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Covering Kids & Families Access Initiative: Final Evaluation Report

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COVERING KIDS & FAMILIES
ACCESS INITIATIVE
(CKF-AI)

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Final Evaluation Report

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This report provides formative evaluation findings from a Robert Wood Johnson Foundation (RWJF) national program titled Covering Kids & Families – Access Initiative **(CKF-AI)**. Supported by $4 million in Foundation funding, the program was carried out during 2003 – 2005 with 18 grantee organizations in 15 states.[1] The National Program Office guiding CKF-AI was the Center for Health Care Strategies (CHCS), an organization with extensive experience in research and technical assistance to improve the quality of publicly financed health care.

Information is presented here on two levels:

- ***The text of the report offers a thematic discussion of cross-cutting evaluation findings and lessons learned from the overall effort***, with individual grantees' experience used selectively for purposes of illustration. While the bulk of this analysis focuses on results in the field, some implications for program management and grantmaking are also included.

- ***The appendix section offers site-specific information.*** Appendix A pulls together a list of materials produced by each of the grantees and notes some possible "best practices" that may be useful for a general tookit on reducing access barriers. So that grantees' circumstances and interventions can be understood in context, Appendix B contains the grantees' final reports describing in detail what each one attempted and achieved, case-by-case.

1. BACKGROUND

CKF-AI focused on one of the thorniest problems currently plaguing the U.S. Medicaid system – namely, that insurance coverage does not automatically translate into meaningful health care access. The fact that millions of Medicaid/SCHIP-eligible children and families remain unenrolled or have difficulty keeping their coverage has been, and ought to be, a primary focus of concern. But important as insurance coverage is, its value is undermined if access barriers block those already enrolled in the Medicaid system from obtaining covered health care services when needed.

While the precise extent of the access problem is not known, reports from the field suggest that it is sizable, particularly in areas with large populations of recent immigrants with limited English proficiency and in rural areas with gaps in transportation and other service delivery systems.[2] The problem is also likely to arise in states and localities where policy changes have recently altered Medicaid's benefit package, co-pays, prescription drug coverage, and/or relationship to managed care organizations (MCOs).[3] If the policy changes were not accompanied by adequate information and training, health care providers are left uncertain about what remains reimbursable and may deny services that are in fact covered.[4]

When illness strikes, the health care choices for Medicaid families facing access barriers are obvious and harsh.[5] They can pay out-of-pocket for benefits that are supposed to be covered, defer treatment until their illnesses reach a crisis level, use emergency services that fit their needs poorly and mark them as "over users," or go without professional health care altogether. Access barriers also impose societal burdens, since unattended health problems may ultimately end up being more expensive to treat, spread communicable disease, and impair employability and healthy child development for those unable to obtain needed care.

Clearly, more needs to be known about the nature of access barriers currently being encountered by families enrolled in Medicaid/SCHIP, and also about the feasibility and implications of various strategies for reducing access barriers.

The CKF-AI Program

Recognizing the importance of the access issue, RWJF undertook CKF-AI as a relatively small exploratory program with two interconnected goals:

- ***To shed more light on the nature of access barriers being encountered by children and families on Medicaid and ways of addressing these problems productively.***

- ***To expand RWJF's experience with a grantmaking approach that seemed especially well suited to investigating the access problem – that is, providing capacity-building seed grants and technical assistance to local community-based organizations.***

CKF-AI builds on several earlier RWJF initiatives. One important foundation is the RWJF national program *Covering Kids* (CK) and its successor *Covering Kids and Families* (CKF), developed under the direction of the Southern Institute on Children and Families. Taken together, CK and CKF represent more than a decade of effort by the Foundation to increase the number of eligible children and adults benefiting from public health care coverage programs. As CK/CKF coalitions in all 50 states worked to enroll and retain more eligible families in Medicaid/SCHIP, it became increasingly evident that some insured families found it difficult or impossible to obtain covered services even after they were successfully enrolled. CKF-AI – referred to in its call for proposals as "Part Three of CKF" – was established as a new initiative to address the access part of the Medicaid/SCHIP under-coverage problem and learn more about it.

CKF-AI also draws on experience with a large-scale initiative called the *Medicaid Managed Care Program* (MMCP), funded by RWJF and directed by CHCS. MMCP focuses on helping states and managed care providers improve their policies and delivery models for providing Medicaid services. Its emphasis on quality-of-care issues is vitally important for Medicaid families who successfully connect with managed care plans, but it did not include much direct community input concerning access barriers that might prevent the connection from being made in the first place. CKF-AI was seen as a way to fill this gap. It linked the eligibility focus of CKF with the care focus of MMCP, through a new program that would focus directly on access barriers.

The CKF-AI program goals as stated in the Foundation's Call for Proposals were very broadly defined: "Funding will enable grantees to (1) identify and document barriers to the use of health care services … and (2) develop and test strategies to improve access to needed health care services" for low-income children and/or adults enrolled in Medicaid or SCHIP. The choice of investigatory methods and interventions was left open, as long as grant activity was focused on *access* issues and "not used to increase enrollment into coverage programs." Consistent with the Foundation's non-profit tax status, the grant funds were not meant to support direct lobbying, litigation, or other political activity. Each primary grantee in CKF-AI received approximately $125,000 to be expended over 2 years.

During Phase I (approximately the first year of the CKF-AI program), grantees were expected to use their grassroots contacts to investigate and document access barriers being experienced by families already enrolled in Medicaid/SCHIP. Each grantee was then supposed to select no more than two specific problem areas as focal points, based on the Phase 1 research findings. In Phase II (approximately the second year of the funding period) they were to develop interventions to reduce access barriers in the areas they had chosen to work on, addressing the problem on the local level but also more systemically if possible. Their Phase II work was to be supported by a state-level organization or individual designated as a "state partner," who would receive a separate small grant ($20,000) from RWJF at the beginning of Phase II.

The CKF-AI program design contained three particularly notable features:

- ***It offered an opportunity to gain further experience with "rapid cycle improvement,"*** a problem-solving approach very familiar to both RWJF and CHCS, that has been used effectively in some previous RWJF initiatives. The premise of rapid-cycle improvement is that small-scale data gathering can indicate a fruitful direction for system change without the large time investment of more elaborate research, and that successive small-scale trials and assessments of an intervention strategy can be useful as a guide to change – perhaps more so than intensive planning of a large but untested program. The idea is related to the concept of "pilot program," but more systematic and explicit. On the plus side, the rapid-cycle approach is pragmatic, flexible, and well suited to finding and fixing system malfunctions within a short time frame, sometimes producing surprisingly large positive effects. Its limitation is that not all problems lend themselves well to the method. At the beginning of CKF-AI, it was unclear whether and how the rapid cycle improvement method could be applied to Medicaid access barriers.

- ***CKF-AI was an attempt at "bottom up" program planning.*** Instead of going to the CKF lead agency, the grants went to CKF local partners (community-based organizations affiliated with the CKF networks in their states), as "trusted community entities" that had direct experience and good rapport with the Medicaid population in their local areas. Prescriptive formulas for data-gathering and intervention were avoided, in hopes that these local-level grantees would develop successful strategies based on their intimate knowledge of site-specific circumstances. In addition to surfacing new insights and fresh perspectives on how Medicaid access barriers are being experienced at the grassroots level, this approach was expected to help clarify whether local organizations could make productive use of CKF-AI's combination of seed grants and technical assistance, and what kind and amount of technical assistance would be needed to help them succeed.

- ***A potential mechanism for linking local intervention with broader system change was built directly into the program design***, through the requirement for each local grantee to select a state partner (SP). In addition to direct technical assistance, the SP was expected to provide entrée to state-level policy making bodies and guidance on how to relate the grantee's locally based efforts to statewide policy. In some cases the SP represented the CKF lead agency in the local grantee's state; in other cases, the grantee selected a different organization or individual because of a need for specialized expertise. These partnerships were expected to be fruitful, but the exact ways the relationship would function could not be predicted at the start of CKF-AI.

CKF-AI's Growing Importance

In the two and a half years since CKF-AI was launched, its significance has taken on new dimensions. Understanding the nature of the Medicaid access problem has become more and more pivotal in policy debates, as governments at both the state and federal level increasingly try to contain Medicaid costs by reducing the use of services among those already enrolled. Many state governments are altering Medicaid benefits and tightening requirements in ways likely to increase access difficulty.[6] Even more dramatically, the recently passed federal Deficit Reduction Act of 2005 (DRA) explicitly aims to realize major savings through increased cost-sharing and other access restrictions likely to reduce service utilization by Medicaid families.[7] The Congressional Budget Office projects that under the DRA, "about 80% of the savings from higher cost-sharing [by Medicaid enrollees] would be due to decreased use of services."[8] The assumption apparently being made in such legislation is that easy access has encouraged unnecessary and expensive overuse of health care services, a problem that could be remedied without adverse health consequences by motivating Medicaid families to make more carefully considered health care choices.

