSDT guarantees health screenings consistent with a periodicity schedule.[13] If a screening or subsequent diagnosis identifies a health condition, Medicaid covers any follow-up treatment needed. This applies equally to medical, developmental, mental, acute, and chronic conditions.[14] Covered services encompass long-term care services and support as well as the acute health services traditionally covered by commercial insurance policies. The EPSDT benefit package was designed to reflect professional pediatric standards of care.[15]

Apart from its comprehensive benefit package, another aspect of EPSDT that distinguishes it from private insurance coverage is a broader definition of "medical necessity" that supports children's health and developmental needs and helps children with serious disabilities or diseases that may be improved, but not cured, to maximize their potential.[16] The definition requires states to provide children with all services necessary to "*correct or ameliorate defects and physical and mental illnesses and conditions…*"[17] Commercial insurers generally use a much narrower definition of medical necessity and limit coverage to services that restore normal function. In addition, commercial policies may exclude some categories of benefits or treatment for certain conditions, or cap the number of certain services a patient can obtain. Finally, whereas EPSDT creates a legally enforceable right to services for children who need them, private insurance contracts can assign broad authority to the plan administrator to make determinations about what is covered under the policy.[18]

Because Medicaid serves a low-income population, premiums and cost-sharing are sharply limited. No premiums and little cost-sharing are allowed for very low-income children. Children with somewhat higher family income may face premiums and modest cost-sharing, but total premiums and cost-sharing in a year may not exceed 5% of family income.[19] (A 5% cap applies in CHIP as well.)

FINDINGS

Jacob, 7-year-old boy with allergies and mild asthma

Jacob's health and health care needs

Jacob is a 7-year-old boy who is generally in good health and loves to play baseball but who, like many children, suffers from allergies and asthma. Upwards of 40% of children live with some form of allergic reaction, such as hay fever and seasonal allergies,[20] and in 2005, almost 9% of children in the United States had been diagnosed with asthma.

Jacob's mother first became aware of his allergic condition when he was two months old and still breast-feeding. She ate some nuts and a short while later he had an allergic reaction. Jacob's current food allergies include dairy products, tree nuts and peanuts. When he eats a food he is allergic to, he can experience an episode of anaphylaxis – a severe, whole-body allergic reaction that can cause difficulty breathing and other serious symptoms and even death. To stop the reaction, Jacob has to be injected with epinephrine (adrenaline). Jacob has an "Epi-pen" with him at all times in case this treatment is needed. Jacob also has environmental allergies that are improved by over-the-counter (OTC) antihistamines such as Zyrtec, which he takes daily.

In addition, Jacob has mild persistent asthma. His asthma symptoms tend to be the most severe when he is suffering from upper respiratory infections. At age 3, he was admitted to the hospital due to complications from an asthma attack associated with an infection, but he has not been admitted since.

As a toddler, Jacob visited the pediatrician up to six times a year for complications from colds and other infections, including ear infections. In addition, he visited an allergist twice a year for treatments to manage that condition. Fortunately, visits to the doctor have become less frequent as Jacob has grown older and had fewer complications from colds and infections. Last year, he saw his allergist and his pediatrician each just once.

Jacob takes a number of prescription medications. During hay fever season, he takes Flonase, a prescription nasal spray that controls the reaction to pollen and other allergens. Throughout the year, he takes Flovent, a low-dose inhaled cordicosteroid, daily to help prevent bronchial asthma attacks. Jacob also uses Albuterol, an inhaler that helps relax his airways if he has an asthma attack, and an Epi-pen if he has a severe allergic reaction. Jacob currently has eight Epi-pens; to be prepared in case he needs one, he must keep them handy at school, at home, at after-school care, and in his science class. He also has his asthma action plan on file at school and at camps and other activities, in case he has an attack. Jacob has also been prescribed a peak-flow meter – a portable hand-held device to help him monitor his asthma.

