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Beyond Stigma: What Barriers Actually Affect the Decisions of Low-Income Families to Enroll in Medicaid?

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Introduction

This Issue Brief reports on the Medicaid-related findings from one of the largest studies ever undertaken on the subject of public benefits and stigma. This study consisted of nationwide in-person interviews with 1400 low-income families who receive health care at community health centers. The study design and findings are unique in that (1) we measured distinct dimensions of stigma associated with the use of public benefits, and (2) we were able to identify the ways in which stigma, as well as other problems, actually affect families' decisions about enrolling in cash assistance and Medicaid programs. Because of the importance of the Medicaid findings in the current health policy debate, these findings, along with specific policy recommendations for addressing these barriers to Medicaid enrollment, are reported here.

^{*} The Center for Health Services Research and Policy (CHSRP), located at the George Washington University Medical Center, School of Public Health and Health Services in Washington D.C., specializes in multi-disciplinary health services research and policy analysis in a broad range of issue areas. The Center, founded in 1990, receives funding from numerous public and private sources. This research was supported by a grant from the Robert Wood Johnson Foundation to examine welfare reform and its implications for access to health care and health insurance coverage.

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Findings in Brief

- The traditionally held notion of so-called ‘welfare stigma’ (i.e., people feel negatively about themselves when they participate in Medicaid) is *not* a barrier to Medicaid enrollment. To the extent that stigma is a barrier to Medicaid enrollment, this stigma is the result of how people are treated for participating and *not* how they feel about themselves or the program.
- Our findings also distinguish between perceived problems and problems that actually affect decisions about enrolling in Medicaid (i.e., barriers). These are important findings because (1) the problems reported by respondents with the greatest frequency were not necessarily the actual barriers, and (2) policies designed to improve enrollment in Medicaid must address actual barriers to enrollment and not perceptions of problems.
- About 50 percent of respondents reported perceiving at least one aspect of stigma-related problems associated with participating in Medicaid. These reports can be broadly characterized in one of two ways: (1) people will feel bad about themselves or think they will be looked down; and (2) people will actually be treated badly. Frequencies of these stigma reports varied ranging from 11 percent (feel bad about themselves) to 35 percent (application process is humiliating).
- More than 80 percent of respondents also reported at least one other type of problem associated with participating in Medicaid (e.g., don’t know how to apply (56 percent), application is long and complicated (41 percent), need a translator (35 percent), lack of transportation (41 percent)).
- Multivariate analyses, however, identified these problems as *significantly likely to affect decisions* about enrolling: (1) being made to answer unfair personal questions; (2) a long and complicated application form; (3) confusion about eligibility; (4) the misperception that you have to be on welfare to get Medicaid; and (5) unequal treatment of Medicaid recipients by many physicians. Only two of these barriers (i.e., one and five) are related to dimensions of stigma; these barriers involve *treatment stigma*.
- Hispanic respondents were more than three times as likely to be eligible but not enrolled compared to white respondents and were significantly more likely to report these enrollment problems: (1) immigrant fears; (2) lack of translators; and (3) people don’t know how to apply.
- Respondents were significantly more likely to report treatment stigma when applying for benefits at the welfare office than at alternative sites. These findings strongly support an increased emphasis on outstationed and alternative enrollment sites. Moreover, the Medicaid take-up rate for this health center patient study sample appeared to be much higher than comparable take-up rates for the general population. This suggests that states should consider the active involvement of safety net providers (SNPs) in their efforts to remove barriers to Medicaid enrollment.
- The consequences of these barriers for Medicaid enrollment are compelling. For this health center patient study sample, we estimated that 27 percent of uninsured adult patients and 70 percent of uninsured child patients were eligible but not enrolled. This suggests that at least 1.4 million health center patients were eligible for Medicaid but not enrolled in 1998.
- States have the authority to ameliorate all of the barriers to Medicaid enrollment identified in this study through changes in enrollment policies and procedures under current federal law.

Background/Policy Context

As the number of uninsured Americans has steadily increased over the past decade, and as welfare reform has dramatically expanded the need for services and supports for low income working families, numerous policy makers have recommended the greater use of existing Medicaid options aimed at improving coverage of uninsured workers with children, either alone or as part of an overall approach for addressing the health insurance crisis.¹ The viability of this approach depends on numerous factors, one of the most important of which is whether lower income families who work would enroll in the program if eligible.

In recent months a number of state program administrators have raised concerns about whether families view Medicaid as so associated with the old welfare system that they would consider receipt of benefits through the program as inherently stigmatizing and would thus resist enrollment. This generalized concern regarding Medicaid's potential to generate stigma has become quite focused in the case of children. The State Children's Health Insurance Program (SCHIP), which was enacted in 1997, assists states fund and administer publicly subsidized health insurance programs for low income uninsured children. SCHIP may be implemented as a Medicaid expansion, as a separate program, or as a combination of the two. As of spring 2000, more than 30 states administered SCHIP as a separate program either in whole or in part. Decisions to separate SCHIP have reportedly been influenced by these concerns about stigma.

