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INDIVIDUALS WITH SPECIAL NEEDS AND HEALTH REFORM: ADEQUACY OF HEALTH INSURANCE COVERAGE

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EXECUTIVE SUMMARY

As the Congress and the Obama Administration continue work on health reform to expand health insurance coverage through a combination of private health insurance and public programs, a key question will be "Coverage for what?" Under legislation pending in Congress, people would be required to obtain health insurance coverage, mostly from private companies. Today private health insurance is generally designed to cover acute care services. The content of coverage varies enormously, however. Studies show that millions of non-elderly Americans are underinsured – that is, their health insurance coverage nonetheless leaves them to pay large amounts out-of-pocket for covered and/or non-covered services. Under-insurance might result from policies that exclude or limit coverage for certain medical care items and services, or it might result from the imposition of high cost sharing for covered services, or both. Under reform, minimum coverage standards would be developed for private health insurance that define what benefits must be covered and what level of cost sharing (deductibles, co-pays, etc.) can apply. Subsidies would be available on a sliding scale to reduce both premiums and cost-sharing for covered services for people who buy private health insurance.

In addition, health reform proposals would broaden eligibility for Medicaid. Today Medicaid covers a broad low-income population, including children and their parents, individuals with diverse physical and mental disabilities and seniors. A critical role of Medicaid is to finance services for people with very high medical costs who often have both acute care and long-term service needs, making it a vital safety net program for those unable to obtain health insurance in the private market or for whom such insurance is inadequate.

How health care reform ultimately defines the content of what health insurance must cover will affect everyone, but it will matter most to people at times when their health care needs are greatest. This issue brief examines the health care needs of three individuals with extensive acute medical care and long-term service needs – a seven year old born prematurely, a 50 year old male with a spinal cord injury and a 45 year old woman with cerebral palsy. It compares their estimated medical expenses to a benchmark private health insurance plan – the Blue Cross Blue Shield Standard Option (BCBSSO) plan offered through the Federal Employees Health Benefits Program (FEHBP.) The BCBSSO plan is the most popular FEHBP option and is often cited an example of generous job-based coverage. This analysis also considers what coverage these individuals have received under Medicaid to meet their medical and long-term care needs.

Key Findings

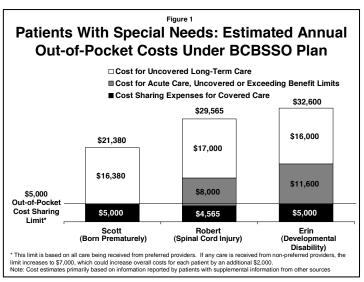
Individuals profiled in this report have very complex health and long-term care needs. They have a broad range of needs for acute medical care as well as long-term services and supports. For example, Scott who was born prematurely, faces a number of developmental challenges that require ongoing, specialized services such as behavioral therapy, occupational

therapy, prescription drugs and personal care services. Robert, who suffered a spinal cord injury as a young adult, is in good health but has ongoing medical issues stemming from his disability that have resulted in a number of hospitalizations and ongoing physical therapy, as well as extensive medical equipment needs to enable him to function in the community and work full-time. People with intellectual disabilities like Erin, rely on speech therapy services, personal care and durable medical equipment such as power wheelchairs to live independently in the community. Each individual profiled has been covered by Medicaid at some point in their lives and greatly values the comprehensive set of services and supports that it provides.

Coverage under the BCBSSO plan is comprehensive for acute care needs. Most of the acute care items and services required by these high cost individuals would be covered under the BCBSSO. The BCBSSO covers services that many private health insurance policies, especially those sold in the individual market do not, including coverage for mental health care, prescription drugs, rehabilitation, and other critical acute care needs. The plan generally does not exclude coverage for key types of medical care.

Despite its comprehensive list of covered services, cost sharing expenses under the BCBSSO plan would be significant for any of the three profiled individuals. Because each of these individuals was hospitalized at least once in the past year, and because they each have other, ongoing care needs, their expected share of costs for covered services under the BCBSSO plan could reach \$5,000, the out-of-pocket maximum (or up to \$7,000 per year if any care is received through non-preferred providers) (Figure 1). For a person at the median US household income (roughly \$50,000), this level of cost sharing alone would consume 10 to 14 percent of

gross income. In addition, like many private plans, the BCBSSO caps coverage for certain kinds of care – in particular, a 75 visit annual limit on rehabilitative care. Two of the individuals who require more than 75 visits annually for speech, occupational, or physical therapy could expect to pay thousands of dollars each year for the non-covered rehabilitation visits. Total cost-sharing for medical services that exceed the benefit limits and non-covered services varies for these individuals but are estimated to range up to about \$12,000 annually for Erin under the BCBSSO plan.



BCBSSO falls short in providing necessary long-term services and supports for individuals with disabilities. Because BCBSSO does not cover long-term services and supports, such as personal care and case management, each of the patients could expect to pay thousands of dollars out-of-pocket each year for the cost of this non-covered care. Coverage of these types of long-term services is critical to millions of individuals with disabilities such as Robert and Erin because it enables them to live independently in the community and maintain employment and

for Scott's continued childhood development. Adding these long-term care costs to out-of-pocket spending for medical costs brings total out-of-pocket spending to between an estimated \$21,000 to over \$32,000 for these individuals. These amounts would be difficult, if not impossible, for low- to moderate-income individuals and their families to shoulder.

Policy Implications

These personal profiles suggest that how policymakers define adequate health insurance coverage is a key issue for people who experience medical and long-term care service needs. The list of medical care items and services needed by individuals with special health needs can be broad, including physician, prescription drugs, mental health services, physical, speech and occupational therapy, rehabilitative services, substance abuse treatment, prosthetic devices, and durable medical equipment. Individuals may also need to access specialized care from a range of providers, some of whom may be "non-preferred" or outside the plan's network. Uncovered services and caps on needed benefits, such as physical therapy or mental health services, can result in steep financial barriers to care. In addition, people with chronic health conditions will be particularly sensitive to cost sharing requirements. The findings from this study illustrate that under a benefit package more generous than most offered in the private insurance market, individuals with extensive medical and long-term care needs will face steep out-of-pocket costs. As policymakers consider the design of health insurance coverage, it will be important to give consideration to limiting deductibles, co-pays, and out-of-pocket maximums on cost sharing to modest levels. Low- and middle-income Americans may need additional cost sharing subsidies to prevent medical bills for covered services from becoming burdensome. Medicaid coverage, which offers a comprehensive set of acute and long-term services and generally does not impose cost sharing, will continue to be an important source of coverage for people with low-incomes and those whose conditions require extensive medical and long-term care services.