Regular visits to the dentist are important for Jacob. Especially because he is prone to cavities, regular check-ups and dental cleanings are essential for his oral health.

What would Jacob's coverage and cost-sharing be under the BCBSSO plan?

Most of the kinds of care Jacob uses would be covered under the BCBSSO plan, but significant cost-sharing would apply, even if Jacob were treated only by preferred providers and facilities within the BCBSSO network (Table 2).

His outpatient physician office visits, except for the well-child visit, would be subject to $20 copayment requirements. His parents would pay the full allowed charge for his allergy testing and peak flow meter (about $180 in all) because these costs would be subject to the annual deductible.

Coinsurance for Jacob's prescription medications would cost his family about $60 per month, or $720 per year. In addition, the family would pay the full cost for his over-the-counter antihistamine, which BCBSSO does not cover. Thus, the family's total spending for Jacob's medications would exceed $1,000 over the course of the year.

Table 2:
Coverage and Cost-Sharing Under the BCBSSO Plan for Jacob's Medical Care Last Year

Service	Number used last year	Covered?	Cost-sharing*	Estimated out-of-pocket cost to Jacob's family for the year**
Outpatient Medical Care				
Well-child visit	1	Yes	$0	$0
Primary care visit	1	Yes	$20	$20
Allergist visit	1	Yes	$20	$20
Allergy testing ($130)	1	Yes	Deductible + 15%	$130
Durable Medical Equipment				
Peak flow meter ($50)	1	Yes	Deductible + 15%	$50
Prescription Drugs				
8 Epi-pens, replaced as needed, and Flovent, Flonase, Albuterol ($300/month)	ongoing	Yes	20%***	$720
Zyrtec OTC ($25/month)	ongoing	No	100%	$300
Dental Care				
Dentist visit ($112/visit)	2	Yes, up to $22 per visit	0	$180
Dental fillings ($175/filling)	4	Yes, up to $25 per filling	0	$600
Estimated cost-sharing expenses				**$940**
Estimated cost of non-covered care				**$1,080**
Total estimated out-of-pocket costs				**$2,020**

* Assumes all care rendered by preferred providers. Higher cost-sharing applies for non-preferred providers.
** Charge information reported by Jacob's family.
*** Assumes generic substitutes.

Additional substantial expenses would arise for Jacob's dental care. Because BCBSSO limits its coverage to nominal reimbursement for check-ups and fillings, Jacob's parents would have to pay nearly $800 out-of-pocket for his dental care.

Considering all the services Jacob used last year, were he covered under the BCBSSO plan, his cost-sharing for covered services, along with spending for non-covered services, would total just over $2,000. In a different year, Jacob might need to have additional lab tests or resume his allergy shots if his asthma or allergies worsened, or he might be hospitalized following a serious asthma attack. Under these circumstances, his family's cost-sharing expenses and spending for non-covered care could increase by hundreds of dollars.

For Jacob's out-of-pocket costs not to exceed 5% of family income – the ceiling on family out-of-pocket costs for children in Medicaid and CHIP – his family would have to have income of more than $40,000.

What would Jacob's coverage and cost-sharing be under Medicaid's EPSDT benefit?

Under Medicaid's EPSDT benefit package, all of Jacob's care would be covered and, depending on his family's income, the family would face little or no out-of-pocket costs for his care. For the lowest-income children covered by federal Medicaid law, states can impose limited cost-sharing only for prescription drugs that are designated "non-preferred" on a state's drug formulary and for non-emergency use of an emergency room. For some other children in Medicaid, states are permitted to impose small monthly deductibles and coinsurance for outpatient services up to 10% or 20% of the cost. However, for all children, Medicaid limits maximum out-of-pocket costs to 5% of family income.[21]

Isabel, 13-year-old girl born prematurely and has cerebral palsy

Isabel's health and health care needs

Isabel is a 13-year-old girl who suffered a brain hemorrhage shortly after birth. She was born prematurely at 31 weeks and was subsequently diagnosed with spastic diplegia cerebral palsy, a central nervous system disorder that impairs movement – in Isabel's case, of her legs. Each year in the U.S., roughly half a million babies are born preterm. Related to their early birth, about 100,000 children develop health problems such as cerebral palsy, blindness, and cognitive and behavioral deficits.

