

Stigma: A Paper for Discussion

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Introduction

The origin of stigma related to government programs that provide health coverage appears to be linked to its negative association with the public welfare system. The stigma currently associated with Medicaid and SCHIP seems to break out into two components: the process and the product. The process end of stigma relates to the reportedly negative treatment of applicants by staff in welfare offices and the often intrusive nature of the personal information required upon application. On the product end, there is a prevailing perception that the delivery system does not provide the same level of care to holders of public coverage as it does to holders of private coverage. The stakes are high. Any success achieved with outreach, simplification, and coordination will be diminished if the stigma attached to these programs continues to prevent the enrollment of children into health coverage programs.

This document is presented in six sections in an attempt to facilitate a discussion on stigma as a barrier to participation in health coverage programs. The first section defines stigma as the literature has defined it. The second section lists what the literature suggests are some causes of stigma. The third section provides information on how recipients internalize and manage the stigma felt from participating in public programs. The fourth section lists symbols that have been described as stigmatizing. The fifth section discusses research and policy projects that are identifying causes of stigma and eliciting suggestions for reducing it. Finally the last section provides examples that are being used in the field to address the stigma associated with government-sponsored health coverage programs.

Most of the research to date has been focused on stigma associated with the former Aid to Families with Dependent Children (AFDC) and Food Stamp programs. Within this body of research it appears that the problem of stigma has been well-defined and continues to be. Much of what is already known and frequently discussed by policymakers and advocates is incorporated into the literature. Stigma is most often thought to be perpetuated through person-to-person contact. Applying for programs and seeking out services by medical providers are person-to-person activities. Stigma is known to be perpetuated by the types of questions asked when applying for programs and the personal information that must be provided in order to make an application. This being said, the information we know about eliminating face-to-face interviews, allowing mail-in applications, and making Medicaid and SCHIP programs seamless from the perspective of the family all should help reduce the stigma associated with government programs, including health coverage programs. It is important to accept a current definition of

the problem (scientific or not) and begin to further explore ways that can help eliminate the welfare associated stigma of Medicaid and other health coverage programs.

How to do this may become a focus for some of the Covering Kids sites.

I. Definitions of Stigma

Webster's dictionary defines stigma as a mark of shame or discredit, and an identifying mark or characteristic.

Stigma is imputed when an individual's behavior is evaluated and deemed to be morally flawed (Gans, 1995).

Stigma is attributed to a personal characteristic that negatively differentiates deviants from non-deviants. Stigmatization, or the devaluation of deviant individuals and groups, entails a negative assessment of personal character. Deviance is a label placed on individuals and groups by others. Those labeled deviant have violated highly regarded rules or norms (Goffman 1963).

II. What the Literature Says About Stigma

Literature on stigma and its effects on participation in public programs has defined the problem of stigma. Work that continues today with regard to eligibility simplification and enrollment has begun to address the stigma affecting program participation, and this work continues to define and re-define the problem. The public in general still perceives Medicaid and welfare as synonymously linked. As you will see below, the way people are treated is a big contributor to the enduring negative perceptions of public-run programs, including health coverage. Yet, what the existing literature and possibly the current work lacks are explicit solutions to the defined problem. Theories exist and evidence is beginning to arise to support the theories. However, more work needs to focus on the stigma associated with government-sponsored health coverage before we can confirm the theories and test the solutions. The following section lists what the literature has stated about why individuals feel stigmatized when using public programs, such as AFDC and Food Stamps.

Dynamics of stigma most vividly operate through face-to-face interaction (Jarrett, 1996);

Stigma is associated with the degree to which recipients accept the traditional ideology of individual self-reliance (Kerbo, 1976);

Stigma can be self-afflicting, emanating from the participants' own recognition that they are engaging in actions they view as self-demeaning, while recognizing it is more than this because it involves other people's evaluation of one's actions (Moffitt, 1983);

Feelings of stigma are dependent on the audience, the specific situation and the individual's life history (Rogers-Dillons, 1995);

Applicants are often treated disrespectfully and judged by case workers in welfare offices as lazy and reluctant workers (Rosier and Corsaro, 1993);

Welfare and public programs are viewed as enabling people to get something for nothing and not being self-reliant and willing to work hard (Besley and Coate, 1992);

The culture of the welfare system needs to build on people's strengths, not reinforce negative stereotypes of welfare mothers (Mills, 1996).