Stigma-related concerns are also reportedly the basis for complaints about another SCHIP feature. States must adhere to a "screen-and-enroll" requirement designed to prevent enrollment into SCHIP until the child's ineligibility for Medicaid is determined. The rationale for this requirement was that lawmakers were concerned that (1) the new funds intended to aid uninsured children would supplant state Medicaid expenditures, and (2) Medicaid eligible children, entitled to coverage that may be broader than that afforded under SCHIP programs and exempt from cost-sharing under Medicaid, would be mistakenly enrolled in a less generous program. While the reasons for this "screen and enroll" requirement may be laudable, if families are in fact foregoing coverage for their children rather than risk Medicaid enrollment due to stigma fears, then the policy potentially merits reconsideration. Indeed, several states have identified the

¹ See, e.g., Guyer, J. and Mann, C. (1998). *Taking the Next Step: States Can Now Take Advantage of Federal Medicaid Matching Funds to Expand Health Care Coverage to Low-Income Working Parents*. Washington, DC:Center on Budget and Policy Priorities, August. Glied, S. (1999). *An Assessment of Strategies for Expanding Health Insurance Coverage*. Washington, DC:The Kaiser Family Foundation.

combined effect of the SCHIP “screen and enroll” requirement and Medicaid stigma as strong enough to have caused a lower than anticipated SCHIP enrollment in their states.

Several studies have identified the possibility of stigma as an important potential barrier in many settings, but none have attempted to define stigma and examine its implications for Medicaid enrollment. Studies have examined non-stigma-related barriers to Medicaid for low-income families such as difficulties with the application process (e.g., a complicated application, inability to find a translator, inconvenient hours when people can apply) to confusion about eligibility.² On the other hand, two recent studies suggested that families do value Medicaid and frequently have attempted to apply for assistance despite the presence or perception of barriers.³

Stigma’s role as a barrier to Medicaid enrollment is challenging to investigate in part because it is inherently complicated to define and measure in this context. The traditionally-held view of stigma involves the negative feelings or negative self-identification that potential and actual participants associate with simply receiving a means-tested public benefit (e.g., cash assistance, Food Stamps, or Medicaid). The dynamics of stigma also involve complex interactions of attitudes and behaviors exhibited by people who need the service, those who furnish it (i.e., local program directors), and the general public. To the extent that traditional stigma is associated with receipt of public benefits and does actually affect people’s decisions to participate, it may be a particularly difficult barrier to measure, assess, and remedy. This study attempts for the first time to disentangle these complex dimensions of stigma and to measure their effect — relative to other barriers — on decisions to enroll in Medicaid.

Methods

The broad goals of this study were to (1) identify/measure various dimensions of stigma along with other potential barriers to Medicaid enrollment reported by respondents, and (2) distinguish between respondents’ perceptions about problems and *actual* barriers — that is,

² See for example: Feld, P. and D. Sandman (1998). *Focus Group Findings on Barriers to Enrollment in Medicaid and Child Health Plus*. New York, The Commonwealth Fund. *Barriers to Medi-Cal Enrollment and Ideas for Improving Enrollment: Findings from Eight Focus Groups in California with Parents of Potentially Eligible Children* (1998). Menlo Park, The Kaiser Commission on Medicaid and the Uninsured. Shuptrine, S. V. Grant, et al. (1998). *Southern Regional Initiative to Improve Access to Benefits for Low-Income Families with Children*. Columbia, Southern Institute on Children and Families.

³ *Medicaid and Children Overcoming Barriers to Enrollment: Findings from a National Survey* (2000). Washington, DC, Kaiser Commission on Medicaid and the Uninsured. *Speaking Out... What Beneficiaries say about the Medi-Cal Program* (2000). Oakland, Ca. Medi-Cal Policy Institute.

barriers that affect whether eligible respondents enroll in Medicaid. This is an important distinction because the problems reported by respondents with the greatest frequency may not necessarily be the barriers that actually affect decisions to participate in Medicaid.

Definition/Measurement of Barriers

Based on a review of the literature on stigma and studies that investigated problems associated with Medicaid enrollment, we defined and measured three broad categories of potential barriers to enrollment: *stigma*, *application costs*, and *confusion about eligibility*.⁴

Stigma: We separated the concept of stigma into three distinct components. The first represents the traditionally held notion of “welfare stigma.” This stigma occurs when a potential program participant thinks that enrolling in Medicaid and/or other public benefits will either cause her to feel badly about herself or will cause her to be looked down upon by others. The second form of stigma is application-related stigma which involves concern about the possibility of a negative experience during the application process, such as condescending or rude treatment by caseworkers, exposure to humiliation, infringements on personal freedom, and having to answer invasive questions. The third type of stigma is provider stigma, which involves a concern that some doctors may not provide quality health care to Medicaid recipients or that patients with Medicaid may not be treated equally to patients with private health insurance.

Application Costs: Application costs are the perceived hassles/problems associated with applying for Medicaid, such as the application forms and paperwork, the process of securing and completing an application, the hours and locations for applying, the required documentation and verifications, and difficulties in getting transportation and/or translators.