Isabel's treatment for cerebral palsy and its complications began early. Since she was about a year old, Isabel has received weekly physical therapy and occupational therapy. The physical therapy includes intensive stretching and massage to keep her leg muscles in tone. Isabel also receives Botox therapy every few months to aid with stretching and range of motion. As a younger child, Isabel had two surgeries to lengthen the muscles in her legs. Still, she has problems walking and uses both a cane and a walker. In addition, she sometimes uses a manual wheelchair.

Another complication of Isabel's condition is scoliosis, or twisting of the spine, that can occur as children with cerebral palsy grow and imbalance in the strength of their opposing muscles distorts the growing skeleton. Last year, Isabel had spinal fusion surgery, including the insertion of rods to help correct her scoliosis. She also has a brace for her back and one for each arm. Isabel sees two specialists – an orthopedist and a physiatrist – to manage care of her spine and

limbs, and she receives weekly physical therapy. She also sees a urologist because of recurring infections.

The cerebral palsy has also caused some cognitive damage. Isabel has vision problems and she had eye surgery this spring to correct her condition. Isabel also has some difficulty using her hands to write. To help overcome this limitation in school, she has a computer equipped with voice recognition that types words as she speaks them. Isabel sees an occupational therapist once to twice per week (80 sessions over the year) to develop and improve her computer skills. Although many children with cerebral palsy require speech therapy, Isabel does not.

Isabel has some anxiety related to her condition, so she sees a psychologist on a weekly basis to help her manage it. She also takes Prozac and a low dose of Risperdal for anxiety and must see a psychiatrist every three or four months to monitor her medications.

Some children with complications like Isabel's become unusually susceptible to infection, such as cold and flu, but so far Isabel has been fortunate in this respect. Visits to her general pediatrician have been limited to annual check-ups, including vaccines and other childhood preventive services. She has been to the emergency room once, for a problem with her eyes.

What would Isabel's coverage and cost-sharing be under the BCBSSO plan?

Many of the kinds of care Isabel uses would be covered under the BCBSSO plan, but significant cost-sharing would apply, even if she were treated only by preferred providers and facilities within the BCBSSO network (Table 3).

The inpatient surgeries on Isabel's back and eye would each trigger a copayment of $200 for hospitalization. The annual $300 deductible plus 15% coinsurance would apply for the services provided by the surgeons and other physicians who cared for Isabel in the hospital and emergency room. Between the two surgeries, Isabel would likely reach the $5,000 annual limit on out-of-pocket costs for covered services. If any of her physicians were not preferred providers, the limit on Isabel's out-of-pocket costs would increase to $7,000.

Isabel's outpatient physician office visits (except for well-child care) and mental health visits would be subject to $20 copayment requirements. Her optometry visits would be covered because of her medical condition, but also subject to a $20 copay. Because of the array of specialists and the intensity of services involved in her care, the copays for Isabel's visits alone could total hundreds or even thousands of dollars in a year. The lab tests, allergy testing, and allergy injections ordered during her visits would cost Isabel's family coinsurance of 15%. However, once Isabel's surgeries caused her to reach the annual out-of-pocket maximum, such copays and coinsurance charges would be waived for the remainder of the year.