III. What the Literature Says About How Welfare Recipients Internalize and Manage Stigma

Welfare recipients tend to view themselves as different from the typical welfare recipient, referring to welfare recipients as "they" not "we," dissociating themselves from the negative stereotype of people on welfare (Briar, 1966);

Recipients view themselves as supplicants, seeking assistance to help tide them over until things get better (Briar, 1966);

Those most likely to internalize the stigma of being a recipient of welfare were also more likely to believe that people were poor because they are lazy and irresponsible about work (Kerbo, 1976);

Recipients who do not internalize stigma were less likely to hold poor people responsible for their circumstances (Kerbo, 1976);

Welfare recipients feeling the most negative impact of stigma are those who identify themselves with the lower class and believe that this country is a land of equal opportunity (Goodban, 1985);

Goodban (1985) identified three strategies used by recipients to cope with welfare stigma: (1) psychologically distancing self with welfare recipients and identifying with middle class; (2) internalizing the negative stigma, which lead to a sense of helplessness and low self-esteem; and (3) accepting welfare roles, not internalizing stigma, and believing that their present status is caused by an unfair society;

Recipients believe they will have control over their future, while having little control over the immediate circumstances that led them into the welfare system. The sense of optimism for the future is an important coping mechanism in the present (Rank 1994).

IV. Stigma Symbols

Separate lines for food stamps in the grocery store.

Using food stamps in the grocery store.

Having a separate, distinctive Medicaid card that looks different from a commercial insurance card.

Having separate windows or rooms for families using Medicaid in provider offices.

V. Public Policy Research on Stigma

A. The Center for Health Policy Research at George Washington University

With funding from The Robert Wood Johnson Foundation, The GWU Center for Health Policy Research interviewed 1,000 community health center patients in 10 states about stigma and other barriers to participation in the Medicaid and TANF programs. Results of this study will be available in March 2000. The survey used a broad definition of stigma as follows: (1) exposure stigma, or concerns about negative experiences that may result from applying for public programs; (2) social identity stigma, or a concern about what others think about individuals receiving benefits from a public program; and (3) self-identity stigma, or a concern that if one participates in a public program they will take on characteristics of others on the program that the applicant perceives to be undesirable.

Program Participation is being defined as:

Family has delayed applying for program.

Family has thought about applying and decided not to.

Family applied for program and was denied benefits.

Family voluntarily removed themselves from program.

Family was dropped from the program.

The study, while examining the effect or stigma on participation in the Medicaid and TANF programs, is also looking at the effect of other barriers that prevent enrollment including: transaction costs (e.g. complexity of the application and the amount of paperwork required to complete an application); knowledge about the program and eligibility rules; fear among immigrant populations; and disabling factors (e.g. transportation and cultural issues).

B. The Southern Institute on Children and Families

1. In a report prepared for the Covering Kids initiative titled, Simplification: The Make or Break Issue for Achieving Full Enrollment of Eligible, Uninsured Children, the authors note the following: "...complicated eligibility rules and regulations for children's Medicaid coverage also thwart efforts at efficiency, deplete the energy of overburdened eligibility staff and significantly restrict the ability of community organizations to be effective in helping families to enroll their children. For those and other reasons, it is highly likely that the eligibility process itself contributes significantly to the reported stigma associated with Medicaid."