INTRODUCTION

As the Congress and the Obama Administration continue on health reform to expand health insurance coverage through a combination of private health insurance and public programs, a key question will be "Coverage for what?" Under legislation pending in Congress, people would be required to obtain health insurance coverage, mostly from private companies. Today private health insurance is generally designed to cover acute care services. The content of coverage varies enormously, however. Studies show that millions of non-elderly Americans are underinsured – that is, their health insurance coverage nonetheless leaves them to pay large amounts out-of-pocket for covered and/or non-covered services. According to one study, in 2007, more than 20 million people with chronic conditions – almost three in ten – lived in families with problems paying medical bills. Among these individuals, one in four went without needed care and half delayed care because of cost concerns.¹

Under-insurance might result from policies that exclude or limit coverage for certain medical care items and services, or it might result from the imposition of high cost sharing for covered services, or both. With reform, minimum coverage standards would be developed for private health insurance that define what benefits must be covered and what level of cost sharing (deductibles, co-pays, etc.) can apply. Subsidies would be available on a sliding scale to reduce both premiums and cost-sharing for covered services for people who buy private health insurance.

In addition, health reform proposals would broaden eligibility for Medicaid. Today Medicaid covers a broad low-income population, including children and their parents, individuals with diverse physical and mental disabilities and seniors. A critical role of Medicaid is to finance services for people with very high medical costs who often have both acute care and long-term service needs, making it a vital safety net program for those unable to obtain health insurance in the private market or for whom such insurance is inadequate.

How health care reform ultimately defines the content of what health insurance must cover will affect everyone, but it will matter most to people at times when their health care needs are greatest. This issue brief examines the health care needs of three individuals with extensive acute medical care and long-term service needs – a seven year old born prematurely, a 50 year old male with a spinal cord injury and a 45 year old woman with cerebral palsy. It compares their estimated medical expenses to a benchmark private health insurance plan – the Blue Cross Blue Shield Standard Option (BCBSSO) plan offered through the Federal Employees Health Benefits Program (FEHBP.) The BCBSSO plan is the most popular FEHBP option and is often cited an example of generous job-based coverage. This analysis also considers what coverage these individuals have received under Medicaid.

STUDY APPROACH AND METHODS

This paper profiles three actual individuals with special health care needs who rely heavily on both acute care and long-term health care services:

- **Scott,** a seven-year-old boy, was born prematurely and, as a result, has ongoing medical care and developmental needs. In particular, he continues to have difficulty breathing and eating and requires various therapies, equipment and supplies. He also has sensory and other behavioral disorders that require management through mental health care, prescription medications, and personal care assistance.
- **Robert** is a 50-year-old man living with a spinal cord injury for more than 25 years as a result of a skiing accident at age 23. He is paraplegic and has a peripheral nerve injury that limits his ability to control his right arm and hand. He has extensive equipment and personal care needs. In addition, his paralysis stresses his body medically in a number of ways. He is especially prone to infections that can quickly become complicated and require hospitalization as well as home antibiotic therapy.
- **Erin** is a 45-year old woman with cerebral palsy and mental retardation. She also has extensive equipment and personal care needs as a result of her disabilities. In addition, she needs care for other medical conditions asthma and hypertension. Complications arising from these conditions can become serious and result in hospitalization.

Based on interviews with these individuals and their families, their health care needs and utilization were identified. This utilization was then compared to the coverage and cost sharing requirements of the Blue Cross Blue Shield Standard Option (BCBSSO) plan offered to Members of Congress and federal workers under the Federal Employees Health Benefits Program (FEHBP.) The BCBSSO is the most popular plan offered under the FEHBP and has often been cited as a benchmark for coverage for all Americans under a reformed health care system.

Overview of Blue Cross Blue Shield Standard Option

Coverage under the BCBSSO plan for acute care needs is relatively comprehensive, with some exceptions. For long term service needs, coverage is much less comprehensive.² See Table 1.

<u>Covered benefits</u> – The plan covers basic acute care benefits including inpatient and outpatient hospital and medical care, prescription drugs, mental health care, medical equipment, diagnostic lab and imaging, home health care, preventive care, and hospice care.

Preventative care and screening services are covered. For pediatric care, the plan covers well child visits and immunizations with no cost sharing.

With respect to long term services, the plan covers medical equipment, such as wheelchairs and prostheses that patients with a long term physical disability might need. It also covers feeding tubes and nutritional supplements.

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

Item/Service	Subject to Deductible?	Additional Cost Sharing When Care Rendered by Preferred Provider		Additional Cost Sharing When Care Rendered by Non- Preferred Provider or Out-of-Network*		Benefit Limits
		Co-Pay	Co- insurance	Co-pay	Co- insurance	
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	\$0	-	\$0	-	
Physician, professional care, inpatient	Yes	ı	15%	ı	30%**	
Physician, professional care, outpatient office visits	No	\$20	-	ı	30%	
Outpatient mental health	No	\$20	-	ı	40%	Limited to 25 visits per year; may seek waiver of limit if treated by preferred provider
Lab, x-ray	Yes	ı	15%	ı	30%	
Durable medical equipment	Yes	-	15%		30%	No coverage for bathroom equipment
Home health care	Yes	-	15%		30%	Limited to 25 visits per year, no more than 2 hours per visit/day
Hospice care (outpatient)	No	\$0	-	\$0	-	
Physical, occupational, speech therapy	No	\$20	-	ı	30%	Limited to 75 visits per year, combined
Eye exam	No	\$20	-		30%	Covered only if related to a specific medical condition
Eyeglasses	n/a					Not covered
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, eg, \$16 for adult cleaning
Case management services	n/a					Not covered
Personal assistance care	n/a					Not covered
Transportation services/equipment	n/a					Not covered
Annual deductible	Annual deductible \$300 (\$600 family)					
	Annual OOP maximum \$7,000 (individual or family); \$5,000 if all care is received from preferred providers					

^{*} In addition to otherwise applicable cost sharing, patients who receive care from non-network providers may be subject to balance billing (additional provider charges above those considered reasonable and reimbursable by the insurer.)