Table 3:
Coverage and Cost-Sharing under the BCBSSO Plan for Isabel's Medical Care Last Year

Service	Number used last year	Covered?	Cost-sharing*	Estimated out-of-pocket cost to Isabel's family for the year**
Inpatient Medical Care				
Hospitalization	2	Yes	$200	$400
Surgeries	2	Yes	Deductible + 15%	$4,600***
ER visit /Medical	1	Yes	15%	$0/$68
Outpatient Medical Care				
Well-child visit	1	Yes	$0	$0
Primary care visit	3	Yes	$20	$0/$60
Urologist visit	2	Yes	$20	$0/$40
Orthopedist visits	4	Yes	$20	$0/$80
Physiatrist visit	4	Yes	$20	$0/$80
Botox treatments	3	Yes	15%	$0/$450
Mental Health Care				
Psychologist visit	50	Yes	$20	$0/$1,000
Psychiatrist visit	3	Yes	$20	$0/$60
Durable Medical Equipment/Orthopedics/Other Equipment				
Wheelchair	1	Yes	15%	$0/$150
Canes	2	Yes	15%	$0/$12
Walker	1	Yes	15%	$0/$11
Back and arm braces	3	Yes	15%	$0/$53
Voice activated computer	1	No	--	Previously purchased
Specialized keyboard	1	No	--	
Rehabilitative/habilitative Therapies				
Physical Therapy ($75/visit)	50	Yes, up to 75 visits, combined	$20 up 75 visit limit, then 100%	$4,125/$5,625
Occupational Therapy ($75/visit)	80			
Prescription Drugs*				
Anxiety medication	Ongoing	Yes	20%	$0/$35
Anti-constipation medication	Ongoing	Yes	20%	$0/$50
Vision/Dental Care				
Dentist visit ($112/visit)	2	Yes, to $22 per visit	0	$180
Optometrist visit	1	Yes	$20	$0/$20
Estimated cost-sharing expenses				**$5,000**
Estimated cost of non-covered care				**$4,305**
Total estimated out-of-pocket costs				**$9,305**

* Assumes all care rendered by preferred providers. Higher cost-sharing applies for non-preferred providers.
** Costs for services subject to coinsurance charges, durable medical equipment, and dental care based on data available at http://www.costhelper.com, http://cerebralpalsycosts.com/overview.html/, http://www.allegromedical.com, and http://www.jansenmedical.com. Where two amounts appear, the amount before the slash is the amount Isabel's family would pay once she had reached the out-of pocket limit for covered services. The amount following the slash is the amount Isabel would face had she not yet reached the out-of-pocket limit.
***Annual out-of-pocket maximum satisfied with this cost (assumes all preferred providers)
****Assumes generic substitutes.

The BCBSSO plan would cover Isabel's wheelchair, canes, walker, and back and arm braces. These services are subject to the annual deductible and 15% coinsurance up to the annual out-of-pocket maximum, but again, once Isabel reached the cap with her surgeries, BCBSSO would pay 100% for these items for the rest of the year. Coinsurance for Isabel's covered prescription medications would also be waived for this period because she reached her out-of-pocket cap.

In addition to out-of-pocket costs of $5,000 for services covered by BCBSSO, Isabel's family would face substantial out-of-pocket costs for non-covered services, for which BCBSSO makes no payment. BCBSSO limits coverage of rehabilitative therapies to 75 visits. Therefore, Isabel's family would have to pay the entire cost of the 55 visits she had beyond the limit. At an estimated $75 per visit, this would total over $4,000 in family spending for the non-covered therapy visits.

The BCBSSO plan's coverage of dental care is limited. The plan would reimburse up to $22 for each semi-annual cleaning. Isabel's family would be responsible for remaining charges for these covered services, or about $180.

In all, under the BCBSSO plan, cost-sharing for the services, equipment, and supplies Isabel used last year would reach the plan's $5,000 cap on out-of-pocket costs for covered services. In addition, Isabel's family would face an estimated $4,300 more in out-of-pocket costs for physical and occupational therapy as well as dental care exceeding the plan's limits. In total, Isabel's family would face some $9,300 in health expenses for Isabel's care. If the specialized computer equipment Isabel needs for school had to be replaced or upgraded, her family could face thousands of dollars more in costs because this equipment is not covered under the BCBSSO plan.