2. In 1993, the Southern Institute on Children and Families interviewed families receiving cash assistance (AFDC) or transitional medical assistance (TMA). The Southern Institute found that there were serious misconceptions about the availability of Medicaid for families leaving welfare and Medicaid for children in low-income families who had no connection to welfare. Of recipients responding to interview questions related to Medicaid, 76 percent answered incorrectly, demonstrating that families believed they had to be on welfare for their children to be eligible for Medicaid. Focus groups conducted by The Southern Institute in 1995 and 1996 in Georgia and North Carolina confirmed the earlier findings, which are discussed in a 1998 report titled Southern Regional Initiative to Improve Access to Benefits for Low-Income Families with Children. The report also discusses how federal error rate sanctions have helped create an eligibility environment that families describe as demeaning. The Southern Regional Initiative was conducted with support from The Robert Wood Johnson Foundation.

C. The Commonwealth Fund

A report titled, *Insuring the Children of New York City's Low-Income Families: Focus Group Findings on Barriers to Enrollment in Medicaid and Child Health Plus*, based on nine focus groups with low-income families (7) and eligibility workers (2), report that parents perceive the Medicaid enrollment process "as time-consuming, burdensome and requiring a great deal of persistence and patience." The process is viewed as demeaning, and the eligibility workers were considered confrontational and uninformative. In addition, the parents reported that they suspect that program administrators attempt to disqualify families whenever possible. The report further found that Medicaid beneficiaries believed they were stigmatized and that they received poorer quality of care than those with private insurance.

D. The Kaiser Commission on Medicaid and the Uninsured

1. A Kaiser project conducted a telephone survey of 1,335 low-income parents and six focus groups to determine barriers to enrollment and ways to overcome them. The findings from this project indicate that Medicaid continues to be linked to welfare, and the negative perceptions of welfare, specifically cash assistance. These negative perceptions are seen as barriers to Medicaid enrollment. Survey respondents who have never tried to enroll their children in Medicaid indicated three reasons for this: (1) parents do not want to go into a welfare office to apply for Medicaid; (2) parents fear poor treatment from eligibility workers; and (3) parents do not want their children to be considered Medicaid recipients.

2. A Kaiser report titled, *The Medicaid Eligibility Maze: Coverage Expands, But Enrollment Problems Persist*, indicates that some Medicaid enrollment problems are due to factors beyond eligibility policies, including: welfare related stigma, that Medicaid is only for families receiving welfare, that Medicaid is time-limited like welfare, and that the eligibility process is burdensome and demeaning. This report goes on to discuss the Medicaid "drop-off" problem of children and families leaving the program while they continue to be eligible. The authors contend that the drop-off rate has led to the development of separate state SCHIP programs that can alleviate the stigma of Medicaid as well as the burdensome application process. Yet, as the authors noted, over time the separate programs may also experience the drop-off problem if the process becomes too bureaucratic and burdensome.

VI. How Can We Reduce Stigma?

Refer to Medicaid and SCHIP programs as "health coverage."

Provide customer service training to eligibility staff.

Continue to outstation eligibility staff.

Improve provider reimbursement rates for Medicaid and work to ensure provider reimbursements are the same for Medicaid and SCHIP.

Explore the use of payroll deduction for coverage program premiums.

Conduct enrollment of children in the workplace and in schools.

Simplify the redetermination process.

Change the look of the application.

Use insurance cards similar to those used in the private market.

Coordinate SCHIP and Medicaid programs. The fact that applying for SCHIP may be easier for families than applying for Medicaid can exacerbate the existing Medicaid stigma.

Review requirements that have been put in place for quality control purposes. Many of these rules are no longer necessary in the current system. In the past, these rules could have driven the welfare stigma that is now being transferred to public health coverage programs.

VII. Conclusion

In the era of welfare-to-work, having the necessary supports for a family in place (health care, child care and transportation) may in fact make or break the welfare-to-work programs being implemented in states. Health coverage needs to be seen not as a welfare program but as a work-support program. Success should no longer be measured by how many people we can keep off the program but by how well we enroll all eligible children into coverage programs, as well as help them maintain health care coverage for the entire period of eligibility. If this can be done, we are well on our way to battling the persistent problem of stigma that prevents many families from enrolling their children in a public health coverage program.

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