In this context, the implications of CKF-AI go well beyond the immediate program itself in two respects:

- As documented in the present report, the grantees' grassroots-level research has revealed ***details about access barriers that appear to be <u>new information</u>*** for many health care professionals, state and local policy-makers, hospital administrators, directors of Medicaid managed care organizations, and other service providers. In some cases, this information alone has caused relevant decision-makers to rethink their assumptions about access and to cooperate with the CKF-AI grantees' barrier-reducing efforts. This kind of information about how access barriers are actually being experienced by children and families on Medicaid badly needs to gain broader visibility.

- Perhaps even more important, CKF-AI has generated a number of ***specific rapid-cycle interventions that show promise as "win/win" strategies for reducing Medicaid access barriers*, **gaining broad-based support from influential stakeholders who had not previously recognized that they might have common interests with Medicaid families seeking care. These interventions have considerable potential to serve as models that others could adopt or adapt.

Because the grant period was relatively short, outcome measures of CKF-AI's impact are just beginning to emerge. However, the initiative already has much to contribute to current policy debates concerning the Medicaid access problem's nature, its causes, its consequences, and some constructive strategies for solving it.

2. EVALUATION APPROACH

As of May 2005 when this evaluation started, CKF-AI was well into Phase II with 18 local grantees actively working on a variety of interventions in collaboration with their state partners. With site visits precluded by resource limitations, information was gathered through the following means:

- ***Review of program documents*** including RWJF program announcements; reports and analyses prepared by CHCS; and selected email exchanges between grantees and CHCS technical assistance staff and consultants.

- ***Analysis of written reports prepared by the grantees and state partners***, including 36 detailed interim reports to CHCS, 36 detailed final reports to CHCS, and all available final narrative reports submitted to RWJF.

- ***Individual telephone interviews with each of the 18 grantees and each of their state partners, plus a number of follow-up calls.*** While the process of scheduling these calls was complex, all of the grantees and SPs were eventually reached and interviewed, with no refusals (although one state partner could grant only a short interview by email, due to serious illness). Prior to each call, the interview respondent was sent by mail and email an explanation of the evaluation's purpose and intended use, along with assurances of confidentiality and a brief description of the evaluator's background. Interviews lasted approximately one hour, following a loosely structured interview guide. The fact that they were done by an independent evaluator and were not taped greatly increased respondents' comfort level and encouraged candid discussion. A detailed summary was prepared from notes immediately after each interview, averaging about 10 single-spaced typed pages for each initial interview and about five pages for follow-up calls.

- ***Meetings with CHCS leadership, staff, and consultants*** to discuss the program and the evaluation approach.

- ***Regular telephone and email discussions with CHCS staff and consultants*** concerning the overall program, the work of specific grantees, and details of the technical assistance process.

The original ending date for grantees' awards was August 31, 2005, but a majority of them requested and received no-cost extensions (in most cases, through December 31, 2005) in order to bring their Phase II work to fruition. This has pushed back submission of the present ***Final Evaluation Report*** to March 2006 so as to include the final reports submitted by grantees and state partners during January and February 2006. The Final Evaluation Report builds on an ***Interim Evaluation Report*** that was prepared shortly after all interviews with grantees and state partners were completed, and submitted to CHCS and the RWJF project director in September 2005.

Because CKF-AI was intentionally customized to fit site-specific circumstances, the grantees' data-gathering efforts and interventions took many different directions. Even in terms of descriptive evaluation, the initiative does not easily lend itself to analysis through a uniform template that assumes common goals. But despite non-comparability in the details of individual grantees' work, useful cross-cutting insights and ideas can be gleaned from what was attempted and accomplished by the group as a whole. The present report is meant to consolidate some of the general lessons learned, supplemented with site-by-site program descriptions in Appendix B.

3. THE CKF-AI GRANTEES AS A GROUP

As a context for "lessons learned," this section gives an overall picture of who the grantees were and what they did. Figure 1 lists the eighteen local organizations that participated as primary grantees throughout the CKF-AI program, along with their state partners. As Figure 2 shows, they were widely distributed geographically throughout the United States (although less well represented in the Midwest, Mountain States and Deep South).

The most striking thing about the grantees as a group is their extreme diversity. While all of them could be described as "trusted community entities," they otherwise ran the gamut.

- Some were well-established organizations accustomed to external funding and experienced in working toward post-grant sustainability for their projects. Others were small local agencies that had never before managed a grant and were very unsure of how to proceed.

- Some grantees were located in major urban centers like Houston and Philadelphia, while others were serving rural areas with low population density and a very thin service infrastructure.

- Some had seasoned project directors with professional expertise in fields such as hospital administration, education, health policy and social work. For them, collaborative problem-solving strategies were a comfortable fit. Others were led by project directors with backgrounds in protest movements and community organizing, who tended to be dubious of collaborative change strategies even though they understood and accepted that their grants were not meant to support direct political activism.

Grantees' policy environments varied widely as well.

- Some, but not all, were working in areas with very rapidly growing immigrant populations and major access problems related to language, literacy, and cultural differences.

- Some, but not all, were located in states that had just begun to make use of Medicaid managed care and were suffering enormous disruption and confusion as the new policies were introduced.

- Some, but not all, faced a wall of political resistance because concerns over escalating Medicaid costs made the whole idea of improving access unpalatable to state-level decision makers.

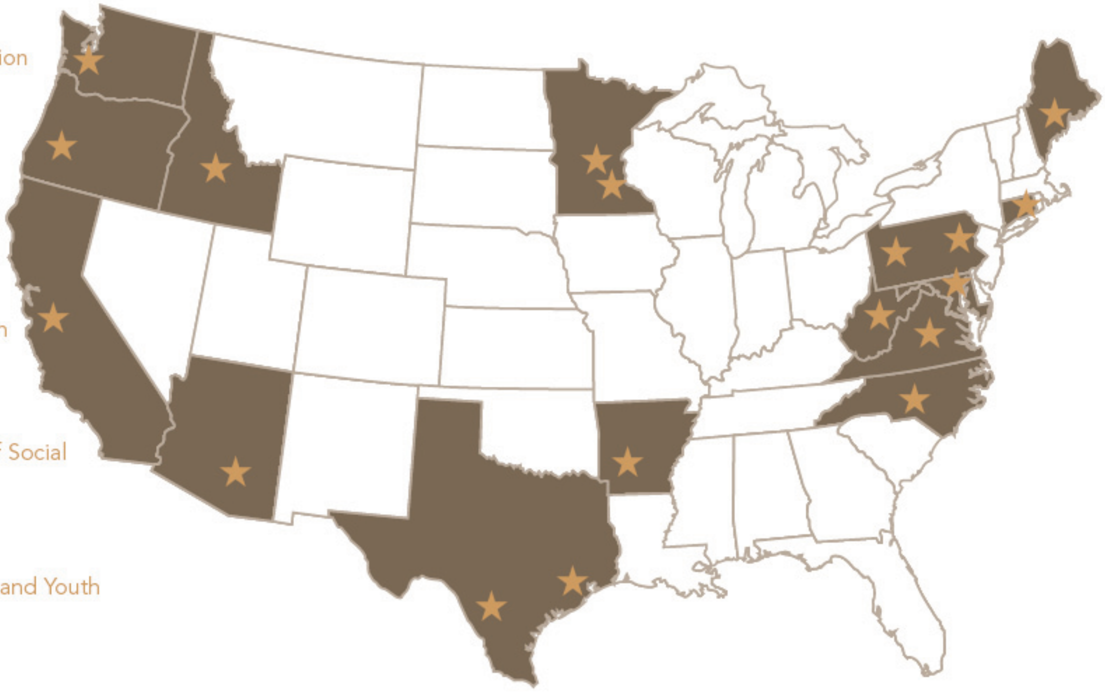
Figure 1: CKF-AI Grantees and Their State Partners

State and City	*Contact Persons and Grantee Organization*	*State Partner*
ARKANSAS Texarkana	Debbie Smart Our Children First Coalition	Rhonda Sanders Arkansas Advocates for Children and Families
CALIFORNIA Fresno	Sam Norman, Margarita Rocha Multicultural Community Alliance	Andrew Alvarado California Southern University at Fresno
CONNECTICUT Bridgeport and "East-of-the-River"	Barbara Edinberg Bridgeport Child Advocacy Coalition, East CT Health Network	Mary Alice Lee Connecticut Voices for Children, Inc
IDAHO Coeur d'Alene	Karen Cotton Kootenai Medical Center	Stephanie Powers University of Idaho, Coeur d'Alene
MAINE Bangor	Jennifer Brooks, Abby Densmore Penquis Community Action Prog, York Community Action Coalition	Joe Ditre Consumers for Affordable Healthcare Foundation
MARYLAND Baltimore	Pam Brown Baltimore HealthCare Access	Laurie Norris Public Justice Center, Inc.
MINNESOTA Rochester	Beth Arendt, Ginnie Westfall Olmsted County Health Care Access Initiative	Elaine Cunningham Children's Defense Fund of Minnesota
MINNESOTA Minneapolis	Patty Bowler, Gretchen Musicant Minneapolis Dept of Health and Family Support	Elaine Cunningham Children's Defense Fund of Minnesota
NORTH CAROLINA Asheville	Lisa Eby Buncombe County Dept of Social Services	Arelys Chevalier University of North Carolina at Greensboro
NEW MEXICO Albuquerque	Robin Hunn, Edwina Moya, Kathy Chavez Youth Development Inc.	Jeff Dye NM Hospitals and Health Systems Association
OREGON Portland	John Duke Outside In	Ellen Pinney Oregon Health Action Project
PENNSYLVANIA Philadelphia	Alisa Simon Philadelphia Citizens for Children and Youth	Mike Campbell Pennsylvania Health Law Project
PENNSYLVANIA Pittsburgh	Kate Robinson Consumer Health Coalition	Mike Campbell Pennsylvania Health Law Project
TEXAS Houston	Barbara Best Children's Defense Fund of Texas	Anne Dunkelberg Center for Public Policy Priorities
TEXAS Progresso	Gracie Camarena Migrant Health Promotion Inc.	Anne Dunkelberg Center for Public Policy Priorities
VIRGINIA Radford	Stan Stanczak Radford University Foundation	Jill Harken Virginia Poverty Law Center
WASHINGTON Olympia	Annett Brown CHOICE Regional Health Network	Julie Davidson HumanLinks Foundation
WEST VIRGINIA Charleston	Beverly Bolles United Way of Central West Virginia	Renate Pore West Virginia Council of Churches