** 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 OOP cap.

<u>Benefit limits</u> – In general, there are no lifetime or annual maximums on covered benefits with some key exceptions. A 25-visit annual limit applies to outpatient mental health care when received from non-preferred providers.³ Limited coverage for routine dental care is included, for example, reimbursement for routine visits to the dentist or hygienist for cleanings is limited to \$16 per visit with the patient responsible for remaining charges.

Some services that might be needed on a long term basis are covered under the plan, though subject to limits. Home health care is limited to 25 visits per year. Rehabilitative care other than cardiac rehab is limited to 75 visits per year.

<u>Excluded benefits</u> – Among acute care services, the plan does not cover eyeglasses or the associated tests and fittings. Eye examinations are covered only when related to a specific medical condition. In addition, genetic testing related to family history of cancer or other diseases is specifically excluded from coverage.

With respect to long-term services, the BCBSSO plan does not cover personal care assistance, such as help bathing, dressing, and transferring. It does not cover specialized transportation services or equipment. It also does not cover case management.

Cost sharing – Significant cost sharing applies to covered services. An annual deductible of \$300 (\$600 for family policies) applies to many benefits. These include surgery, inpatient professional care, durable medical equipment, lab, and imaging. Once the deductible is met, coinsurance applies – usually 15 percent or 30 percent, depending on where care is received. That is, the patient pays 15 or 30 percent of the allowed charge, with the plan paying the other 85 or 70 percent, respectively. Higher patient coinsurance applies for mental health care from a non-preferred provider, and for prescription drugs filled at a non-preferred pharmacy. In most cases, when covered services are not subject to the deductible, a co-pay applies instead. For example, a co-pay of \$200 applies to each hospitalization. Many outpatient treatment and diagnostic services, office visits, and rehabilitation visits are subject to a \$20 co-pay.

There is no annual deductible for prescription drugs, but tiered coinsurance applies. For generic drugs, patients must pay 20 percent of the allowed charge. Brand name drugs are subject to 30 percent coinsurance.

Adult preventive services, such as an annual mammogram or a screening colonoscopy, are not subject to the annual deductible. Instead, for most preventive services adults pay a \$20 co-pay with no other cost sharing if care is received from a preferred provider. Most adult preventive services are not covered unless they are received from a preferred provider. For children, the plan pays 100 percent of allowed charges for covered preventive services rendered by preferred and non-preferred providers, alike.

Cost sharing for covered services, whether deductibles, co-pays, or co-insurance, is limited by an annual out-of-pocket cap of \$7,000. This is high relative to most job-based health plans, where the annual out-of-pocket limit tends to be less than \$3,000. On the other hand, under most other employer-based plans, the annual out-of-pocket cap generally does not limit patient cost sharing for prescription drugs and other co-pays.⁴ For patients who require frequent or ongoing

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treatment, even modest co-pays for medical care and prescription drugs could add up to \$1,000 or more per year.⁵

Within the overall cap of \$7,000, a lower limit of \$5,000 applies to cost sharing for care received from "preferred providers" in the BCBSSO plan network. If patients receive care from a combination of preferred and non-preferred providers, cost sharing might accumulate to more than \$5,000 but cannot exceed \$7,000 for the calendar year.

Unlike the annual deductible, which is twice as high for family contracts compared to individual policies, the annual out-of-pocket limit for the BCBSSO plan does not vary depending on family size; rather, it is applied per contract. Several other FEHBP plans also have a family limit at the same level as the self-only limit. By contrast, under most other employer-sponsored plans, the annual out-of-pocket limit for family coverage is double that applied for self-only coverage.⁶

<u>Provider network-within-a-network</u> – Like most health plans, the BCBSSO plan has a network of participating providers. Within the network, a subset of providers is designated as "preferred." The lowest level of cost sharing applies only when patients receive care from a preferred provider. Higher cost sharing applies when care is received from a non-preferred provider within the plan network or from a nonparticipating provider. In addition, care received out of network may be subject to balance billing.

Enrollees can view a list of preferred participating providers on the Blue Cross Blue Shield web site. Plan officials report that roughly 80 percent of all participating providers are preferred; among specialists, the participation rate is lower, although plan officials did not provide more specific data. 8

"Inadvertent" use of non-preferred providers – When patients are hospitalized, certain doctors who provide inpatient care may not be in the BCBSSO plan network or may not be preferred providers. Patients may have little choice in the selection of such doctors. For example, a patient who needs an operation may select her surgeon, but not the anesthesiologist who puts her to sleep or the pathologist who reads her slides during the procedure. Yet, bills incurred from these physicians can be significant and are subject to higher cost sharing under the plan.

The BCBSSO plan makes several different types of accommodations to limit patients' cost sharing exposure in such circumstances. Coinsurance for radiology, pathology, and assistant-at-surgery care is limited to 15% for patients admitted to preferred hospitals, even when these doctors are not preferred providers. However, cost sharing is counted toward the higher \$7,000 annual limit and, for non-network providers, the patient may also be subject to balance billing. For inpatient anesthesia care and emergency room physician care, if a non-preferred provider cares for the patient, a flat co-pay applies (\$350 for emergency care and \$800 for anesthesia care) with no other cost sharing or balance billing. However, these co-pays do not count toward the out-of-pocket limit.

Overview of Medicaid Coverage

Medicaid covers a broad range of services to address many different health and long-term care needs of its diverse enrollees, and their limited ability to afford care out-of-pocket. Medicaid covers the services typically covered by private insurance, but also many additional services, such as dental and vision care, transportation, and long-term services and supports.

<u>Covered benefits</u> – State Medicaid programs are required to cover certain "mandatory services" specified under federal law. These include: physician services, hospital services (inpatient and outpatient), laboratory and x-ray services, early and periodic screening, diagnostic and treatment (EPSDT) services for children, federally-qualified heath center and rural health clinic services, family planning services and supplies, pediatric and family nurse practitioner services, nurse midwife services, nursing facility services, home health care, and transportation.

States also have the ability to cover certain optional services which commonly include: prescription drugs, clinic services, care furnished by other licensed practitioners, dental services and dentures, prosthetic devices, eyeglasses, durable medical equipment, rehabilitation, physical therapy, speech therapy, occupational therapy, case management, intermediate care facility for individuals with mental retardation (ICF/MR) services, home and community-based waiver services such as adult day care and respite services for family caregivers, inpatient psychiatric services for individuals under 21, respiratory care services for ventilator-dependent individuals, personal care services, and hospice services.

