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## Impact of Current Health Care Reform Proposals on People with Chronic Illnesses

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State high-risk insurance pools serve people who have been denied coverage because of pre-existing conditions or who don't have access to employer based coverage. There are 35 state high-risk insurance pools across the country serving approximately 200,000 people. The U.S. Congress is considering various proposals to expand high risk pool coverage as part of health care reform to cover people with pre-existing conditions. However, data suggest that high risk pools as currently proposed will not adequately meet the needs of those with potentially serious health conditions. Many risk pool enrollees fall into a gray area between being chronically ill, but able to work at least part-time, and being disabled to the point of qualifying for federal disability programs and their accompanying health care coverage. As Congress astutely noted in its 1999 Ticket to Work legislation, moving just one half of one percent of people off of disability programs and back into the workforce would result in \$3.5 billion in federal savings. *Preventing* one-half of one percent of people from being *added* to the disability rolls would result in an additional net savings of \$3.5 billion to the federal government.<sup>1</sup>

### Current High Risk Pool Costs and Coverage

In 2008, lawmakers called for the Government Accountability Office (GAO) to examine the ability of state risk pools to meet the needs of high-risk individuals. In their request, the lawmakers noted that people covered by the individual insurance market are often "offered insurance coverage that turns out to be inadequate, or too expensive, or both" (Johnson, 2008). The GAO (2009) found that state high risk pools had on average:

- monthly premiums of \$485 (compared to \$135 employee share for the federal employees health benefit plan);
- high annual deductibles (for the most heavily enrolled state risk pool plans) of \$1,593—nearly 3 times higher than for employer-based plans; and
- enrollees with average gross household income of \$41,000.

These figures mean that a typical enrollee paid out 18% of income just for premiums and deductibles, plus more for co-pays and other cost-sharing requirements.

Even at this high cost to the individual, many enrollees were at best *underinsured*, and in some cases, essentially *uninsured for all but catastrophic events*. High risk pools often limit or do not cover important health benefits. For example, mental health care is one of the most commonly restricted services (recently passed federal requirements for mental health parity *do not apply* to

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<sup>1</sup> Challenges Facing Social Security Disability Programs in the 21<sup>st</sup> Century, House Ways & Means, Subcommittee on Social Security, July 13, 2000, Serial 106-94.

these pools because they are considered non group plans). Preventive services are sometimes covered outside the deductible, but only in amounts so limited that expensive screening tests, such as a colonoscopy, are not affordable.

The majority of state high risk pools have lifetime maximum payouts, typically \$1 million, but ranging to \$3 million. Three states have lifetime maximums of only \$500,000 and a fourth \$750,000. Once beneficiaries have received this maximum benefit, they have *no other options* for health insurance coverage.

Lastly, because all risk pools operate at a loss, their managers have an incentive to limit the breadth of coverage for participants. Many states, for example, limit the number of visits or dollar amount for some services, do not count prescription costs in meeting the deductible, and impose waiting periods for pre-existing conditions. A recent GAO study (2009) found that federal grants to state high risk pools from the Centers for Medicare and Medicaid Services (CMS)—intended to expand coverage by reducing premiums, cost-sharing and other participant costs—were largely used to offset operational losses instead.

### **Impact of Current Health Care Reform Proposals**

Congress is considering the best way to provide access to coverage for people with chronic conditions who are unable to access employer-based group coverage due to a pre-existing condition or health status, or who are considered the “pre-disabled” – not disabled enough to meet a federal disability standard to be eligible for Medicaid or Medicare. H.R. 3962, the Affordable Health Care for America Act of 2009, creates a National High-Risk Pool Program designed to serve as a “bridge” to coverage between 2010 – 2014 when the proposed state health insurance exchanges are in place.<sup>2</sup>

While we laud Congress’ attempt to address the critical need of people with significant health care needs, we have several concerns about the proposed parameters of the proposed National High-Risk Pool Program.

As demonstrated below, cost-sharing requirements under the proposed National High-Risk Pool would be expensive and would likely exceed benchmark limitations on health expenditures specified under other components of health care reform. Proposed consumer protections under cost-sharing are still problematic. These protections include setting premium ratios (from highest to lowest) to not exceed a ratio of 2 to 1; consideration of geographic variations; setting premiums at 125% of standard rate for comparable coverage in the individual market; a \$1500 deductible (higher for families) and cost-sharing up to \$5,000 for individuals (\$10,000 for a family)<sup>3</sup>.

Preliminary analysis of this proposed cost-sharing for the National High-Risk Pool<sup>4</sup> indicates that the premium and cost-sharing will not make a high-risk pool option affordable for many individuals who will be forced to rely on it.

Premiums -- \$485 x 12 months=\$5820  
+ \$1,500 Deductible  
+ \$ 5,000 Cost-sharing (maximum for an individual)  
= \$12,320 potential annual out of pocket costs

<sup>2</sup> H.R. 3962, Affordable Health Care for America Act, Sec. 101, National High Risk Pool Program.

<sup>3</sup> H.R. 3962, Affordable Health Care for America Act, Sec. 101, (g) Covered Benefits, Cost-sharing, Premiums & Consumer Protections.

<sup>4</sup> Based on the average risk pool premium cited by the GAO, 2008.