Confusion and Misinformation about Medicaid Eligibility Criteria: This concept concerns confusion about who is eligible for Medicaid. In addition to general lack of information about Medicaid eligibility, this includes misperceptions about Medicaid eligibility that may related to welfare reform such as: (1) a person has to be on welfare to obtain Medicaid; (2) the work requirements and time-limits of the welfare program apply to Medicaid recipients; (3) a person can only apply for Medicaid in a welfare office; and (4) immigrants’ apprehensions that they cannot apply for Medicaid without risking their status.

⁴ Stuber, J. (2000) Literature review on barriers to Medicaid enrollment and how these barriers affect participation in Medicaid, Dissertation Proposal, Yale University School of Public Health.

Data Collection

We surveyed 1400 community health center patients in 30 community health centers located in ten states⁵ and the District of Columbia. Health centers and states were selected to ensure geographic variation. We selected patients at random, with an overall response rate of 80 percent and obtained a sample of respondents representative of community health center patients nationwide. Collecting the data at health centers allowed us to interview families who are predominantly low-income, and who frequently have had personal experiences with the Medicaid program.

We developed a questionnaire/survey that included approximately 350 questions about a broad range of demographic characteristics, family income, family composition, insurance history, health status and use of the health system, participation in cash assistance and Medicaid, and perceptions of problems and stigma associated with enrollment in Medicaid and cash assistance. The survey was pre-tested before being administered. Administration of the surveys was done in person at the health centers by the same project staff; administration took approximately 20 to 30 minutes. About 16 percent of the surveys were administered in Spanish.

Data Analysis

For the frequencies presented in the first part of the findings, we examined respondents who either had one or more family members enrolled in Medicaid or whose families included one or more individuals potentially eligible for Medicaid (N=1139). This sample included families living below 300 percent of the federal poverty level (FPL) and single adult respondents who reported they were in fair to poor health.

For the multivariate analysis presented in the second part of the findings, we estimated respondents likely to be eligible for Medicaid but not enrolled using information we collected about household size, family composition, state Medicaid eligibility levels, and household income. We then constructed a logistic regression model that predicts whether a respondent is eligible for the Medicaid program and not enrolled or whether the respondent is enrolled in Medicaid (N=659). Twenty-two problems reported associated with enrolling in and participating in Medicaid were initially entered into the model along with sociodemographic characteristics of the respondents. The purpose of this multivariate model was to consider all of these potential

⁵ California, Colorado, Indiana, Massachusetts, Michigan, Missouri, Pennsylvania, South Carolina, Texas, and West Virginia.
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problems at once to decipher their relative effects and determine which of them are actually barriers to enrollment in Medicaid (i.e., can predict whether someone is eligible but not enrolled). We were also able to discern from the model the magnitude of the effect of each of these barriers on Medicaid enrollment and their actual and relative degree of importance to decisions about participation.

Results/Findings

Presence of Stigma

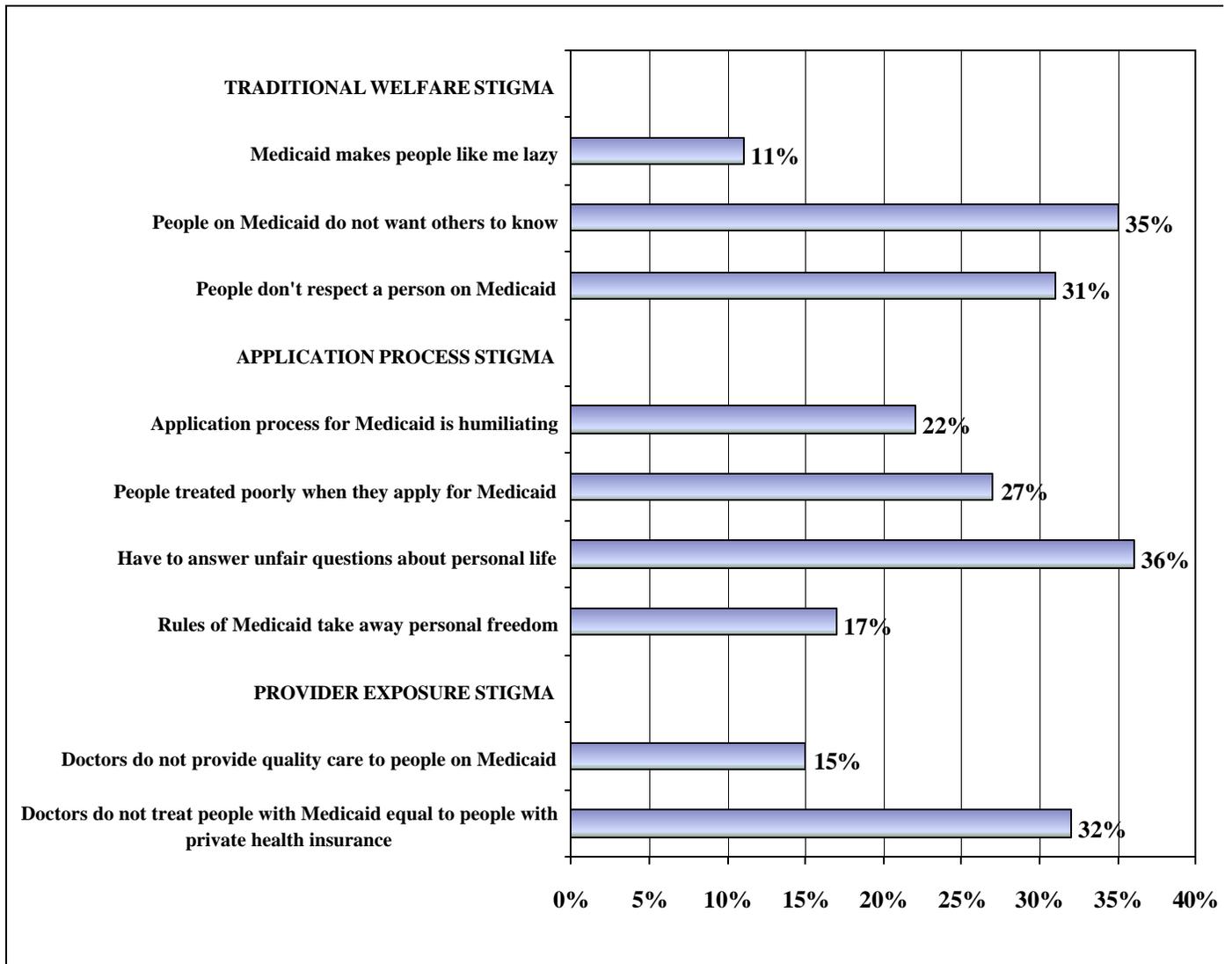
About 50 percent of respondents reported perceiving at least one aspect of stigma-related problems associated with participating in Medicaid. Figure 1 shows the frequency of the traditionally-held notion of “welfare stigma,” that is, a potential program participant thinks that enrolling in Medicaid will either cause her to feel badly about herself or will cause her to be looked down upon by others. Eleven percent of respondents perceived people on Medicaid as lazy, 34 percent thought that many people on Medicaid do not want others to know about it, and 31 percent thought that the general public does not respect those who are on Medicaid.