Medicaid benefits vary widely across the states. States cover different optional services, and they determine the amount, duration, and scope of coverage for each mandatory and option Medicaid service they cover. Except for children, states can place limits on covered services, for example, by capping the number of physician visits or prescription drugs that are allowed. Also, while federal law includes a "medically necessary" standard to ensure appropriate use of Medicaid services, states define and apply medical necessity differently.

Cost Sharing – States can charge premiums and cost sharing in Medicaid, subject to some federal limitations. Premiums are permissible for most children and adults with income above 150% FPL. Cost sharing is largely prohibited for mandatory children, and it is prohibited for preventive care for children, regardless of income. For adults, cost sharing is limited to nominal levels for those below poverty. Total cost sharing and premiums cannot exceed 5% of family income for any family.

FINDINGS

Scott, A Child Born Prematurely

Scott's Health and Health Needs

Of 4 million live births in the US each year, roughly one-half million, or 12.5 percent are preterm, and 100,000 children develop health problems because of their early births. Preterm birth is defined as one that occurs before 37 weeks of gestation. The preterm delivery rate increased 30 percent since 1981. A characteristic associated with prematurity is low birth weight. Normal birth weight is considered to be at least 2500 g (5.5 pounds) and newborns weighing less are considered to have a low birth weight. Very low birth weight is defined as newborns weighing less than 1500 g (3.3 pounds). A study of very low birth weight babies found that 30 years after birth they had significantly higher rates of chronic conditions than control subjects. The use of sophisticated technology has increased the survivability of low birth weight and prematurely delivered babies, but this has been accompanied by increased rates of subsequent health problems, such a cerebral palsy, blindness, reactive airway disease (a condition related to asthma) recurrent infections, poor growth, and cognitive and behavioral deficits. Associated disabilities and dysfunctions in children include learning disabilities, attention deficit disorder, lower academic achievement and greater need for educational assistance.

Scott is 7 years old. When he was born in 2002 at 25 weeks gestation, he weighed just under 2 pounds and had to stay in the neonatal intensive care unit for 76 days. After he first got home, Scott seemed to be developing well. But between the ages of one and two, he gradually stopped eating and drinking. Scott was diagnosed with gastro-esophageal reflux disease, reactive airway disease, and failure to thrive. His airway was so inflamed from reflux that it closed up. He was hospitalized for a month with a gastric feeding tube and his mother worked with a nutritionist as they struggled to maintain his weight. Over the next year, he twice developed respiratory syncitial virus (RSV), a serious respiratory infection, and was hospitalized three more times. Every time he developed any viral infection, he had to be hospitalized and placed on intravenous fluids and nutrition to keep him alive. In 2005, he had surgery to strengthen his esophageal sphincter to help control his reflux.

Scott has had a feeding tube since he was two years old. After the operations to implant the tube and control the reflux, Scott's mom took him to a nutrition clinic and, for two years, worked with specialists there to improve his eating. By the time he was 4, Scott could take some food and drink by mouth, but he continues to need the feeding tube. A variety of supplies and equipment are required to keep the feeding tube clean and operating effectively, including a pump, bags, IV pole, sponges, syringes, and medical tape. Specialized connectors join the feeding tube to the pump and must be changed after each feeding. The connectors for the feeding tube are the most expensive of these supplies, at a cost of about \$75 per box; Scott's mom buys two boxes of connectors each month. The formula that Scott takes through the tube costs about \$300 per month.

Other continuing health problems persist. He continues to have breathing irregularities and must sleep with an apnea monitor at night in case he stops breathing. He is also prone to infection. Last year, he developed three more cases of RSV. As a result of those infections and other problems with his feeding, he was hospitalized 7 times in 2008. Each hospitalization lasted about one to two weeks.

Scott is small for his age – in the 25th percentile on growth charts. He is developmentally delayed and was held back in school last year. He was also diagnosed with an attention deficit disorder. In addition, Scott has a sensory integration dysfunction – the way he experiences the space around him, pressure, heat and cold is different than other people. This has led to problems with self-injury and other behavioral problems, including aggressiveness. He needs ongoing occupational therapy to help with sensory integration. Weekly mental health therapy and medications also help to manage his attention and behavior problems.

In addition to his regular checkups with his pediatrician, Scott continues to see a feeding specialist at a nutrition clinic. He takes three prescription drugs on an ongoing basis – Focalin for his ADHD, Pulmacort for asthma, and Topamax for aggressive behavior disorder. Scott also needs case management services to coordinate the many kinds of care that he needs.

Finally, Scott receives attendant care services. An aide comes to his house weekday afternoons and stays until bedtime to help Scott with feeding, homework and bedtime and to manage his behavioral problems. Without this help, it would be very difficult for his mother to care for his younger sister at the end of every day.

How would BCBSSO cover Scott's care?

Much of the acute care that Scott needs would be covered under the BCBSSO plan, though cost sharing would be significant (Table 2). Scott's seven hospitalizations last year would generate \$1,400 in hospital co-pays alone. His estimated coinsurance for professional care provided in the hospital would total another \$2,000. Visits to the nutrition clinic and for mental health and occupational therapy would generate another \$60 per week (\$3,120 per year) in additional co-pays. Coinsurance for his prescription medications might total another \$1,380 per year. Total cost sharing for his covered care would likely reach the annual out-of-pocket maximum of \$7,000. Depending on whether or not Scott is able to receive all of this care from the subset of preferred providers in the BCBSSO network, this amount might be reduced to \$5,000. Once Scott reaches the annual out-of-pocket maximum, any remaining covered care for the year – as well as any covered care for Scott's mom and sister – could be reimbursed at 100 percent. This is because the BCBSSO plan annual out-of-pocket limit is applied on a per contract basis, no matter whether the contract covers one individual or an entire family.

Other long-term services and supports that Scott needs would not be covered at all. This includes the personal care assistant who helps take care of Scott nightly, and the cost of the case manager who helps to coordinate all of Scott's services. The annual cost of these non-covered services could surpass \$15,000.

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If Scott were covered under the BCBSSO, his family's total expenses for cost sharing and non-covered services could easily exceed \$20,000 in a year. Such costs would be prohibitive for his mom, Ruthanne, on her limited income.