For Isabel's out-of pocket costs not to exceed 5% of family income – the standard for children in Medicaid and CHIP – her family income would have to be more than $185,000.

What would Isabel's coverage and cost-sharing be under Medicaid's EPSDT benefit?

Under Medicaid's EPSDT benefit package, all of the care Isabel used last year would be covered and with little or no cost-sharing. No limits on medically necessary rehabilitative services or other care would apply. Because EPSDT is designed to meet the needs of children with special needs as well as other low-income children, and to ensure that they do not face cost barriers to care, it covers many services, including long-term services and supports that commercial insurance rarely does. Thus, the specialized computer equipment and devices that Isabel needs to function and learn in school would be covered under EPSDT. Other educational assistance, such as tutors, could also be covered if it were included in the Individual Education Plan (IEP) developed for children like Isabel, who have special needs due to their medical conditions. Personal care services (such as help bathing or dressing), case management, and private-duty nursing, would be covered as well.

POLICY IMPLICATIONS

The findings from this analysis illustrate how the content of coverage provided under health care reform will have significant implications for children's access to care and their families' financial security. As the study demonstrates, under a benefit package more generous than most offered in the private insurance market, even a relatively healthy child who receives care covered by the private plan can face significant out-of-pocket costs; deductibles and copays can quickly accumulate to levels that many families may be unable to afford. For a child with special health care needs, large gaps in covered services can leave the family to shoulder not only high out-of-pocket costs for covered services, but also the full costs of expensive, often ongoing care that exhausts the plan's limits or that the plan does not cover at all.

In contrast, Medicaid's EPSDT benefit covers the full range of care children need, including both acute care and long-term services and supports. In addition, under EPSDT, little or no cost-sharing is required and total cost-sharing in a year is limited to 5% of family income, providing important financial protection for low-income families. The American Academy of Pediatrics has recommended EPSDT as the model for the benefits package provided to children under health reform.[22]

As policymakers consider standards for coverage provided to children under reform, it will be important for them to consider not only what benefits will be covered, but also the limits that will apply to covered benefits and cost-sharing requirements, including deductibles, copayments, and coinsurance charges. Further, in any system that discourages the use of out-of-network providers through sharply higher cost-sharing schedules, the adequacy (or inadequacy) of provider networks will have a significant impact on the financial burdens families incur in obtaining the care their children need.

Children have a broad and unique range of health care needs. Beyond acute care, children need regular preventive care, including dental, hearing, and vision care, for their healthy development. Further, children with special health care needs often need a variety of additional acute and long-term care services and supports. A large body of research shows that low- and moderate-income families are very sensitive to cost-sharing and may delay or forgo needed care due to costs. As such, providing children a benefit package that covers the full range of their health care needs and provides meaningful financial protection for families will be key to assuring that children have access to and can afford necessary and appropriate care.

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ACKNOWLEDGMENTS

The authors would like to thank the families of Isabel and Jacob who gave generously of their time and shared their stories to inform this report. In addition, we would like to thank Claire Booth and Dr. Chen Kenyon from the American Academy of Pediatrics for their assistance in reviewing Isabel's and Jacob's profiles.