Figure 2: Geographic Distribution of CKF-AI Sites

Covering Kids and Families Access Initiative Participants

AR - Our Children First Coalition
CA - Multicultural Community Alliance
CT - Bridgeport Child Advocacy Coalition and Eastern Connecticut Health Network/East of the River HUSKY Collaborative
ID - Kootenai Medical Center
MD - Baltimore HealthCare Access
ME - Penquis Community Action Program and York Community Action Coalition
MN - Minneapolis Department of Health and Family Support
MN - Olmsted County Community Services
NC - Buncombe County Department of Social Services
NM - Youth Development Incorporated
OR - Outside In
PA - Philadelphia Citizens for Children and Youth
PA - Consumer Health Coalition, Inc.
TX - Migrant Health Promotion
TX - Children's Defense Fund
VA - Radford University Foundation
WA - CHOICE Regional Health Network
WV - United Way of Central West Virginia



The issues that grantees addressed through their barrier-reducing interventions were similarly wide ranging. Some of the barriers they tackled proved a good fit with the assumptions, resources, and time frame of CKF-AI. Others did not. Grantees' intervention choices are discussed in detail with illustrative examples in Section 5, following Section 4's discussion of how they went about gathering data on access barriers as a basis for planning.

4. LESSONS FROM PHASE I: DOCUMENTING ACCESS BARRIERS

CKF-AI started with a diagnostic effort. Grantees were expected to collect data directly from Medicaid families in their local areas so as to learn what barriers these families were encountering. They were also encouraged, although not required, to learn more about access barriers as perceived by health care providers and administrators in their local area – pharmacists, physicians, community clinics, managed care directors, hospital emergency departments. Figure 3 summarizes the information sources and data-gathering methods used by the grantees in Phase I.

Three major lessons emerged from the grantees' diagnostic work.

- **Simple is Good:** ***When carried out by trusted community entities, small-scale qualitative research methods can work well in clarifying the access problems being experienced by Medicaid families.***

CHCS's technical assistance staff and consultants reported that one of the biggest challenges in Phase I was to steer grantees away from being overly academic in their data gathering approach. TA staff felt strongly that the purpose of the effort was not to document the magnitude and distribution of access barriers in the community, but rather to explore qualitatively the ways that families actually experience, interpret, and respond to access problems.

This was not an easy sell to the grantees, who tended to feel that small-scale qualitative research would be "unscientific." Some initially wanted to do elaborate community surveys, which would not have given them the in-depth qualitative insight and illustrative case material that could come out of simpler data gathering methods. A great deal of tact and finesse was needed to move them away from unrealistic or inappropriate research plans. In the end, however, the grantees generally understood and accepted that they should not be trying to gather the kind of data needed for an academic policy analysis. Instead, they should simply be trying to gain qualitative insight into a range of access problems as perceived by Medicaid families, as a basis for selecting one or two focal points to work on in Phase II.

Most of the grantees ultimately ended up using focus groups as their primary method for collecting information from Medicaid families. They tried to tap different aspects of the access problem by running multiple focus groups drawn from different neighborhoods and by conducting some of the focus groups in Spanish. Because their existing community networks gave them good rapport with Medicaid families, grantees generally found it easy to recruit focus group participants. Some of them felt a little unsure about how to actually run a focus group, and they said in retrospect that it would help to provide written guides (a good resource for this would be Kreuger's *Focus Groups*).[9]

Figure 3: Grantees' Data-Gathering Methods in Phase I

Grantees	***Result ratings****	***Information Sources and Methods Used***
CONNECTICUT	Excel	Families --- 9 focus groups in English/Spanish, 28 1-on-1 interviews. Providers -- 11 telephone interviews w pediatric offices; 4 in-person interviews pediatricians; 1 focus group w community-based providers; surveyed 12 pharmacists.
TEXAS (CDF)	Excel	Families --- 11 bilingual focus groups (112 participants); survey of 48 parents. Providers -- survey of 8 pediatric offices by computer/fax; 37 pharmacists surveyed (survey form hand-delivered/faxed back).
VIRGINIA	Excel	Families --- Mailed surveys, telephone followup (77 = 38% return) ; 4 group sessions through Job Readiness Program (23 participants). Providers -- Telephone survey of 200 physician offices & 40 dentists. Other ------ Analysis of 9,390 pediatric ER visit reports from 2003.
WASHINGTON	Excel	Families --- 4 focus groups in English/Spanish (52 participants); 18 in-depth interviews with Hispanic clients; accompanied 26 Spanish-speaking clients to provider visits and observed barriers. Providers -- Provider survey planned for Phase II, scaled back as focus shifted.
NORTH CAROLINA	Excel	Families --- Interviews with 62 parents from sample lists based on claims data. Other ------ 3 group interviews with key stakeholders & professionals; interviews with community leaders; community meetings
PENNSYLVANIA (PCCY)	Excel	Families --- Focus groups in English/Spanish; survey of 50 clients through Spanish-speaking community organizations. Providers – Informal discussions with providers at professional forum.
MINNESOTA (Minneapolis DHFS)	Excel	Families --- Chart review for representative sample (N=88) of DHFS's "new families"; 4 focus groups in clients' native languages. Providers -- Survey of 12 clinics used by DHFS clients.
WEST VIRGINIA	Excel	Families --- 101 in-depth interviews through Parents as Teachers program.
NEW MEXICO	Good	Families --- Focus groups (10 participants); community discussions; info on access barriers from clients being enrolled (average 110/month). Providers -- Meetings with coalition including MCOs; physician survey planned
MARYLAND	Good	Families --- 2 focus groups (8 participants); 6 bilingual individual interviews; 50 interviews with Hispanic women with newborns. Providers -- Discussions with hospital/clinic administrators.
MAINE	Good	Families --- Mailed survey (1,198 = 30% return rate); 64 1-on-1 interviews. Providers -- Mailed survey (247= 36% return rate).
CALIFORNIA	Good	Families --- 4 focus groups; 200 bilingual interviews with Hispanics, SE Asians. Providers -- Stakeholder meetings.
MINNESOTA (Olmsted Cty DSS)	Fair	Families --- Survey administered by bilingual interviewers to 220 Medicaid-enrolled recent immigrants; contacts at 14 community-wide events.
TEXAS (Migrant Hlth Prom)	Fair	Families --- 4 focus groups (51 participants); ~1000 contacts by *promotoras*. Providers -- Individual contact with 75 pediatric/family docs, dentists (planned roundtable discussions declined by providers due to no time).
IDAHO	Fair	Families --- Data from 61 Medicaid families (subgroup in a related survey); 2 focus groups with 16 participants, followup individual interviews.
OREGON	Fair	Families --- Staff interviews with homeless addicted youth in community settings. Providers -- Discussions with treatment center directors and staff.
ARKANSAS	Fair	Families --- Initially planned large survey, "downsized" to 96 interviews; 5 focus groups (not well attended, conflict with working hours). Providers -- 5 interviews with family & pediatric nurses/nurse practitioners.
PENNSYLVANIA (CHC)	Fair	Families --- Mailed surveys (278 =30% return); focus groups. Providers -- Survey of 106 providers in Healthy Beginnings Plus. Other ------ Legal review of managed care contracts & practices.

* **Excel** = excellent results, **Good** = good results, **Fair** = limited results. In all cases, lower scores indicate intractable problems, unexpected obstacles, or more time needed rather than a lack of grantee effort. Scores reflect only the results achieved or expected to date, and could improve as projects develop further over time.

A number of grantees followed up their focus groups with individual face-to-face interviews with Medicaid family members, allowing them to dig deeper into the access problems that were coming to light. These interviews were carried out not with elaborate probability samples, but rather with purposive samples or samples of convenience – an appropriate approach, given the effort's goal of qualitative insight.[10]

As data gathering progressed, it became clear that the focus group/individual interview approach was proving a very fruitful choice of method. Grantees found a number of surprises in the information being reported by Medicaid families:

- ***Access problems were sometimes quite different from what the grantees had expected to find.*** For example, one project director said, "Because of our rural location, we expected transportation to be a major problem, but it wasn't. People had ways of getting to where they needed to go. But prescription drugs were a huge problem, one that we hadn't known about. People were being given prescriptions, but they couldn't get them filled."