In terms of application-related stigma, 22 percent of respondents thought that the Medicaid application process is humiliating, 27 percent thought that people are treated poorly when they apply for Medicaid, 36 percent associated the Medicaid application process with having to answer unfair questions about their personal lives, and 17 percent perceived Medicaid eligibility rules as taking away personal freedom.⁶

Fifteen percent of our respondents perceived provider-related stigma arising from physicians’ failure to provide quality healthcare to those on Medicaid, while 32 percent reported that doctors did not treat Medicaid beneficiaries in a manner equal to those with private health insurance.

⁶Although not shown here, it is worth noting that these respondents reported comparable measures of application-related stigma and traditionally-held notion of welfare stigma for cash assistance/TANF about twice as frequently as they reported measures of stigma for Medicaid (e.g., 45 percent of respondents thought that the TANF application process is humiliating and 54 percent thought that people are treated poorly when they apply for TANF).

Figure 1. Frequency of Medicaid Stigma |N|= 1139



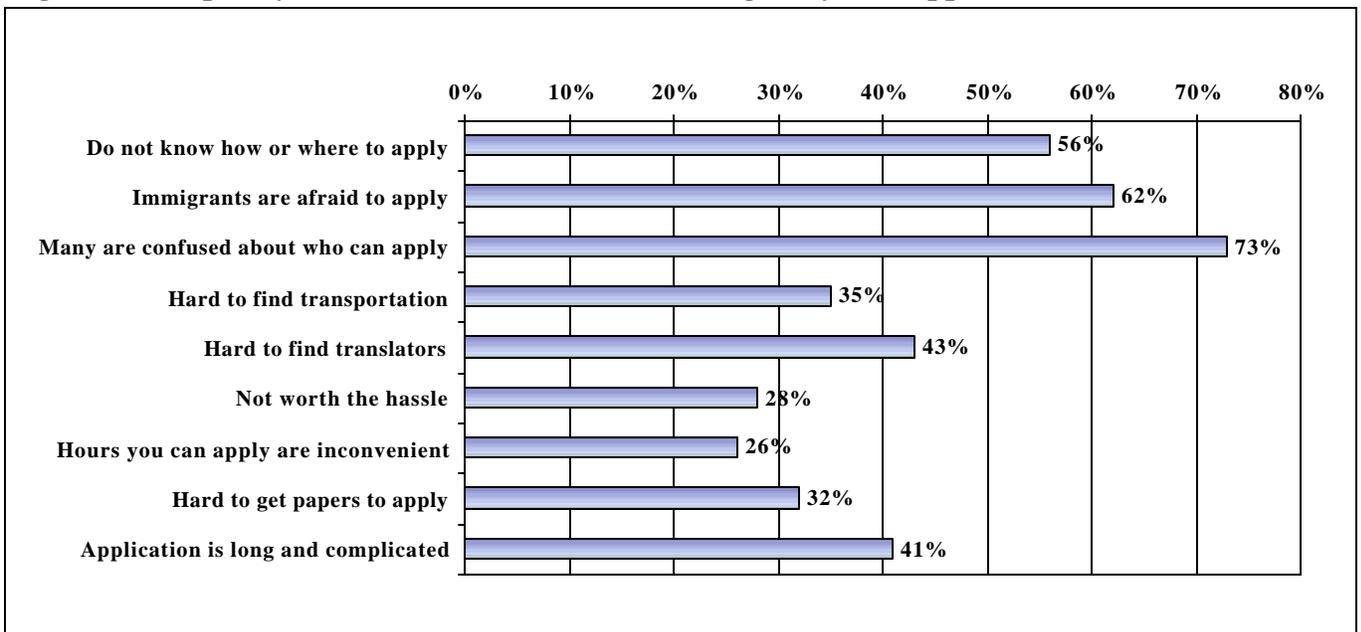
Presence of Application Costs and Confusion about Eligibility