***This equals 30% of pre-tax income of the average risk pool participant!***

### **High Risk Pool Enrollees' Experiences**

The GAO (2009) noted in its report that little national data are available on the characteristics of people enrolled in risk pools. However, a recent Centers for Medicare and Medicaid Services demonstration project focused on enrollees in the Kansas high risk pool sheds some light on the nature of who enrolls in these pools and the problems they encounter with risk pool coverage.<sup>5</sup>

Historically, people exiting the pool have transitioned to federal disability programs at a rate *eight* times that of the general population. Findings from the Kansas study indicate that one-quarter of risk pool enrollees experience *medical debt* despite their participation in the pool. Of those with medical debt, more than half reported that it caused them to delay seeking medical care. Their debts ranged from less than \$1,000 to more than \$60,000, and were due primarily to high deductibles, services not covered, and co-payments. Including premiums, deductibles and co-pays, the average individual paid more than \$12,000 in annual out-of-pocket medical expenses. Comparing that amount with the average income of participants, almost 90% of participants' family had out-of-pocket medical expenses greater than 10% of family income, which meets the definition of being *underinsured*.

The combination of medical debt and high out-of-pocket burden resulted in many study participants *not accessing care* when they needed it. In fact, high premiums and deductibles limited participants' ability to afford even basic health services such as preventive screenings and diagnostic testing, as well as more expensive services. One study participant commented, "I have car accident insurance, not wellness insurance." Another stated, "with a \$7,500 dollar deductible and a total of \$15,000 out of your pocket and only a \$100,000 limit [annual coverage cap], if my heart were to go bad, I'd choose death. And my wife knows this, we've already got it arranged." Participants also often attempt to limit their out-of-pocket burden through cutting back on expensive medications. For example, one participant related, "I take insulin and I cut my insulin in half." Such behaviors may save costs in the short-term, but will have long-term, and probably more expensive, consequences.

### **Better Outcomes through More Comprehensive Coverage**

As part of the Kansas Demonstration study, half of the participants in the study sample were provided with Medicaid-like coverage as a wraparound to the risk pool coverage, including greatly reduced premiums and co-pays, no deductibles, and enhanced coverage for mental health, dental, vision, and other services. Over the course of the study, these individuals with wraparound coverage showed slower progression of their health conditions when compared to those who

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<sup>5</sup> The Kansas Health Policy Authority received a Demonstration to Maintain Independence and Employment grant under the Ticket to Work and Work Incentives Improvement Act of 1999 (TWWIIA) to study how the provision of enhanced health care coverage for enrollees in the state high risk pool might prevent or forestall loss of employment and reliance on federal disability programs due to worsening of health conditions. The Kansas Demonstration project tested the hypothesis that the provision of enhanced health care coverage for enrollees in the state high risk pool might prevent or forestall loss of employment and reliance on federal disability programs due to worsening of health conditions. About 70% of the study population, representing both rural and urban areas of the state, was self-employed, and therefore did not have access to employer-based health insurance. At the same time, they experienced a variety of potentially disabling conditions, including diabetes, cancers, heart disease, mental illnesses, muscle and joint conditions, multiple sclerosis, cystic fibrosis, rheumatoid arthritis, and lupus.

received only the usual risk pool services. The individuals with wraparound coverage also reported *much improved health overall* as compared to the control group, who received standard risk pool coverage.

If Congress chooses to use high risk health insurance pools as a stop-gap coverage for people with pre-existing conditions, whether that coverage is long-term or short-term, it will be vitally important to regulate the use of federal funds and the structure of plan benefits. Funds allocated to these pools should help *expand coverage* (e.g., mental health services parity, prescription medications), *cap premiums* and out-of-pocket costs, and *assure affordability* based on income. A potential model for structuring premiums and cost-sharing could be the nation's forty-two state Medicaid-Buy-in programs created for working people with chronic conditions that meet or equal a federal disability standard.<sup>6</sup> While the proposed National High-Risk Pool program parameters promise coverage and access to critical benefits for people with chronic conditions, the proposed cost-sharing will still serve as a barrier to accessing care.

## Conclusion

The issues outlined in this policy brief are just a few of the most challenging issues facing people with special health care needs. Since 2000, the federal government has funded more than forty-two states with Medicaid Infrastructure Grants through the Ticket to Work and Work Incentives Improvement Act of 1999 to build comprehensive infrastructure with the ultimate goal of “bridging” Medicaid and Medicare to private insurance. Through the Medicaid Infrastructure Grants and other grants, states have been working together to identify cost effective strategies for providing access to coverage for individuals with chronic conditions.

*For more information about the Medicaid Infrastructure Grants and what they are learning in covering people with chronic conditions please go to [www.nchsd.org](http://www.nchsd.org) or contact Barbara Otto ([botto@hdadvocates.org](mailto:botto@hdadvocates.org)). For more information about the Demonstration to Maintain Independence and Employment grant in Kansas, please contact Jean Hall ([jhall@ku.edu](mailto:jhall@ku.edu)) or Janice Moore ([janmoore@ku.edu](mailto:janmoore@ku.edu)) at the University of Kansas.*

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<sup>6</sup> Medicaid Buy-In authority in the BBA of 1997 and TTWWIIA of 1999. The following states have MBIs: AK, AR, AZ, CA, CT, GA, IA, ID, IL, IN, KS, KY, LA, MA (1115 waiver), MD, ME, MN, MO, MS, MI, NC, ND, NE, NH, NJ, NM, NV, NY, OH, OR, PA, RI, SC, SD, TX, UT, VA, VT, WA, WI, WV, and WY; MT has passed legislation authorizing a Medicaid Buy-in but has not yet implemented the program