- ***Access problems were more complicated and multifaceted than had previously been appreciated***. For example, what looked initially like a language barrier for recent immigrants with limited English proficiency was actually a whole constellation of communication issues. Some newly arrived immigrants were not familiar with the concept of "symptom" or the use of thermometers to measure fever, so they could not easily answer the doctor's questions or understand medical advice even in their native language. Moreover, because physicians' offices did not always consider that cultures can have different conventions concerning last names, immigrants' medical records and paperwork were sometimes misfiled and lost.

- ***Access problems were often rooted in system malfunctions that were going unrecognized by policy makers and administrators, either because they were unaware of the problem or they thought it had been solved by existing formal requirements.*** For example, one grantee found that most pharmacists in her area did not know that their Medicaid managed care plan allowed them to give an emergency supply of prescription drugs without prior authorization and still get reimbursed. On weekends and after hours, when prior authorization was hard to obtain, this could mean the consumer would have to pay out of pocket or leave without the medication. The focus groups yielded heart-wrenching stories about the consequences of such problems – for example, parents unable to get prescribed asthma medication for children who were struggling to breathe. These stories had a strong impact when brought to the attention of policy makers.

- **Two Levels of Data are Better than One:** ***Researching the perspective of Medicaid providers as well as Medicaid consumers gives a fuller understanding of access problems and helps build cross-stakeholder coalitions.***

Some grantees carried out additional data-gathering with providers – physicians, managed care administrators, physicians' office staff, pharmacists, staff at community health clinics, hospital staff, etc. In terms of methodology, grantees found that focus groups were usually not feasible with health care professionals, who were too overloaded and short of time to participate. Mail-back surveys to providers did not work well either, although there was some success with ***short questionnaires that were hand-delivered and could be faxed back.*** The data-collection method that grantees usually fell back on for provider input (sometimes after attempts at more elaborate surveys failed) was ***individual face-to-face interviews*** with small numbers of health care professionals, kept very short and carried out in the person's place of employment so as to maximize convenience. While the grantees referred to such data gathering as a "survey," it was done with samples of convenience rather than the probability samples that the term "survey" usually implies.

While data-gathering from providers was difficult, it yielded very useful qualitative information. For example, in one state, pharmacists revealed that they had received no clear instructions on which prescription drugs were covered under different managed care plans and were extremely confused about what was allowed and reimbursable. Physicians in several states explained the great difficulty they had obtaining medical translators to help them communicate with non-English speaking patients. Important misunderstandings came to the surface; for example, physicians tended to blame missed appointments on patients' poor motivation, without considering that better medical transportation might help the problem. Physicians also explained the pressures they faced – for example, low Medicaid reimbursement rates – that led them to limit the number of Medicaid patients they would accept for treatment, intensifying the problem of provider shortage as an access barrier.

In addition to adding important new information, gathering data from health care providers strengthened the grantees' ability to build broad coalitions that included a wide range of stakeholders. By understanding the perspective of providers as well as consumers, some (although not all) grantees were able to gain the cooperation and active support of local medical societies, pharmacist associations, managed care plans, medical schools, community clinics, and hospitals. As we shall see in Section 5, creating broad coalitions of this sort was a key element in the success of the grantees that made the most progress.

- **TA Matters Greatly – But It Has To Be the Right Kind:** ***Intensive, individualized, site-specific technical assistance appears to be an essential ingredient in a "bottom-up" initiative like CKF-AI. To guide effectively without dampening the enthusiasm of local organizations, the technical assistance needs to be exceptionally sensitive and empathetic.***

The importance that CKF-AI grantees placed on the technical assistance (TA) they received from CHCS in Phase I can hardly be emphasized enough. Without exception, they said the customized individual support they received was indispensable and welcome, even when it occasionally involved disagreement and some level of stress. Grantees received help through ***group conference calls***, ***annual meetings***, but most of all through ***frequent individual telephone and email consultations*** with CHCS technical assistance staff and consultants. When requested to do so, CHCS staff and consultants also ***reviewed and gave individual feedback on various grantee products*** – research plans and instruments, consumer/provider educational materials, project publicity materials, and grantee reports and documents in draft form. CHCS provided ***specialized support on literacy issues*** by retaining a consultant with expertise in this area to give feedback when requested concerning the readability and language appropriateness of grantees' educational materials – a resource the grantees much appreciated.

Because CHCS's technical assistance was frequent, supportive and provided on an as-needed basis, it acquired the flavor of a collaborative working relationship, with a tone more like a friendship than an impersonal institutional resource. Grantees spoke glowingly of the CHCS technical assistance staff and consultants: "They were amazing." "We couldn't have done it without that guidance." "I knew I could always pick up the phone and call [my CHCS support person] with a question – that helped so much, because initially I felt very confused about how to approach this project."

This tone was important. Many of the grantees, being relatively inexperienced with external grants and somewhat awed by the Foundation's reputation, were nervous about "doing things right." Without the TA staff's warmth, empathy, and willingness to listen and brainstorm with individual grantees about site-specific questions in a freewheeling and interactive manner, grantees say they might have felt inclined to "lay low" and stay out of trouble. But because the TA was delivered in a sensitive way, grantees made heavy use of it on a number of different fronts, including:

- ***Traditional TA*** on the technical aspects of research and program development.
- ***Understanding and working within the initiative's boundaries*** – for example, keeping the emphasis on access rather than expansion of coverage, on Medicaid/SCHIP rather than on publicly funded health and safety net programs more generally, and on collaborative problem solving strategies rather than more political forms of advocacy.
- ***Choosing an appropriate state partner***. The majority of grantees needed little help with this. However, about a third of them found it difficult because they lacked pre-existing relationships to draw upon, and needed guidance to make a good choice.

- ***Selecting a productive focus for Phase II interventions***. This was one of the most challenging aspects of CKF-AI, and one where the quality of TA mattered most. In their Phase I data-gathering, grantees typically uncovered about six important access barriers. The grant required them to select no more than two as their focal points for Phase II interventions. CHCS staff and consultants worked extremely hard to help them make choices that would "get underneath" the access problems being reported by families and address deeper causes, while at the same time staying realistic about what could reasonably be accomplished within limited resources and a one-year time frame. Some grantees were determined ("hell-bent," as one put it sheepishly in retrospect) to work on interventions that had little chance of success within the grant constraints. CHCS staff and consultants had to exercise considerable diplomacy to guide them on different paths without killing their enthusiasm.

- ***Managing CKF-AI's political implications***. Because the grantees' work was intentionally steered toward systemic problem-solving where possible, it inherently had political implications that needed careful handling in both Phase I and Phase II. Some grantees requested advice on how to keep their contacts with state agencies and legislators in the realm of education rather than direct lobbying. Some requested advice on how to deal with the fact that other community organizations they were allied with were marching in protest and bringing lawsuits related to access barriers. A few wanted to engage in militant advocacy strategies themselves. These issues were understood to be sensitive ones that potentially could jeopardize the funding, so it is much to the credit of the CHCS staff and consultants that grantees felt they could raise such concerns for discussion rather than concealing them. Some grantees wished for additional TA related to mediation and negotiation skills (a good resource for this would be Fisher, Patton, and Ury's *Getting To Yes*).[11]

It is important to note that the CHCS team of staff and consultants included individuals whose professional expertise on Medicaid and public health policy was supplemented with ***extensive personal work experience at the state/local level***. Having "been there, done that" themselves, they understood from the inside the kinds of situations faced by CKF-AI's grantees, and could communicate easily, insightfully and credibly with them about community concerns and pressures, realistic strategies for change, and front-line program development issues. ***Without this fortunate combination of policy expertise and familiarity with grassroots realities based on personal work experience, the TA would not have been nearly as effective as it was.***

5. LESSONS FROM PHASE II: DEVELOPING INTERVENTIONS

In Phase II, the CKF-AI grantees shifted from data-gathering to designing and implementing their interventions, with the aim of reducing some of the access barriers they had identified in Phase I.

Type A, Type B, and Type C Barriers

The first challenge in Phase II was selecting an appropriate and realistic focus for intervention – not an easy task. Grantees' Phase I research typically uncovered access barriers occurring on very different levels. They fell roughly into three categories, termed here "Type A," "Type B," and "Type C" (resisting the temptation to call them the good, the bad, and the ugly).