More than 80 percent of respondents also reported at least one other type of problem associated with enrolling and participating in Medicaid. Shown in Figure 2 are the frequencies of confusion about Medicaid eligibility and Medicaid application costs as perceived by our respondents. The frequencies of reports about application costs are as follows. Forty-one percent of respondents agreed that the application for Medicaid is long and complicated. Thirty-two percent of respondents thought that it is hard to get papers needed to apply for Medicaid, 26 percent indicated that the hours a person can apply for Medicaid are inconvenient, and 28 percent thought it is not worth the hassles/problems to apply for Medicaid. Forty-three percent of

respondents agreed it is hard to find translators to assist with the Medicaid application, and 35 percent reported that it is hard to find transportation to complete a Medicaid application.

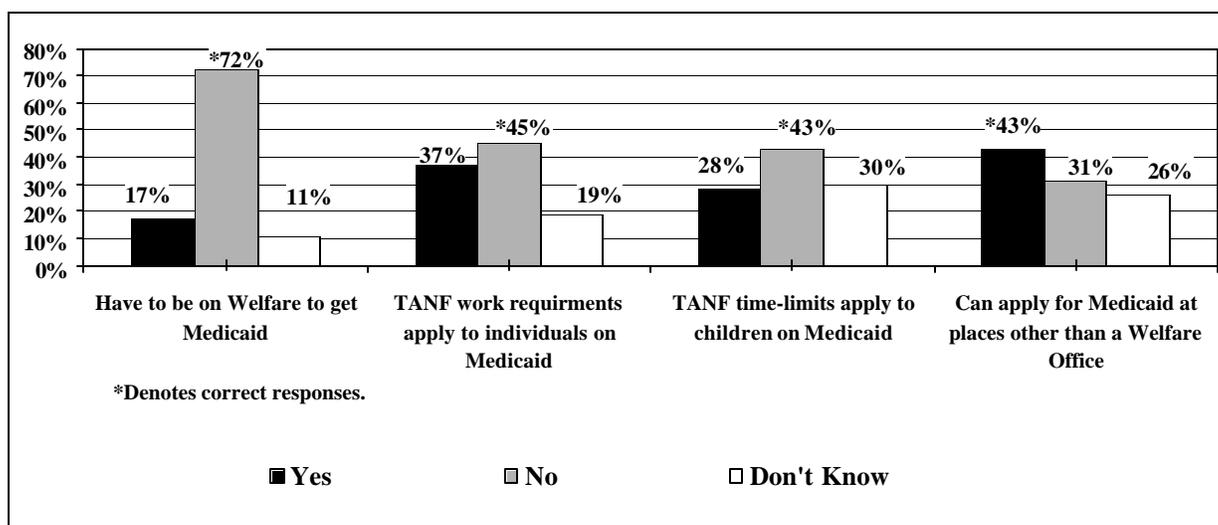
The three most frequently reported problems related to confusion about eligibility are as follows. Seventy-three percent of respondents thought that many people are confused about who can apply for Medicaid. Sixty-two percent of respondents reported that immigrants are afraid to apply for Medicaid, and 56 percent indicated many people do not know how or where to apply for Medicaid

Figure 2. Frequency of Confusion about Medicaid Eligibility and Application Costs |N| = 1139



As shown in Figure 3, many respondents also reported misperceptions about eligibility for the Medicaid program that may be related to changes post-welfare reform. Thirty seven percent of respondents believed that the work requirements of the welfare program apply to individuals on Medicaid, 19 percent were uncertain. Twenty-eight percent of respondents thought that the welfare time limits apply to children on Medicaid and an additional 30 percent were unsure. Thirty-one percent of respondents thought they were not able to apply for Medicaid in places other than a welfare office and 26 percent were unsure. Finally, 17 percent of respondents thought that you had to be on welfare to obtain Medicaid, while 11 percent were uncertain.

Figure 3. Confusion about Medicaid Eligibility Related to Changes in the Welfare Program



Barriers to Medicaid Enrollment—Multivariate Analysis

In our multivariate analysis, we predicted whether respondents fell into one of two categories: eligible for Medicaid and not enrolled, and enrolled in Medicaid. In the model we accounted for all of the problems respondents identified at once, so that we could distinguish which of these problems are actual barriers to enrollment. Twenty-two problems (identified in the preceding findings) were entered into the model.