ENDNOTES

[1] R. Mangione-Smith, et al., The Quality of Ambulatory Care Delivered to Children in the United States, New England Journal for Medicine, 357(15): 1515:1523 (October 11, 2007). Adults do not fare much better: under 47 percent of children studied received recommended care, but nearly 55 percent of adults studied did.
[2] C. Provost Peters, "EPSDT: Medicaid's Critical But Controversial Benefits Program for Children," National Health Policy Forum (November 20, 2006).
[3] FEHBP has been a part of health policy discussions concerning the uninsured for more than 15 years. In 1994, President Bill Clinton, in his State of the Union Address, suggested giving everyone health benefits comparable to those of federal employees. In the 2004 election, Senator John Kerry also proposed expansion of FEHBP via the establishment of a new group insurance pool, called the Congressional Health Plan, which would have been open to all employers and individuals who needed health insurance coverage (Collins, Davis, and Lambrew, 2004). In the 2008 presidential election, a number of candidates incorporated FEHBP or a similar program into their health care reform proposals. http://www.randcompare.org/options/mechanism/open_enrollment_in_fehbp
[4] E. Wehr and E. Jameson, "Beyond Benefits: The Importance of a Pediatric Standard in Private Insurance Contracts to Ensuring Health Care Access for Children," The Future of Children 4 (3) Winter 1994 115-133.
[5] For more information on *Bright Futures*, see www.brightfutures.aap.org.
[6] G. Kenney and S.Dorn, "Health Care Reform for Children with Public Coverage: How Can Policymakers Maximize Gains and Prevent Harm?" Urban Institute and Robert Wood Johnson Foundation, June 2009.
[7] National Business Group on Health, "Investing in Maternal and Child Health: An Employer's Toolkit" (November 2007).
[8] For example, see: E. Keeler, "Effects of Cost Sharing on Use of Medical Services and Health," *Journal of Medical Practice Management*, 8:317-321 (Summer 1992); U.S. Congress, Office of Technology Assessment, "Benefit Design in Health Care Reform: Patient Cost-Sharing" (September 1993); U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, "Children's Health Insurance Expansions: State Experiences in Developing Benefit Packages and Cost-Sharing Arrangements" (February 17, 1998); and M. Wong, *et al.,* "Effects of Cost Sharing on Care Seeking and Health Status: Results From the Medical Outcomes Study," *American Journal of Public Health*, 91(11): 1889-1894 (November 2001).
[9] L. Ku & V. Wachino, "The Effect of Increased Cost-Sharing in Medicaid," Center on Budget and Policy Priorities (July 7, 2005).
[10] An annual deductible of $500 is more typically required under job-based health plans. See "2008 Annual Employer Health Benefits Survey," Henry J. Kaiser Family Foundation.
[11] Balance billing refers to excess provider charges above the level recognized by the insurance company as reasonable and reimbursable. Generally network providers contract with the insurer to accept the recognized fee as payment in full. Non-network providers that do not contract with the insurer can and often do balance bill patients.
[12] For more information about coverage under the BCBSSO, see "A Benchmark for Coverage: How the FEHBP Blue Cross Blue Shield Standard Option Plan Covers Medical Care for Patients with Serious Chronic Conditions," American Cancer Society Cancer Action Network, July 2009.
[13] C. Provost-Peters, "EPSDT: Medicaid's Critical but Controversial Benefits Program for Children," National Health Policy Forum," Issue Brief No. 819, November 20, 2006.
[14] Ibid.
[15] S. Rosenbaum & P. Wise, "Crossing the Medicaid-Private Insurance Divide: The Case of EPSDT," *Health Affairs,* 26(2): 382-393 (March/April 2007).
[16] C. Provost-Peters, November 2006.
[17] 42 *CFR* 441.50 (2008).
[18] S. Rosenbaum and P. Wise, "Crossing the Medicaid-Private Insurance Divide: The Case of EPSDT," Health Affairs March/April 2007, 382:393.
[19] See *Cost-Sharing for Families in Medicaid and CHIP* (Washington, DC: Georgetown Center for Children and Families) March 2009. Available at ccf.georgetown.edu.
[20] "Asthma Statistics," American Academy of Allergy Asthma and Immunology, available at http://www.aaaai.org/media/statistics/asthma-statistics.asp
[21] Georgetown University Health Policy Institute Center for Children and Families, "Cost-Sharing Rules for Children in Medicaid and SCHIP," March 2009.
[22] J. Hagan, *Access to Prevention and Public Health for High-Risk Populations*, Testimony before the U.S. Senate Committee on Health, Education, Labor, and Pensions (January 27, 2009).

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