Table 2: Estimated Annual Coverage and Out-of-Pocket Costs for Scott's Ongoing Care Needs under BCBSSO

Needed care, items, Services	Amount/frequency	Covered by plan?	Cost sharing?	Annual estimated out of pocket costs*
Pediatrician visits (routine)	1/year	Yes	None	None
Pediatrician visits (for breathing, eating problems, other illness care)	6 last year	Yes	\$20 co-pay per visit, 30% coinsurance if non-preferred provider	\$120
Mental health counseling/behavioral therapy	52/year (weekly)	Yes, limited to 25 visits from non- preferred	\$20 co-pay per visit, preferred 40% coinsurance if non-preferred provider	\$1,040 if preferred \$2,900 if non-preferred*
Feeding specialist	Weekly	Yes	\$20-copay per visit	\$1,040
Feeding tube supplies	\$150/month for connectors	Yes	Deductible plus \$15% coinsurance	\$525
Nutritional formula	Costs \$300/month	Yes	15% coinsurance	\$540
3 Rx drugsFocalinPulmacortTopamax	Daily	Yes	30% coinsurance for Pulmacort, 20% for Focalin and Topamax	\$1,380**
Apnea monitor	1 per year	Yes	15% coinsurance	\$75
Hospitalizations	7 last year		\$200 co-pay per hospitalization	\$1,400
Inpatient medical care	7 weeklong stays	Yes	15 % coinsurance	\$2,200
Occupational therapy	1 per week	Yes	\$20 co-pay per visit	\$1,040
Case management services	Ongoing	Not covered		\$780
Personal care services		\$15,600***		
Total estimated cost sharing	\$5,000-\$7,000			
Total estimated out-of-pock	\$16,380			
Total estimated out-of-pock	\$21,380-\$23,380			

^{*} Unless otherwise indicated, cost estimates reflect information reported by Scott's family.

How would Medicaid cover Scott's care?

When Scott was born, Ruthanne was covered under Medicaid and so was Scott subsequently. The Early and Periodic, Screening, Diagnostic and Treatment Services (EPSDT) benefit under that program requires that all children's health care needs will be met with minimal cost sharing. Under the EPSDT benefit, children up to the age of 21 are provided a comprehensive array of screening and prevention services and treatment for all medical needs identified, including health education services, vision, dental and hearing services, as well as various therapies and other long-term services and supports. This benefit has been described as a preventive benefit rather than a treatment benefit because it is designed not just to cure or treat an illness or injury, but to

^{**} Cost sharing for mental health from non-preferred provider assumes allowed charge of \$85 per visit and no balance billing

^{**} Cost sharing based on prices posted on drugstore.com; 20% coinsurance for Focalin and Topamax, 30% coinsurance for Pulmacort

^{***} Based on estimated hourly charge of \$15

cover acute care and long term services that will prevent or ameliorate the long-term effects of chronic illness and disability in order to help a child attain or maintain an optimal level of health.

While Scott was covered by Medicaid, all of his medical care and long term service needs were covered, with little or no cost sharing. When Scott turned four years old, Ruthanne returned to work and her income made the family ineligible for Medicaid. Though covered under private health insurance through her job, cost sharing and benefit limits under the policy made the cost of Scott's mental health visits prohibitive, so Ruthanne discontinued that care. She also had to cut back on visits to the occupational therapist and the feeding clinic. Ruthanne worried about Scott's health and development as she made these difficult decisions to forego care that he needed but that she could not afford. Scott since re-qualified for Medicaid coverage under a disability waiver and the program has resumed coverage of all of his needed care.

Robert, An Adult with a Spinal Cord Injury

Robert's Health and Health Needs

People with spinal cord and traumatic brain injuries have unexpected and financially catastrophic health and long-term services needs. Roughly 250,000 Americans have spinal cord injuries, and each year about 11,000 new injuries occur. Over half of all spinal cord injuries occur in young people between the ages of 16-30. These injuries are financially catastrophic with average first year treatment costs varying from roughly \$219,000 to \$741,000, depending on the severity of the injury. Ongoing costs for each subsequent year range from roughly \$15,000 to nearly \$130,000. ¹⁰

Service needs of people with spinal cord injuries involve two distinct phases. The initial rehabilitation phase often involves extensive medical management to ensure that patients recover and heal from their injuries. It also involves teaching individuals how to adapt to their new impairment and perform basic activities such as getting dressed, going to the bathroom, and transferring in and out of bed. It also involves training on community reintegration so that people have the supports they need to seek out employment, education, and other forms of social engagement.

The second phase involves ongoing health maintenance and assistance. Depending on the level of impairment, individuals have varying needs. Spinal cord injuries create several health challenges and stress the body in ways that require close monitoring on a lifelong basis. This includes a special emphasis on maintaining the health of the skin, bowels, and bladder. When individuals are re-hospitalized after the initial rehabilitation, it is often because of problems with these critical organs. Another critical type of ongoing support is personal assistance.¹¹

Robert is 50 years old. In 1982, when he was 23, a skiing accident caused multiple serious injuries, including a collapsed lung, injury to his spinal cord that caused paraplegia, and peripheral nerve injury that limits his ability to control his right arm and hand. Following two weeks in a trauma center, Robert spent four months at a spinal cord injury center. At the time of the accident, Robert was privately insured. He became eligible for Medicaid while at the trauma center, as his private health insurance was not sufficient to cover his extensive rehabilitation costs. By 1989, Robert was working

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full time again. For a while he continued to receive Medicare and Medicaid benefits while working, but eventually he earned too much to remain eligible.

Robert describes his current health as good, but he has ongoing health issues related to his disability. He has recurring cellulitis – a serious bacterial skin infection in his lower legs. It is a relatively common problem among people with a disability like Robert's, though left untreated, the infection can spread and become life threatening. Because of this condition, Robert has been hospitalized four times in the past 9 months for approximately one week per admission. Following discharge, he must continue IV antibiotic therapy at home for five weeks. He receives this therapy daily for 30-minutes per session for the five weeks of treatment. He also has had four emergency room visits in the past year, some relating to the infections and one for a broken leg. Because he cannot use his right arm, Robert's left arm is constantly strained from overuse. Visits to a physical therapist (p.t.) every other week help keep his shoulder comfortable. However, because his insurance caps the number of covered visits for all rehab therapies (physical, occupational, and speech), Robert sometimes substitutes some of the p.t. visits with massage therapy, at about \$40 per visit, which he pays for himself.