- ***Type A barriers appeared to exist primarily because of unrecognized or neglected needs.*** They were "unintentional," in the sense that multiple stakeholders were at least potentially in agreement that the barrier should not exist, removing it would be in everyone's best interest, and removing it might even be cost-saving as well as beneficial for quality of care. Within these "win-win" areas of goal and interest convergence, a broad range of stakeholders (including professional/provider associations and managed care organizations as well as consumers and consumer advocates), could be expected to support the grantees' interventions – once all parties were convincingly informed about the problem and presented with a practical and affordable solution. Typical Type A barriers included:

    - ***Problems with getting drug prescriptions filled.***

    - ***Families making inappropriate use of emergency department services because they were not well equipped to use better alternatives.***

    - ***Language and literacy barriers due to shortages and poor organization of medical interpreter services.***

    - ***Problems with available medical transportation due to cultural insensitivity, unnecessary restrictions, and misuse of the transportation system by providers.***

    - ***Families needing greater "health literacy" on common illnesses and preventive care.***

    - ***Lack of understanding among consumers concerning Medicaid benefits and system navigation.***

    - ***Lack of understanding among health care providers and pharmacists concerning allowable benefits and/or access barriers faced by families.***

    - ***Enrolled families being unconnected with the health care system.***

- ***Type B barriers resulted from deliberate policy decisions, but might be open to change if approached carefully.*** To reduce Type B barriers, it would be necessary to persuade hospital administrators, directors of managed care organizations, school administrators, state agencies and/or state-level policy makers to cooperate with changes in their established way of doing things, through interventions that would not necessarily be cost saving in the short run. Typical Type B barriers included:

    - ***Certain barriers to care in managed care and hospital practices*** (for example, unrealistic policies on prior authorization for prescription drugs, that could be changed if managed care organizations were willing; barrier-creating emergency room and treatment policies that could be changed if hospitals and clinics were willing).

    - ***Certain barriers to care in state-level policies*** (for example, poorly drawn state contracts with providers of medical transportation, which potentially could be revised so as to reduce access barriers).

- ***Type C barriers occurred in "battleground areas" where the material interests of powerful stakeholders conflicted with each other, reflecting unresolved debates over national health care policy and resource allocation.*** While in many ways most central to the access problem, these barriers were also the most intractable. Interventions addressing Type C barriers were inherently long-term efforts, likely at any moment to spill over into political or legal action. Typical examples of Type C barriers included:

    - ***Shortages of health care facilities due to lack of resources.***

    - ***Inadequate provider capacity due to low reimbursement rates.***

    - ***Increased cost-sharing and exclusion of certain benefits so as to cut state Medicaid costs*** (for example, higher co-pays; caps on service utilization; no coverage for dental or mental health services).

    - ***Provider noncompliance with federally mandated standards of care*** (for example**,** failure to provide required EPSDT, vision, or pre-natal services; poor after-hours call-in services; no emergency prescription supply; no recognition of patients' right to have an interpreter).

To help with referencing the case-by-case descriptions in Appendix B, Figure 4 shows which grantees worked on which issues.

Figure 4: Access Barriers Addressed by CKF-AI Grantees in Phase II

	Result	Type A								Type B		Type C			
	Ratings*	1	2	3	4	5	6	7	8	9	10	11	12	13	14
CONNECTICUT Bridgeport CAC	Excel	X					x	x		X	x				
TEXAS ChildrensDefenseFund	Excel	X					x	x		x	x				#
VIRGINIA Radford University	Excel		X			x	x	x		x	x	x		#	#
WASHINGTON CHOICE RegHlthNet	Excel		X			X				x	x		#		
NORTH CAROLINA Buncombe County	Excel		x	X		X				x	X				#
PENNSYLVANIA PCCY	Excel			x	X		x			x	X				
MINNESOTA Minneapolis DHFS	Excel			X	x	#	X	x	X	x	X			#	
WEST VIRGINIA United Way	Excel		x			X							#		
NEW MEXICO Youth Devel Inc.	Good		x			X	x		x	x		X			
MARYLAND Baltimore Hlth Access	Good		x	x		X	x	x		x					
MAINE PenquisCAP/YorkCAC	Good	x					X	X			x				
CALIFORNIA Multicultural Alliance	Good	x			x		X	X	x	x		x			
MINNESOTA Olmsted County	Fair			x	x		X		x						
TEXAS MigrantHlthPromotion	Fair						X	x	x						
IDAHO Kootenai Med Center	Fair						X	#							
OREGON Outside In	Fair								X	x				x	
ARKANSAS Our Children First	Fair							x			X				x
PENNSYLVANIA Consumer Hlth Coalit	Fair										X				X

X = major focus **x** = supplemental focus # = explored but not selected

* **Excel** = excellent results, **Good** = good results, **Fair** = limited results. In all cases, lower scores indicate intractable problems, unexpected obstacles, or more time needed rather than a lack of grantee effort. Scores reflect only the results achieved or expected to date, and could improve as projects develop further over time.

Type A Barriers

1 = Prescriptions not getting filled at pharmacies
2 = People using ER instead of better alternatives
3 = Language and literacy barriers
4 = Medical transportation barriers
5 = Families need greater "health literacy" on common illnesses and preventive care
6 = Consumer ed needed on system navigation
7 = Provider ed needed on benefits or barriers
8 = People officially enrolled but not connected with the health care system

Type B Barriers

9 = Unintended MCO/hospital/provider barriers
10 = Unintended state policy barriers

Type C Barriers

11 = Inadequate hospital, clinic, or pharmacy facilities
12 = Inadequate provider capacity
13 = Intentional access barriers (cost-sharing, caps on use, exclusion of specific benefits such as dental care)
14 = Provider noncompliance with mandated standards of of care (EPSDT, pre-natal, vision care, on-call 24/7, emergency Rx supply)

On a conceptual level, the typology above parallels some models of social change commonly used in professional training for advocacy practice.[12] Two particularly relevant models, old but still applicable, are:

- Jack Rothman's three types of community organizing:
    - "***Locality Development***" for high-consensus but neglected issues that can be solved by mobilizing slack resources through broad coalitions.
    - "***Social Planning***" for issues where enough consensus and resources exist to enable professional experts to develop top-down solutions within the service delivery system.
    - "***Social Action***" for issues where major interests conflict, resources are scarce and very little goal consensus exists, making political and legal pressure the preferred tactics for change agents.
- Roland Warren's three styles of advocacy:
    - "***Collaborative***" strategies through coalition building and problem-solving, appropriate for issues with high goal consensus and adequate resources.
    - "***Campaign***" strategies such as lobbying and planning, for issues where resources are in principle adequate but decision-makers need to be persuaded.
    - "***Contest***" strategies such as picketing and lawsuits, for issues where solving a problem implies significant reconfiguring of power and money, and major stakeholders oppose the change.

In both conceptual models, the three categories roughly correspond to the Type A, Type B, and Type C access barriers described above.

Grantees' Choice of Intervention Focus

Under the CKF-AI funding guidelines grantees were expected to focus on no more than two barriers in Phase II, addressing problems that were serious enough to make solving them important and at the same time "fixable" to some degree within the resources and one-year time frame remaining in Year Two of the grant. In addition, grantees were expected to design interventions that matched well with the change strategies emphasized or implied in RWJF's program concept – for example, using rapid cycle improvement methods, collaborating with an expert state partner, building on pre-existing CKF coalitions, and avoiding direct involvement in political activism.

These constraints led away from "Type C" issues, including one access barrier that many grantees identified as particularly serious and urgent: insufficient provider capacity, especially a shortage of specialists. Despite its clear importance, provider capacity was felt by CHCS (and most of the more experienced grantees) to be beyond the reach of this particular initiative. Grantees were strongly encouraged to make pragmatic choices that would have a realistic chance of making some headway within a fairly short time frame, using the resources and opportunities actually available.

Most of the grantees heeded this advice, after much brainstorming and discussion with the CHCS technical assistance staff and state partners. ***Their choices concentrated on Type A and Type B barriers*** whose solution could realistically become the basis for collaborative intervention efforts aimed at near-term results. Several project directors were still determined to try addressing Type C problems, but ended up changing their intervention focus to a Type A or Type B barrier part-way through Phase II after realizing they had underestimated the time, resources, and political complexity involved in addressing a Type C problem.

The fact that Type C problems did not fit well with CKF-AI does not mean that the Type A and Type B barriers the grantees chose to work on were easy, trivial, or unimportant. On the contrary, preventable Type A and Type B barriers are extremely challenging and affect hundreds of thousands – possibly millions – of children and families on Medicaid, blocking access just as completely as do Type C barriers. Moreover, Type A and Type B barriers appear to be especially problematic among extremely vulnerable Medicaid populations, those with the least resources and preparation for dealing with illness and negotiating the health care system. Type A and Type B barriers also appear likely to need continuing attention even if Type C problems are solved on a national level. As one grantee put it,

> *In any Medicaid population, there are many families – let's say 50% – who will do fine simply with written information on how to access care. There are another, say, 30% who need a little more than that – some special supports. Then there are the others, the last 20%, who just won't be able to get health care for themselves and their children for a variety of reasons, unless there's continuous hard work to reduce the access barriers they face. It's kind of like an inverted pyramid. A big top layer may do OK, but those at the middle and especially the bottom will always need help. Without help, they'll always suffer if confronted with barriers to access. And they'll always be there, no matter what kind of health care system we have.*

Some Examples of CKF-AI Interventions

While Appendix B's case-by-case descriptions are the best way to understand the grantees' work in context, a few brief examples here may help give a flavor of what was attempted and accomplished.