Figure 4. Barriers to Medicaid Enrollment [N] = 659

Variable/Barrier	Parameter Estimate	Standard Error	P-value ⁷	Odds Ratio (OR)
Must answer unfair personal questions	.77	.26	.003*	2.2
Application is long and complicated	.61	.23	.010*	1.8
Many are confused about who can apply	.57	.30	.050*	1.8
Have to be on welfare to get Medicaid	.56	.26	.030*	1.7
Doctors do not treat people with Medicaid equal to people with private health insurance	.51	.26	.050*	1.7
Hours you can apply are inconvenient	.50	.27	.060	1.7

Our analysis suggests that five barriers significantly predict whether a respondent is eligible but not enrolled in Medicaid. Figure 4 presents these findings. The significant barriers

⁷ P-value of .05 or less is considered statistically significant and the asterisk indicates the statistically significant barriers.

in order of magnitude of effect were: (1) having to answer unfair questions about one's personal life during the application process; (2) the length and complexity of the Medicaid application; (3) confusion about who is eligible for Medicaid; (4) the misperception that you have to be on welfare to get Medicaid; and (5) unequal treatment of beneficiaries by Medicaid providers. We included the sixth barrier in Table 4, which involves the inconvenience of application hours, because it was marginally statistically significant and is easily remedied by policymakers. Only two of these barriers are related to dimensions of stigma; these barriers involve treatment stigma.

The impact of these six barriers on enrollment was pronounced. Respondents who associated the Medicaid application with having to answer unfair questions about their personal lives were 2.2 times more likely to be eligible but not enrolled in Medicaid as compared with those who did not express this concern. Respondents who perceived the Medicaid application as long and complicated or felt that many people are confused about who can apply were approximately 1.8 times more likely to be eligible but not enrolled as compared with respondents who did not perceive these barriers. Respondents who perceived that providers engaged in unequal treatment of beneficiaries, or hold the misperception that you have to be on welfare to obtain Medicaid, or who saw inconvenient hours as a barrier were approximately 1.7 times more likely to be eligible and not enrolled as compared with those who do not perceive these barriers. Hispanic respondents were more than three times likely to be eligible but not enrolled in Medicaid as compared to white respondents. This finding confirms recent studies finding that Hispanics are disproportionately affected in comparison to other ethnic groups in the US in terms of their lack of access to health care services and health insurance.⁸

The multivariate analyses allowed us to identify the actual barriers to Medicaid participation and to distinguish them from the long list of perceived problems with Medicaid participation. It is also interesting that the frequencies did not necessarily predict what barriers would be significant in the multivariate model.

Evidence that Application-Related Stigma is a Barrier to Medicaid Enrollment

In Figure 5, we show that the presence of reported stigma varies dramatically depending upon where the respondent applied for Medicaid. Among our patients who applied for Medicaid

⁸ Quinn, K. (2000). "Working without Benefits: The Health Insurance Crisis Confronting Hispanic Americans," New York, NY: The Commonwealth Fund, February.

in the last two years, 73 percent applied in a welfare office. Fourteen percent of our patients applied for Medicaid in a health clinic, and 13 percent applied in a hospital, a department of public health, a school, or in a WIC office. Our results show convincingly that respondents who apply for Medicaid at places other than a welfare office are much less likely to report stigma associated with the Medicaid application process. In particular, respondents who applied for Medicaid in a welfare office were twice as likely to report worse treatment during the application process and feelings of greater discomfort when applying as compared with respondents who applied for Medicaid in locations other than the welfare office.

Figure 5. Differences in the Experience of Stigma by Where Respondents Applied for Medicaid

Experience of Stigma Associated with the Medicaid Application Process	Applied for Medicaid in a Welfare Office (N=538) %	Applied for Medicaid in place other than a Welfare Office (N=190) %	P-value⁹
Experience of applying uncomfortable	53%	32%	.001*
Did not feel trusted when applied	64%	39%	.001*
Did not feel respect when applied	69%	42%	.001*
Did not feel valued as a person when applied	60%	33%	.001*

The Significance of these Barriers to Medicaid Enrollment

The implications of the barriers identified in our multivariate analysis as affecting entry into the Medicaid program are substantial when we consider the uninsured respondents in our sample who we estimated were eligible for Medicaid and not enrolled. Forty percent of respondents were uninsured, while the uninsured rate among their children was reported at 21 percent. These figures, which are comparable to the rate of uninsured health center patients generally,¹⁰ are significantly higher than the general population where approximately 16 percent of non-elderly adults and 15 percent of children are without health insurance.¹¹

Among the 429 uninsured adult respondents interviewed, we estimated that 27 percent were likely to be eligible for Medicaid. Among their 406 uninsured children, we estimated that

⁹ P-value of .05 or less is considered statistically significant and the asterisk indicates statistically significant barriers.

¹⁰ Rosenbaum, S., Shin, P., Markus, A., Darnell, J. (2000). *Health Centers' Role as Safety Net Providers for Medicaid Patients and the Uninsured*. Washington, DC: The Henry J. Kaiser Family Foundation, February.

¹¹ Fronstein, P. (1998). "Sources of Health Insurance and Characteristics of the Uninsured: Analysis of the March 1998 Current Population Survey," Employee Benefit Research Institute, Issue Brief Number 204, December.