Robert takes three prescription medications on a regular basis. Oxybutin and Baclofen are muscle relaxers, and Fosamax treats osteoporosis.

His medical equipment needs are extensive. Robert has two wheelchairs – one manual with a power assist, which cost about \$9,000, and a power chair that he can operate with one hand. The wheelchairs need quarterly service at an annual cost of about \$1,600. In addition, the batteries for the chairs cost \$1,200 each and must be replaced annually. Robert also wears pneumatic compression stockings to promote circulation in his legs. He also needs a shower chair and sliding boards to move between his wheelchair and bed.

Robert requires personal care services daily. An assistant comes every morning for two hours to help him get up, out of bed, shower, and dressed. She comes again in the evening for 15 minutes to help him undress and get into bed.

Robert's other routine care needs include quarterly visits to his physician and an annual visit to the neurosurgeon, a dental cleaning every six months, eye glasses and a visit to the optometrist every few years. His largest single ongoing expense related to his disability is transportation. A specially equipped car costs approximately \$48,000 and must be replaced approximately every 10 years.

How would BCBSSO cover Robert's care?

In Robert's case, the BCBSSO plan appears to cover most of the acute care items and services that he needs, though coverage for some care would be capped and cost sharing for covered services is substantial (Table 3). The co-pays for Robert's four hospitalizations last year would total \$800. In addition, professional services while in the hospital would be subject to the \$300 annual deductible and 15% coinsurance, or another approximately \$1,500. The home health visits for IV antibiotic therapy would be subject to 15% coinsurance per visit up to the annual limit of 25 visits, which would have been exhausted after the first infection. Thereafter, Robert

would have had to pay out of pocket for the entire cost of IV antibiotic therapy for his remaining three infections last year. At roughly \$100 per visit, Robert would need to pay \$7,500 for the uncovered IV therapy visits.

Table 3: Estimated Annual Coverage and Out-of-Pocket Costs for Robert's Ongoing Care Needs under BCBSSO

Needed care, items, Services			Cost sharing?	Annual estimated out of pocket costs*
Physician visits (routine)	4/year	Yes	\$20 co-pay per visit,	\$80
			30% coinsurance if non- preferred provider	
Neurosurgeon visit	1/year	Yes	\$20 co-pay per visit,	\$20
			30% coinsurance if non- preferred provider	
Hospitalizations	4 last year	Yes	\$200 co-pay per admission	\$800
Inpatient medical care	4 week-long stays	Yes	Deductible plus 15% coinsurance	\$300 deductible plus \$1,200 coinsurance
Home IV therapy	100 visits last year	Yes, up to 25 visits per year	15% coinsurance	\$375 coinsurance plus \$7,500 not covered
Physical Therapy	24/year	Yes, up to 75 visits per year	\$20 co-pay per visit	\$480
3 Rx drugsOxybutinBaclofenFosamax	Daily	Yes	20% coinsurance per prescription, generic	\$500**
Annual service for power wheelchair	1 replacement battery and 4 service calls/year	Yes	15% coinsurance	\$420***
Annual service for manual wheelchair with power assist	1 replacement battery/year		\$200 co-pay per hospitalization	\$180***
Compression stockings	7 pair per year	Yes	15% coinsurance	\$210
Shower chair	1	Not covered		\$36 [†]
Personal care services	2.25 hours per day	Not covered		\$12,000 ^{††}
Routine dental care	2 per year	Reimbursement limited to \$16 per cleaning		\$168 ^{†††}
Vision care	1 visit per 3 years, plus one pair glasses	Not covered		\$300 (glasses) + exam
Handicapped modified car	1 per 10 years	Not covered		\$4,800 per year
Total estimated cost sha	ces	\$4,565		
Total estimated out-of-po		\$25,000		
Total estimated out-of-po	\$29,565			

^{*} Unless otherwise noted, cost estimates based on information reported by Robert.

His physical therapy needs fall within the BCBSSO plan's annual cap of 75 visits. Co-pays for each covered visit would amount to nearly \$500 annually. Robert's regular physician visits and prescription medications would generate another estimated \$600 in co-pays and coinsurance each year.

^{**} Cost sharing based on prices posted on drugstore.com; 20% coinsurance for each

[†] Based on cost information available at http://www.allegromedical.com.

^{††} Based on estimated hourly charge of \$15

^{†††} Cost of dental care based on estimates for an average cost of routine dental services, from costhelper.com

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The BCBSSO would cover the cost repairs and maintenance of his wheelchairs, with 15 percent coinsurance required, or about \$600 per year. When the chairs need to be replaced, this would also be covered. Robert would also pay about \$30 in coinsurance for each of pair of compression stockings.

The most costly of Robert's long term services, his daily personal assistance care, would also not be covered by the plan. This cost could reach approximately \$12,000 per year. The cost of his car that is specially equipped for him to drive also would not be covered under the BCBSSO. Neither would the cost of his shower chair or his routine vision care and eyeglasses be covered.

In summary, if Robert had been covered last year under the BCBSSO – a relatively generous plan – his out-of-pocket medical care and long-term service bills would have been almost \$30,000. Of this total, nearly \$5,000 would be due to cost sharing for covered services (assuming Robert would receive all care from preferred providers. If Robert would seek or inadvertently receive care from non-preferred providers, his cost sharing liability would increase.) Almost \$8,000 in expenses would result from limits on covered care under the plan for home IV therapy and dental care. Robert's long-term care service and equipment needs account for another approximately \$17,000.

How would Medicaid cover Robert's care?

When Robert was covered by Medicaid, the program paid for all of his acute care and long-term service needs, with little cost sharing at all. As Robert returned to work and his income grew, he eventually lost eligibility for Medicaid.

Erin, An Adult with a Developmental Disability

Erin's Health and Health Needs

There are approximately 4.5 million people in the U.S. with developmental disabilities. These are severe, life-long disabilities attributable to mental and/or physical impairments manifested before age 22. Developmental disabilities result in substantial limitations in three or more areas of major life activities such as the capacity for independent living, learning, mobility, expression, and self-care. There are numerous types of developmental disabilities including autism, cerebral palsy (CP), and epilepsy.