- ***Reducing Language Barriers***

The North Carolina grantees found that ***hospital emergency departments and the county health clinic were the only places where families with limited English proficiency could reliably get medical interpreter services 24/7.*** To address this problem, they recruited and trained a group of Spanish-language medical interpreters, following a rigorous curriculum developed by a university-based expert in medical translation who served as the project's state partner. These interpreters were used to provide translation services through the community's four urgent care centers, which previously had lacked any interpreter services, thus reducing access barriers and at the same time lightening the burden on overcrowded emergency departments. As CKF-AI reached the end of its funding period, the interpreter bank had grown into an organized medical interpreter network providing service in several languages. The program has helped bring the need for more medical interpreters to the attention of policy makers. It has strong support from providers and is organized on a business model that gives it a chance for long-term sustainability. The NC grantees are encouraging its replication in nearby counties and have begun to make progress on the level of state policy as well through ongoing efforts to gain Medicaid reimbursement for medical interpreters and establish statewide certification standards. Preliminary data suggest the program has already helped limited-English-proficiency families on Medicaid use the health care system in ways that are more beneficial to health and also cost-saving for the state. Longer-term evaluation would put some firmer data behind this conclusion.

- ***Improving Prescription Drug Access***

Several grantees focused on barriers related to prescription drugs. For example, in Texas, CDF's Phase I research showed that ***providers and pharmacists were unclear about the state's new preferred drug list and prior authorization policies, and were getting insufficient guidance in implementing a 72-hour emergency supply policy***. As a result, Medicaid families had problems getting prescriptions filled, sometimes going without needed drugs or having to go to the emergency room to obtain medications. The state's annual cap on Medicaid co-pays for prescription drugs was not being recognized or honored by pharmacists because they were unaware of it. In addition, families were being given incorrect and disadvantaging information regarding Medicaid vision services. ***To address these barriers, the Texas grantees decided to focus their Phase II intervention on educating pharmacists, providers, and consumers about what was allowable and reimbursable.*** They were able to organize broad, multi-stakeholder coalitions around the effort, enlisting support from city and state medical and pharmacists' associations, the state's largest children's health plan, existing state-wide CHIP advocacy coalitions, and the University of Texas School of Public Health. The result has been a series of heavily attended continuing-education workshops for pharmacists and providers; a large "town hall meeting" to inform staff of managed care health plans; and widely distributed consumer educational materials in both English and Spanish. CKF-AI findings are being highlighted at state conferences, in professional newsletters, in manuals for Medicaid health plans, and in a Health and Human Services Commission subcommittee newly created to monitor access barriers in the Houston area. Feedback so far from providers, pharmacists, and consumers has been extremely positive and the program's impact appears to be spreading well beyond the local area.

In Connecticut, the prescription drug problem was similar – i.e., ***both pharmacists and consumers were confused about the differing formularies and emergency-supply policies of the state's four Medicaid managed care plans.*** As a result, Medicaid families often had difficulty getting their prescriptions filled. ***Working with a capacity-building model, the Connecticut grantees developed a multi-faceted program of provider/consumer education.*** They developed and widely distributed a flyer for parents with advice on navigating the benefit system; a fact sheet for pharmacists clearly outlining steps to take in each of the four managed care plan; and a "provider toolkit." Policies kept changing even as these materials were being written, but they still represented a giant step toward clarity and have been welcomed by consumers, providers, and pharmacists in the project's local area. A notable feature of this project is its already apparent state-wide impact. It came to light that one of the four Medicaid managed care plans had a "best practice" regarding prior authorization – i.e., to automatically override all first-time denials so that a Medicaid family could have a 30-day supply of prescribed drugs while the insurance details were resolved, instead of going without. The health advantages of this procedure were so compelling that the state's Department of Social Services directed two of the other MCOs to adopt it, and the state's fourth MCO is in the process of adopting it voluntarily. Barrier-reducing effects, while not yet assessed, seem likely to be significant. The same holds true for two additional aspects of the project that are currently underway**:** electronic alerts and reminders flashed on the computer screen whenever pharmacists submit a Medicaid prescription drug claim, and five specific changes recommended for the state's managed care contract language when the contract is next renewed.

- ***Improving Access through Health Literacy and Community Health Workers***

Especially in rural areas and areas with rapidly growing immigrant populations, many grantees found that ***large numbers of Medicaid families were completely out of touch with the non-emergency health care system,*** and were relying on emergency services in ways that were neither good for their health nor fiscally wise for the state. Some specific problems included:

  - ***Covered families lacked a medical home and were unsure of how to use their Medicaid benefits for primary health care.*** They turned to emergency rooms as the only way they knew to manage illnesses, even minor ones – thus in some cases unnecessarily risking further disease exposure, the stress of long waiting times at the ER, and ER treatment not well suited to their needs.

- ***Parents did not know how to assess the seriousness of common childhood illnesses and were unfamiliar with common symptoms and diagnostic tools such as thermometers.*** They lacked confidence in distinguishing true health emergencies from minor childhood illnesses that could be managed at home or through a primary healthcare provider – so everything went to the ER.

- ***Non-emergency services were closed on weekends and after hours, and doctors' answering machines were directing callers to use the emergency room "if the need was urgent."*** Without being able to make that determination, parents took children with non-emergency illnesses to the ER just to be on the safe side.

To address such problems, ***grantees in a number of states developed health literacy and community health worker (CHW) programs based on the "promatora" (lay health promoters) outreach model***. Their outreach efforts included culturally comfortable one-on-one counseling that went beyond passive consumer education based solely on written materials. While some grantees' CHW programs were more successful than others, all of these interventions had learning value, as shown in these examples:

Because their CKF-AI local site was flooded with new immigrants, ***the Minnesota (Olmsted County) grantees developed a culturally sensitive multi-lingual community health worker program to provide outreach to Somali, Sudanese, Cambodian, Hmong, Bosnian, and Latino families.*** Families were counseled in their homes or at a community drop-in center and were helped with choosing a healthcare plan/provider, understanding insurance coverage, medical bills and co-payments, and communication issues. Subsequent assessment through random telephone calls revealed that almost all clients who were counseled felt they had a better understanding of issues that had previously baffled them. However, the program proved unexpectedly hard to manage due to difficulties in recruiting and training effective outreach workers for some of the ethnicities involved. While not an outstanding "success story," this grantee's project showed that outreach is desperately needed for new immigrants, and it yielded important insights into the daunting challenges of setting up a multi-ethnic CWH program.

In rural West Virginia, non-emergency health services had limited hours of availability, leaving families with no option but the ER on weekends and evenings. Deciding that direct work on this "Type C" access barrier went beyond the resources of CKF-AI, ***the West Virginia grantees decided to focus on empowering Medicaid families to better assess and home-treat their children's minor illnesses (and also to recognize those illnesses that genuinely needed emergency care).*** Building on an existing "Parents as Teachers" program, they developed a community health worker program of outreach to families in their homes, distributing and explaining a very reader-friendly book entitled "What To Do When Your Child is Sick." This book, developed by two nurses in California and brought to the attention of the West Virginia grantees by their state partner, has been extremely well received by Medicaid families, who are actively using it and sharing it with friends and neighbors. It has also been shared within the CKF-AI grantee group, and has great potential for further spread as a useful consumer education tool. Self-reported data from parents show an increase in confidence, decrease in ER use, increase in well-child care, and a decline in days of work missed due to children's illness.

In North Carolina, the grantees developed a health literacy program using materials and counseling in both Spanish and English to help build Medicaid families' knowledge and confidence concerning childhood illnesses. They developed, pre-tested, and widely distributed a packet of materials containing a thermometer, a laminated checklist of common symptoms, information on how to interpret levels of fever, etc. Through home visits, community health nurses from the grantee's county health clinic demonstrated the use of the thermometer and encouraged posting the laminated checklist on the refrigerator door where it would not get lost. Interviews before and after the intervention showed an increase in parents' confidence about managing children's minor illnesses at home, as well as an increase in their ability to recognize true emergencies (in one case, a parent followed the guidelines and sought emergency help for her child when she otherwise might not have, for what turned out to be a ruptured appendix). Providers note that the program has equipped parents to describe and respond to children's symptoms and fevers in much more detail (e.g., checking a specific temperature against a fever chart, not just knowing that "my child is hot"). For this reason, providers have supported the program enthusiastically and have joined in the search for additional funding to keep it going. The program materials seem like promising tools for spread. Meanwhile, before-and-after comparison of Medicaid claims data shows a modest but encouraging decrease in inappropriate use of the emergency department – something that begs for further assessment.

- ***Improving Medical Transportation***

While most grantees found medical transportation to be less of a problem than expected, the issue still loomed large for some – particularly where ***the local area had enclaves of limited-English-proficiency (LEP) Medicaid families for whom existing medical transportation services were not working well for language and cultural reasons***. For example, in Pennsylvania, the Medical Assistance Transportation Program (MATP) had many deficiencies in terms of serving the local Latino population – no Spanish-speaking schedulers; a policy that prohibited parents from bringing their well children with them when they used the service to transport a sick child to the doctor's office; unnecessarily cumbersome procedures for applying for the service and purchasing tokens; inadequate interfacing with the public transportation system; and insensitivity to consumer satisfaction and cultural concerns. In addition to local activities aimed at consumer education and reducing language barriers, ***the Pennsylvania grantees (PCCY) took advantage of the fact that the state contract for MATP was due for renewal, and were able to make a number of far-reaching policy changes.*** Based on their Phase I research and with the help of their state partner, they secured a role in assisting the Pennsylvania Department of Public Welfare to develop the RFP for a new medical transportation contract. They also secured a position on the consumer RFP committee that reviewed the competitive bids. Once the new medical transportation provider was selected, they worked with the new contractor to make a number of changes that should result in both increased ridership and lower costs – a classic win-win situation. Documenting these anticipated positive outcomes as the policy changes go into effect needs a longer time frame.