70 percent are eligible for Medicaid.¹² Applied to the community health center patient population as a whole in 1998, this estimate translates into 833,000 Medicaid-eligible but uninsured children and 580,000 such adults for a total of approximately 1.4 million eligible but uninsured patients.¹³

Policy Implications

The findings from this study provide compelling evidence that the traditionally held notion of “welfare stigma” plays no significant role in explaining why individuals are Medicaid eligible but not enrolled because they have decided not to participate. The types of stigma that do have a significant, measurable impact on the likelihood of Medicaid enrollment are related to how people are or expect they will be treated during the application process and how they believe they will be treated by providers once they are enrolled.

This study has certain limitations including that the respondents are representative of community health center patients and, thus, the findings cannot be generalized to the general population of eligible but not enrolled individuals. It is unlikely, however, that the barriers identified in these findings would be less important to potential enrollees who are not health center patients. The fact that these respondents were already able to access the health system despite their uninsured or Medicaid status may mean that barriers such as transportation and culture/language are of greater importance than our findings suggest. The estimates of Medicaid eligibility that we used to create the eligible but not enrolled group did not account for individual disregards such as child care and earned income. However, this approach to calculating these estimates means that we probably *underestimated* the percentage of eligible but not enrolled.

Consequently, these findings have strong implications for addressing enrollment barriers and provide a credible basis for recommending steps that states can take to reduce barriers to Medicaid enrollment. All of the following recommended actions fall within the discretion given states under current law.¹⁴

¹² We were not able to determine eligibility for 8 percent of our adult respondents due to missing information about income, and were not able to determine Medicaid eligibility for 57 or 14 percent of the children in this sample due to missing information about the number of kids in the household, the ages of children in the household, or the respondents’ income.

¹³ We used data from the 1998 Uniform Data Set (UDS) maintained by the DHHS Bureau of Primary Health Care for community and migrant health centers receiving grants from the Health Resources and Services Administration to calculate these estimates.

¹⁴ State Medicaid Director Letter from Timothy M. Westmoreland, Director of Center for Medicaid and State Operations, HHS/HCFA, April 7, 2000 at hcfa.gov/medicaid/smd40700.htm.

Place increased emphasis on outstationed enrollment at health centers, community clinics, hospitals, and other alternate locations such as schools, and child-care centers. Since 1990 federal Medicaid law has required states to offer outstationed enrollment assistance at health centers and disproportionate share hospitals. Outstationing was intended by Congress to permit individuals to not only begin but complete the application process at a site other than a welfare office. Earlier research conducted by CHSRP concluded that nearly half of all health centers were not engaged in outstationed enrollment activities and that state support -- the most important factor in centers' decision to offer outstationing -- was lacking.¹⁵ The findings from this study underscore the importance of an aggressive outstationing program that combines alternate enrollment sites with simplified applications and on-site application assistance.

We also separately calculated the Medicaid "take-up" rate (i.e., the rate of actual enrollment into Medicaid among eligible respondents) among our respondents. We determined that among the respondents, the take-up rate was 83%, while among children, the rate was 82%. These take-up rates are higher than the general population where estimates are approximately 70%¹⁶ and may provide further evidence of the importance of outstationed enrollment sites in that they suggest being a health center patient may be associated with a higher Medicaid take-up rate. This also suggests that states should consider the active involvement of safety net providers (SNPs) in their efforts to remove barriers to Medicaid enrollment.

To the maximum extent possible, minimize welfare office encounters as part of the Medicaid application process. Our results show convincingly that the site of application is a key influence on the likelihood of reporting application-related stigma. Respondents who applied for Medicaid in locations other than a welfare office report better treatment during the application process and greater comfort as compared with respondents applying for Medicaid in a welfare office. Federal law requires neither an in-person interview by a welfare worker for Medicaid eligibility nor the filing of an application at the welfare office and requires only that the final eligibility determination for Medicaid be made by employees of state agencies designated.

¹⁵ Rosenbaum, S., Maloy, K.A., Stuber, J. & Darnell, J. (1998). *Initial Findings from a Nationwide Study of Outstationed Medicaid Enrollment Programs at Federally Qualified Health Centers*; Washington, DC: The Center for Health Policy Research, The George Washington University, February.

¹⁶ Selden, T., Banthin, J. Cohen, J. (1998). Medicaid's Problem Children Eligible But Not Enrolled; Results from the 1996 Medical Expenditures Panel. *Health Affairs* Vol. 17 No.3, May -June.

Eliminate all unnecessary questions. Our findings suggest that many of the respondents applying for Medicaid were asked unnecessary questions during the application process and that these questions represented a significant barrier to Medicaid enrollment. We asked patients who had applied for Medicaid in the last two years if they were asked questions about their income, their assets, how they handle money, alcohol and drug use, their sex lives, and the father of their children. Ninety-six percent of respondents were asked about their income, 84 percent were asked about their assets, 55 percent were asked about how they handle money, 48 percent were asked about alcohol and drug use, 16 percent were asked about their sex life, and 77 percent were asked about the paternity of their children. Other than income and assets, these questions were irrelevant to Medicaid eligibility. State Medicaid agencies historically have had to address the issue of irrelevant and unnecessary questioning by welfare workers dealing with Medicaid-only applicants. Medicaid agencies that continue to use welfare offices as their primary or sole means of family applications should consider focusing attention on how welfare workers are trained to handle both the Medicaid application process and the Medicaid eligibility re-determination process.