Intellectual disabilities are the most common type of developmental disability. Between one and three percent of the U.S. population has an intellectual disability. ¹² An intellectual disability (sometimes called mental retardation, though that term is associated with a high level of stigma) is characterized by significantly low intellectual functioning combined with deficits in adaptive behavior.

Erin is a 45-year-old woman with cerebral palsy and a communication and mobility disability. In addition, she suffers from epilepsy, mental retardation, asthma, hypertension and high cholesterol. Erin's acute care needs are extensive. She sees her CP specialist on average about

six times per year. She takes 5 prescription medications to control her blood pressure, cholesterol, and seizures, and to calm her nerves and limit drooling. Also, about 3 times per year she receives Botox injections to help tone the muscles in her legs. With her various medical conditions, complications can arise. In the past year Erin went to the emergency room on five occasions, once for a seizure. She was admitted to hospital six times in the last year, once for complications from the flu.

In terms of routine care, Erin gets regular annual checkups. She sees a dentist twice each year for cleanings. She wears eyeglasses and has her vision and prescription checked annually.

Erin cannot walk without assistance. She has a power wheelchair and two arm braces. She also has a power lift so she can get her wheelchair into a car. The wheelchair is fitted with a special lap tray and an adaptive device so Erin can eat on her own. The wheelchair needs regular maintenance.

Unlike some people with developmental disabilities who have been placed in state institutions, Erin has always lived in the community with her family. Erin lives with her mother who is her primary caregiver. At home, her mom (now in her 70s) provides all of Erin's personal assistance with dressing, bathing, etc. However, as her mother ages, increasingly she needs help with this care. During the day, Erin works at a local United Cerebral Palsy clinic where she sorts and counts printed materials that are included in patient information packets. She takes public transportation between home and the clinic. While at the clinic, Erin also participates in a Medicaid home-and community-based services waiver program and receives extensive long-term services, including day habilitation services, occupational therapy, skilled nursing, speech therapy, and case management services. The weekly occupational therapy visit helps Erin do her job. She also has daily speech therapy for an hour that helps her participate in a literacy program to teach her to read. In addition, each day Erin receives several hours of personal care services while at the clinic, including help going to the bathroom. A social worker at the clinic provides case management, making sure Erin gets all of her prescribed care and keeping all of her providers informed of her progress. The case manager meets with Erin in person three times per week, sometimes just for a few minutes, other times for up to an hour.

How would BCBSSO cover Erin's care?

Most of Erin's acute care services would be covered under the BCBSSO plan, though extensive cost sharing would apply (Table 4). Her six hospitalizations last year would generate \$1,200 in hospital co-pays alone; the \$300 annual deductible and coinsurance of 15 percent would apply to the cost of professional care she received in the hospital and emergency room, or another \$1,800. Her prescription drugs would also be covered with coinsurance of 20-30 percent, or another \$400 in cost sharing per year.

Table 4: Estimated Annual Coverage and Out-of-Pocket Costs for Erin's Ongoing Care Needs under BCBSSO

Needed care, items, Services	Amount/frequency	plan?	Cost sharing?	Annual estimated out of pocket costs*	
Physician visits (routine)	6/year	Yes	\$20 co-pay per visit, 30% coinsurance if non- preferred provider	\$120	
Specialist visit	As needed	Yes	\$20 co-pay per visit, 30% coinsurance if non- preferred provider	\$20	
Botox treatments	As needed (3 times last year)	Yes	15% coinsurance	\$450*	
Hospitalizations	6 last year	Yes	\$200 co-pay per admission	\$1,200	
Inpatient medical care	4 week-long stays	Yes	Deductible plus 15% coinsurance	\$300 deductible plus \$1,200 coinsurance	
Emergency room visits	5 last year	Yes	15% coinsurance	\$300	
Occupational therapy	1 per week	Yes, up to 75 visits per year	\$20 copay	\$1,040	
Speech therapy	1 hour per day	75 visit limit for speech, physical & occupational combined	\$20 for 23 visits, 100% for remaining 227 visits @\$50/ visit	\$460 co-pays plus \$11,350	
5 Rx drugs (for blood pressure, seizures, cholesterol, anxiety, drooling)	Daily	Yes	20% coinsurance per prescription, generic	\$400**	
Power wheelchair maintenance	1 replacement battery/year	Yes	15% coinsurance	\$180	
Lap tray	1	Yes	15% coinsurance	\$15 ^{***}	
Arm braces	2	Yes	15% coinsurance	\$45 ^{††}	
Personal care services	2-3 hours per day	Not covered		\$12,000 ^{††}	
Case management services	75 hours per year	Not covered		\$4,000	
Routine dental care	2 per year	Reimbursement limited to \$16 per cleaning		\$168 ^{†††}	
Vision care	1 visit plus one pair glasses per year	Not covered		\$100	
Total estimated cost sharin	\$5,000-\$7,000				
Total estimated out-of-pock		\$27,600			
Total estimated out-of-pock		\$32,600-\$34,600			

^{*} Unless otherwise indicated, cost estimates based on information reported by Erin

cost sharing based on estimates for cost of care and frequency based on http://www.costhelper.com and http://cerebralpalsycosts.com/overview.html/

Coverage for her therapy services would be far more limited. The 75-visit annual cap on this benefit means Erin would exhaust coverage for weekly occupational therapy and daily speech therapy within about ten weeks. Each covered visit would be subject to a \$20 co-pay; once her annual limit is reached, however, she would have to pay the entire cost. That would mean \$1,500 in co-pays and more than \$11,000 in cost for non-covered therapies.

^{**} cost sharing based on prices for common generics for each condition, posted on drugstore.com;

^{***} Cost of DME based on cost information available at http://www.allegromedical.com.

[†] Cost of DME based on cost information available at http://www.dme-direct.com/rcai-pediatric-basic-arm-brace-universal/

^{††} Based on estimated hourly charge of \$15

^{†††} Cost of dental care based on estimates for an average cost of routine dental services, from costhelper.com

The plan would cover the purchase of Erin's wheel chair and maintenance, and her lap tray and arm braces. Coinsurance of 15%, totaling about \$240, would apply to these covered expenses. The BCBSSO would pay up to \$16 toward the cost of each semi-annual dental cleaning, with Erin left to pay the remaining cost.

If Erin were to receive all covered care by preferred providers, her cost sharing would be capped at \$5,000. However, because Erin's doctor is not part of the BCBSSO preferred network, her cost sharing expenses would likely approach or reach the \$7,000 annual limit.