- ***Rethinking Emergency Room Services***

Two grantees found that ***the way emergency services were structured was itself creating barriers to appropriate care.*** For example, the problem in Virginia was a gap in service facilities – too few urgent care centers. By fortunate accident, the CKF-AI grant was directed by an individual with many years of experience as a health care administrator. His project included a variety of local consumer education and support activities, but in addition, his sophisticated understanding of the health care delivery system allowed him to ***negotiate with the major hospital in the area to establish a new urgent care center across the street from the hospital's ER,*** making appropriate triage easier for all parties. When patients come to the ER with non-emergency problems, they will be able to cross the street and get care better suited to their needs with less waiting time. At the same time, the Medicaid system will realize cost savings.

In Washington state, the grantees decided to focus on ER practices after their initial focus (on provider capacity – a Type C problem) collapsed due to tougher-than-anticipated obstacles. They "pulled a rabbit out of the hat" in a surprisingly short time by working on a specific ER problem: ***better service for Medicaid patients who use the ER very frequently, several times a month, for non-emergency health complaints that typically include chronic pain.*** Frequent users represent a fairly small number of individuals, but they contribute heavily to ER costs and their health needs may be inadequately met once they get labeled as "over-users." Working collaboratively with health care providers and hospital staff, the CKF-AI grantees set up professional teams to identify a group of frequent ER users, look more deeply into their health complaints, and develop more satisfactory treatment supports for their chronic pain problems. Again, the result was both better care and cost savings. The grantee's analysis of the first four patients in this program (all that their time frame would allow) showed the ER visit rate dropped by 50%, from an average of 34 in the year prior to the intervention to 17 in the year following it. Patient satisfaction with care improved, as did health outcomes, and the hospital saved an average of $15,203 per client per year. This small pilot project, with 57 participants so far, seems to have strong potential for scaling up.

What Made a Program Successful?

More time needs to pass before the impact of the grantees' work can be fully assessed, since most of their interventions have started very recently. However, at the end of the CKF-AI funding period it was already apparent that, in terms of getting promising programs up and running, results were mixed. Grantees fell roughly into a bell-shaped curve with some spectacular successes, some that achieved fairly limited results despite great effort, and the remaining grantees located somewhere in the middle. ***While they focused on a variety of different access barriers, the more successful projects seem to have five characteristics in common:***

- **Pragmatic choice of program focus**. Successful grantees typically targeted Type A and Type B barriers, took advantage of some specific "open policy window"[13] in their state or locality, and chose an intervention focus that was consistent with the project staff's idiosyncratic strengths and expertise. They showed what might be called ***"constructive opportunism,"*** matching their intervention focus to their perceived opportunities and choosing mid-range interventions where they could realistically expect to make a difference. As one grantee put it, "If you turn over a rock and find an access problem you can do something about, that's enough to go on."

- **Reliance on collaborative strategies that emphasized convergent interests.** Successful grantees typically formed advisory boards made up of diverse stakeholders including both providers and consumers (or consumer representatives) who met regularly to discuss access problems. In these meetings, all parties looked hard for "win-win" solutions. This did not necessarily mean avoiding difficult discussions, but when issues arose that could have turned confrontational, the successful grantees found creative ways of redefining them in terms of mutual benefit. Two areas in particular – ***getting prescriptions filled*** and ***appropriate use of emergency services*** – seemed well suited to being defined as "win-win," in that many different but overlapping agendas could be served by solving problems in these areas. Successful grantees were able to gain broad support for other access concerns – for example, consumer/provider education on system navigation, improved medical transportation, community health education, and improved medical translation services – by linking them to these two central themes.

- **Targeting Both Providers and Consumers**. Successful grantees typically designed their interventions to affect the resources and behavior of health care providers as well as Medicaid families. For example, consumer education on the differences between various health plans' drug coverage was matched with a laminated one-page form that pharmacists could post next to their computers for easy reference. Development of medical translation services for limited-English-proficiency families was matched with training of (initially resistant) urgent care clinic staff on how to use the service effectively. A community health worker outreach program helping families understand how to answer doctors' questions about symptoms was matched with a continuing medical education course for physicians on how to ask Medicaid caregivers about things that only they could know, such as changes in their children's normal behavior.

- **Ability to "humanize" the access problem**. Successful grantees got enormous mileage from the vivid stories that came out of their focus groups, and made active, frequent use of Medicaid families' personal accounts. In one meeting, the administrators of five managed care plans were reportedly almost in tears over reports from the field, saying "We had no idea this was happening." It was apparently one thing to know abstractly that access barriers exist, and another thing entirely to hear that last Tuesday Mrs. Gonzales was unable to get the medicine prescribed for her son's ear infection, leaving him screaming in pain all night. Real accounts of real families having access problems seem to cut through a lot of denial and resistance. In this project, one of the MCO administrators said to the CKF-AI state partner, "If this ever happens again, here's my number, call me at home even if it's late." She did call, repeatedly, and eventually at least some of the MCOs became eager supporters of policy changes to reduce access barriers related to prescription drugs. Grantees found "real stories" to be so effective that some of them produced written materials illustrating what access barriers can mean to children and families on Medicaid -- for example, a booklet called "Conversations with Real People" which reportedly opened the eyes of many decision-makers in Maine. A more detailed "Toolkit for Reducing Medicaid Access Barriers" is posted at www.chcs.org.

- **An enthusiastic program champion**. The more successful projects all seemed to have some one person who took ownership of the project and was ready to "eat, breathe, and live it," putting in weekends and evenings out of sheer commitment. In most cases the champion was the project director, but not necessarily. In some cases the role was played by the state partner, and sometimes by a consultant hired through the grant who functioned as the de facto project director or state partner. Once a primary champion was in place, "secondary champions" sometimes emerged in the form of highly committed volunteers, student interns, or organizational partners not funded through this grant. It was important for the CHCS staff and consultants to recognize and work with not only the project's official leaders, but also the actual program champions, whoever they might be.

Linking Local Programs with Broader System Change

CKF-AI's program concept called for using local interventions as a basis for promoting broader changes – in effect, creating pilot programs that would be replicated elsewhere or that would stimulate state-level policy changes. While this goal was very ambitious for the short time frame of the grant, it did begin to happen in some cases. As the funding period ended, some grantees were seeing interest from nearby localities for developing similar local programs. Some could already point to policy-level changes that held promise for broad impact, such as new procedures for state-wide Medicaid managed care plans and new barrier-reducing provisions in state contracts for service providers. Of course, it is not certain that formal policy changes will result in actual reduction of access barriers in the field, so further monitoring seems indicated in order to evaluate the system-change effects over time.

Two things seemed to strengthen the potential for local interventions to move beyond the local level toward system-level change:

- **A well-positioned state partner**. The pairing of local organizations and state partners – somewhat of an unknown at the start of CKF-AI – turned out to be an excellent idea, as long as the state partner was well-chosen. In about a third of the sites, state partners were chosen for specialized expertise and did not have much to contribute to system change, but in the remaining sites the results were sometimes spectacular. The partnership worked best when the SP already had good working relationships with state policy makers, and could help the local project director gain entrée to high-level meetings and forums. State partners were also able to alert local project directors to the history and current dynamics of state policies related to their intervention focus, and help them obtain relevant state documents and reports that they otherwise might not have known about. It is important to recognize that while the SPs helped the local grantees a great deal, this linkage was a two-way street. From the relationship, the state partners gained a wealth of grassroots case examples of the suffering caused by access barriers, which they were able to use to very good effect as ammunition in their own state-level advocacy work.

- **A strong pre-existing CKF network or its equivalent**. Both the local grantees and their state partners say that a strong pre-existing base of organizational networks and relationships – such as has been developed in many states through CKF – was important to making CKF-AI work as planned. Where pre-existing organizational networks were weaker and/or the state political climate was particularly resistant, the CKF-AI efforts necessarily went first into building organizational infrastructure as a preliminary step, which delayed direct work on interventions to reduce access barriers. In effect, grantees in this latter situation got a late start, and reached the level of readiness needed for systemic change efforts at about the time the grant period was ending – if indeed they reached it at all. By contrast, the grantees in states with strong CKF networks were ready to move on both the local level and on broader system changes throughout Phase II or even earlier.

Sustainability and Spread

One of the most intriguing features of CKF-AI is that – at least for some of the grantees – the local programs and system changes that the initiative has produced have potential to continue after the end of the funding period. Although long-term sustainability is by no means assured, the program champions mentioned above are working hard to keep their access-improvement efforts alive.