Shorten the application form. This study emphasizes the essential nature of continued efforts to redesign and shorten Medicaid application forms in order to provide clear questions and instructions and to eliminate unnecessary questions. Translation of forms and easy to follow instructions are also key. All documentation-driven verification should be eliminated in accordance with the flexibility permitted under federal law.¹⁷ Simplified applications also make alternative enrollment sites more effective and will make it easier for community organizations to help families navigate the Medicaid application process.

Add hours and locations for enrollment. If Medicaid is to function for working families, then families need to be able to apply for Medicaid at times when they are not required to be at work. Families who must leave a job to apply for Medicaid and deal with overcrowded offices and long waits may simply forego coverage. Application sites need to have evening and weekend hours to sign-up families for Medicaid as do alternative enrollment sites. This problem

¹⁷ State Medicaid Director Letter from Timothy M. Westmoreland, Director, Center for Medicaid and State Operations, HHS/HCFA, April 7, 2000 at hcfa.gov/medicaid/smd40700.htm.

would also be reduced with increased emphasis on outstationed enrollment at health providers, mail-in applications, and applications by telephone.

Do more to reduce Medicaid confusion. We found that confusion about Medicaid was a significant barrier to Medicaid enrollment. Seventeen percent of respondents incorrectly believed that that welfare receipt was a precondition to Medicaid eligibility. A striking 37 percent incorrectly thought that the welfare work requirements under TANF applied to Medicaid applicants and that TANF time limits applied to children on Medicaid. States clearly need to consider more aggressive community education, with heavy use made of indigenous programs and community outreach efforts that are known and trusted by community residents.

Pay special attention to minority families, particularly those of Hispanic heritage. The fact that the barriers identified in this study appear to fall with particular weight on Hispanic families merits particularly close attention. The Medicaid eligible but not enrolled families identified in this study were primarily of Hispanic or Spanish background. These families were over three times more likely than whites to be eligible for Medicaid and not enrolled, and were significantly more likely than whites and African Americans to report these problems with Medicaid enrollment: (1) immigrants are afraid to apply; (2) it is hard to find translators; and (3) people don't know how or where to apply. These results demonstrate that addressing barriers to Medicaid enrollment for Hispanics must involve the Immigration and Naturalization Service (INS) as well as state Medicaid agencies. While state Medicaid agencies can stress the fact that receipt of Medicaid benefits will not adversely affect immigration status, recent studies suggest that the INS must work harder to offer ongoing and credible assurances to immigrant families regarding their eligibility for Medicaid.¹⁸

¹⁸Maloy, KA., Darnell, J., Nolan, L. (2000) *Effects of the 1996 Welfare and Immigrant Reform Laws on Immigrants' Access to Medicaid and Healthcare Services*; Washington, DC: The Center for Health Services Research and Policy, The George Washington University, May. Ku, L. and Matani, S. (2000). *Immigrants' Access to Health Care and Insurance on the Cusp of Welfare Reform*, Washington, DC: The Urban Institute, June.

Conclusion

In this study we identified the most important *actual* barriers to Medicaid enrollment in a sample of community health center patients; these findings can be generalized to community health center patients nationwide. We found that stigma defined in the traditional manner (e.g. as a function of how respondents will feel about themselves or what they perceive others will think of them for enrolling in Medicaid) is not a barrier to Medicaid enrollment. To the extent that stigma is a barrier to Medicaid enrollment, it is a function of how people are treated during the application process and by health care providers. Specifically, we identify the actual stigma-related barriers to Medicaid enrollment as the following: (1) very personal questions that are asked during the application process, and (2) the perception that providers don't treat those on Medicaid equal to people with private health insurance. Additionally, we have shown the location where respondents apply for Medicaid has a significant effect on their perceptions of how they are treated when they apply. These stigma-related barriers are associated with how states have elected to design their Medicaid enrollment processes and conditions of participation after welfare reform. Existing state laws permit states to institute changes to rectify these barriers.

Four of the six significant barriers to Medicaid enrollment we identified are not stigma-related. These barriers include: (1) confusion about who is eligible for Medicaid; (2) the misperception that you have to be on welfare to get Medicaid; (3) the perception that the Medicaid application is long and complicated; and 4) that the hours when people can apply are inconvenient. These barriers have all been identified in other studies and many states have begun to address them. This study confirms the critical importance of state efforts in this regard because these barriers have a pronounced effect on Medicaid enrollment. These findings also provide clear guidance about which barriers are most important to address for states that want to improve their Medicaid enrollment.

Finally, these findings also strongly suggest that stigma-related concerns about the SCHIP "screen and enroll" requirement (i.e., families will forego coverage to avoid risk of Medicaid enrollment due to stigma) are unfounded and should not provide the basis for reconsidering this requirement.