With respect to long-term services and supports, the plan would not cover any of Erin's personal care or case management services, the cost of which are estimated at roughly \$16,000 annually. Neither would the plan cover her annual vision checks or eyeglasses. The combination of medical bills arising from cost sharing and the cost of non-covered or limited covered services would leave Erin with medical bills in excess of \$32,000 per year for the care and equipment she needs.

How would Medicaid cover Erin's care?

Erin currently qualifies for Medicaid. The program covers almost all of her care needs with no cost sharing. Routine dental care for adults is not covered by Medicaid in Erin's state, but she receives free care under a special arrangement between the dental school at the State University and the United Cerebral Palsy Clinic.

Erin is mostly happy with the services she receives. Thanks to Medicaid and the ongoing support of her mother, Erin has been able to remain in the community and lead a fulfilling life. However, she worries that as her mother ages, this might not continue. The answer will depend on whether Medicaid and other programs are available to provide her enhanced services even after her mother can no longer continue as her primary caregiver.

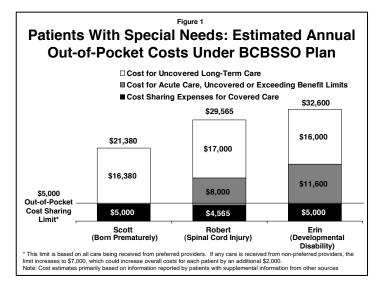
POLICY IMPLICATIONS

These personal profiles suggest that how policymakers define adequate health insurance coverage is a key issue for people who experience medical and long-term care service needs. An important consideration in health care reform is to ensure policies provide coverage for the care that patients need when they get sick. Further, it is also key to consider cost sharing charges to assure a plan provides meaningful cost sharing protections so that expenses are manageable and patients are not deterred from seeking needed care. In particular, people with chronic conditions may need additional levels of cost sharing subsidy or protection to prevent expenses from becoming overwhelming.

The BCBSSO plan is an example of a health insurance plan designed to cover a comprehensive list of acute care services. By contrast, today many private health insurance policies, especially those sold in the individual market, have significant gaps in covered benefits – for example, excluding or limiting coverage for mental health care, prescription drugs, rehab, and other critical acute care needs. Despite its comprehensive list of covered services, cost sharing under the BCBSSO plan is high. For patients such as Scott, Robert, and Erin, with ongoing and extensive medical care needs, cost sharing will not arise occasionally, but frequently, and could

easily become burdensome. Under the BCBSSO plan, each of these individuals could easily experience cost-sharing on covered medical services that reaches the \$5,000 out-of-pocket cap (Figure 1).

Further, while the BCBSSO plan provides broad coverage for acute care services, the limits on certain services, such as mental health and physical occupational, or speech therapy and the exclusion of coverage for long-term care services leave substantial gaps in coverage for individuals with special needs. Like most private health insurance policies, the BCBSSO plan covers little in the way of non-medical, long term service needs. Personal assistance care and case management are critically important for persons with disabilities who need a range of



services. While insurance policies may draw a distinct line between coverage for acute care versus long term service needs, for individuals, the continuum of care is what matters. For the individuals profiled in this report, costs for services that exceed benefit limits, such as physical therapy or mental health services, and non-covered medical services can add thousands of dollars in out-of-pocket costs. Further, additional spending for long-term care services, which all of the individuals profiled in this report needed to function in the community, brought total estimated out-of-pocket spending to between about \$21,000 up to \$32,000. These amounts are clearly unaffordable for low- and moderate-income individuals and families.

In contrast, Medicaid coverage offers a comprehensive set of both acute and long-term services and generally does not impose cost sharing. As such, Medicaid plays a vital role in financing services for people with very high medical costs who often have both acute care and long-term service needs, who are often unable to obtain health insurance in the private market or for whom such insurance is inadequate. Thus, continued access to Medicaid coverage for those who need it is an important consideration in health care reform. Further, as policymakers consider the design of plans for individuals above Medicaid eligibility limits, it is important to recognize that if coverage does not provide adequate cost sharing protections and does not cover long-term care services, individuals with significant health needs may face substantial out-of-pocket costs that could impede their ability to obtain needed care.

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ENDNOTES

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¹ Tu, H. and Cohen, G., "Financial and Health Burdens of Chronic Conditions Grow," Center for Studying Health System Change, Tracking Report No. 24, April 2009. Available at www.hschange.org

² For additional information about the BCBSSO plan, 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.

³ The plan brochure states that coverage for all outpatient mental health care is subject to an annual cap of 25 visits, which may be waived for services received from preferred providers. However, staff at OPM clarified this language in the brochure is incorrect. Instead, outpatient mental health care from preferred providers is not capped as long as a treatment plan for care is filed with and approved by the plan in advance. If an approved treatment plan is not in place, the plan reserves the right to refuse to cover care beyond 25 visits unless medical necessity of further treatment is established. OPM staff indicated that the misleading language in the brochure will be corrected for future years.

⁴ HRET and Kaiser Family Foundation, "2008 Employer Health Benefits Survey." Robert J. Kaiser Family Foundation.

⁵ Pollitz, K., et al, "Coverage When It Counts: What Does Health Insurance in Massachusetts cover and How Can Consumers Know?" Robert Wood Johnson Foundation, May 2009. Available at http://www.rwjf.org/files/research/coveragewhenitcountsfinal.pdf

⁶ HRET and Kaiser Family Foundation, "2008 Employer Health Benefits Survey." Robert J. Kaiser Family Foundation. ⁷http://www.fepblue.org/provider/

⁸ Personal communication, BCBSA staff, June 2, 2009.

⁹ Crowley, J. and O'Malley, M., "Profiles of Medicaid's High Cost Populations," Henry J. Kaiser Family Foundation, December 2006.

¹⁰ The University of Alabama National Spinal Cord Injury Statistical Center, March 2002, as cited in "Spinal Cord Injury Facts and Statistics," http://www.sci-info-pages.com/facts.html

¹¹ Crowley, J. and O'Malley, M., "Profiles of Medicaid's High Cost Populations," Henry J. Kaiser Family Foundation, December 2006.

¹² Crowley, J. and O'Malley, M., "Profiles of Medicaid's High Cost Populations," Henry J. Kaiser Family Foundation, December 2006.



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