Some of CKF-AI's local project directors are now officially included in state-level planning bodies and professional gatherings that give them a permanent, ongoing voice in policies relevant to Medicaid access. In addition, most grantees are actively working on long-term development plans, and about a third have already secured resources to keep some aspects of their programs going. Sources of continuing funding and/or collaborative support include:

- Foundations other than RWJF
- State agencies
- Federal agencies
- Managed care organizations
- Hospitals and clinics
- Medical and pharmacy associations
- Graduate professional schools
- WIC programs
- School systems
- Self-financing programs built on a business model

It is too early to know how successful the grantees' post-CKF-AI efforts will ultimately prove, especially in light of the severe state budget pressures that can be expected as Medicaid cuts in the federal Deficit Reduction Act of 2005 go into effect. But the situation certainly bears watching.

The same applies to the issue of spread. If the access-improvement strategies developed by some of these grantees do indeed become institutionalized and self-sustaining, there would be great value in facilitating their adoption in other states and localities. Some of the CKF-AI grantees have already begun to contact each other independently of RWJF and CHCS, sharing ideas and providing ongoing technical assistance among themselves. It seems likely that they would willingly play a role in helping to spread their CKF-AI experience. As mentioned above, the "Toolkit for Reducing Medicaid Access Barriers" potentially could be a very useful resource for spread.

6. IMPLICATIONS FOR PROGRAM MANAGEMENT AND GRANTMAKING

Because CKF-AI seems to have yielded remarkably fruitful results for a relatively small initiative, it seems worthwhile to spell out some of the implications for future program management and grantmaking.

Reality Checks and Confirmations:

One important evaluation conclusion is that key assumptions in CKF-AI's program concept held up well in the field. Specifically:

- **The combination of seed grants and technical assistance to local community organizations worked well, as had been hoped.** With these resources, most of the grantees were successful in gathering useful data and at least getting started on promising interventions. Where the interventions have been in place for more than a few months, preliminary outcome data (in some cases quantitative as well as qualitative) are starting to come in. While still very sketchy, these data indicate positive impacts on:

    - Connecting underserved Medicaid families with a "medical home."
    - Lightening the burden (on both providers and consumers) of inappropriate emergency room use.
    - Improving Medicaid families' confidence and skills for making good health care choices.
    - Improving Medicaid families' ability to navigate the health care system.
    - Increasing Medicaid families' use of preventive well-child services.
    - Improving pharmacists' ability and willingness to fill covered prescriptions.
    - Increasing providers' and policy makers' awareness concerning Medicaid access barriers.
    - Increasing appropriate use of medical transportation.
    - Improving the capacity and quality of medical translation services.

- **Rapid-cycle improvement methods worked well, within limits**. Rapid-cycle methods were not very applicable to conflict-ridden Type C access barriers such as shortages in provider capacity, lack of facilities, intentional benefit cuts in order to control state costs, and deliberate provider non-compliance with mandated service requirements. However, they worked well for Type A and Type B access barriers where the problem fell into an area of interest convergence and a win-win solution could be negotiated. While Type A and Type B barriers might be considered the "low-hanging fruit" of access improvement efforts, they affect large numbers of children and families on Medicaid and prevent them from getting needed care just as surely as Type C barriers do. Reducing them is a practical, realistic way to make a near-term dent in the very large, very complex problem of medical access for low-income families.

- **Linking local organizations with state partners proved to be mutually beneficial.** At the start of CKF-AI, it was unclear whether this kind of partnership would in fact help community-based organizations connect their local programs to broader system change. For a majority of the grantees, it clearly did. The state partners also gained from the linkage, since they could make use of vivid case examples from the local community to strengthen their own credibility in broader policy efforts. Interestingly, the relationship between local organizations and state partners proved resilient enough to continue working despite some personnel substitutions due to illness or job change on one side or the other. There was sometimes strain related to substitutions, but not breakdown. Since personnel turnover due to illness and life events is fairly inevitable in a multi-year grant, it is important to note that CKF-AI's program design was not fragile.

Some Cautions

Two aspects of the program design proved problematic, suggesting a need for fine tuning. Specifically:

- **Customized, site-specific technical assistance was essential for grantee success, but providing it proved much more labor intensive than anticipated.** Much to its credit, CHCS rose to the occasion and grantees were unfailingly given the support they needed. However, it seems apparent to this outside observer that a great deal of extra time and effort was in effect donated by CHCS's highly committed staff and consultants. Particularly in Phase II, where CHCS's technical assistance was planned to taper off, the grantees felt a continuing need for it and could have used even more than they received. As a lesson learned, future initiatives involving seed grants and TA to local organizations would do well to budget very generously for individualized TA and related administrative costs.

- **The two-year funding period was too short**. The initiative's structure allowed only one year (Phase II) for grantees to design their interventions, implement them, and begin assessing results. Most of the grantees found this compressed time frame unworkable – particularly if their interventions required time-consuming up-front work such as building coalitions, setting up advisory boards, securing permissions and information from state agencies, etc. In addition, the timing of Phase II (starting in spring of 2005) was awkward for many. State legislatures typically meet in the spring, and for several months during the legislative session the staff of state agencies become unavailable for meetings or non-urgent work. For all these reasons, many of the CKF-AI grantees were just beginning to roll out their interventions in June and July of 2005, with a September end date looming on their grants. Most of them requested and received no-cost extensions for an additional 3 months or so in order to get their interventions off the ground, but they knew they would not be in a position to report on outcomes even with the extensions. Without exception, the eighteen grantees say that a three-year time frame, allowing two years for implementation and assessment, would have been more realistic and more productive.

Pleasant Surprises

Some unexpected positive lessons emerged, with implications for future program management and grantmaking. Specifically:

- **The initiative's flexibility was a major plus.** With so much internal variation, a program like CKF-AI could be seen as being all over the map, too messy and vaguely defined to be useful. However, while the diversity does prevent easy comparison of grantees' results, it has an important positive side. CKF-AI's flexibility has made the program unusually productive as a laboratory for generating ideas and exploring creative change strategies, customizing a funding initiative to fit site-specific circumstances, and experimenting with novel solutions to the problem of access barriers. Exactly because of its internal variation, this initiative may have promoted "outside the box" thinking better than a heavily pre-structured one would have.

- **"Bottom-up" program planning involving community organizations brought fresh perspectives to the surface and unleashed extraordinary levels of energy.** The local grantees' daily contact and rapport with the client population gave them useful insights and ideas that were new to providers, and sometimes new even to very sophisticated CKF lead agencies working on the policy level. The local grantees approached the project with extreme enthusiasm, since they had for a long time been "dying to work directly on access barriers." They put their hearts and souls (and evenings and weekends) into their CKF-AI work. They were also very creative in trying to plan ahead for sustainability. While working with these local organizations was sometimes challenging, it appears to have tapped a huge reservoir of commitment and positive energy.

- **Information coming directly from the grassroots level was a powerful tool for system change**. In the projects that worked through collaborative strategies, even the CKF-AI project directors and state partners were sometime surprised at the way providers, administrators, and policy makers reacted to "real stories" from the field. "Their hearts just melt," one project director exclaimed. After hearing about the human impact of access barriers, it became more difficult for those with decision-making power to ignore the problem and more appealing to help solve it through procedural and policy changes. This reaction fits a well-known psychological process of people reacting differently to a problem in the abstract (say, one in five children living in poverty) than they do to an individualized case example (little Mary on Maple Street living in poverty). Politicians, knowing this process, often use anecdotes rather than "dry" statistics to make an argument. CKF-AI demonstrated that, in the context of improving Medicaid access, case material from the grassroots can be extremely useful for promoting change at the system level.

- **In attacking a complex social problem, momentum and continuity were major resources**. The CKF-AI grantees could hardly stress enough how important they felt it was to have many years of prior CKF effort standing behind their present efforts. Without the groundwork and organizational networks already created through CK and CKF in their respective states, they said they would not have been able to accomplish much. Concerning their own CKF-AI projects, they felt the same way – that it was important to build on what they had started, keep it going, and not lose momentum. This is why so many of them were putting serious effort into plans (hopeful but still uncertain) for post-grant sustainability. A lesson for grantmaking might be that nurturing long-term efforts through lengthier grant periods or successive renewal grants to the same group of grantees is an approach well suited to complex social problems such as Medicaid coverage and access. These problems may be simply too big to fit well with short, one-shot initiatives.

Possible Followups

At the time of this report, the majority of CKF-AI grantees had promising initiatives up and running, and hoped to continue them. Several had gathered early outcome data suggesting fairly dramatic positive effects. In their final reports, many of them say something along the lines of:

- *"We wish there could have been a third year in the grant, for assessment."*
- *"Tangible results should be evident within a year."*
- *"It would have been nice to have a third phase to this initiative that could determine long-term effects…on utilization."*
- *"It would be helpful for these types of major access projects to be continued over a longer time frame."*
- *"Recommendation for the future: Test results from the self-reported data by analyzing actual claims data before, during, and after the intervention."*
- *"The project came to an end before we could perform 'before and after' analyses of ER utilization."*

The situation seems ripe for followup research and/or grantmaking to learn more about their interventions' further evolution, impact, and potential for sustainability after the official end of the CKF-AI initiative.

To further increase understanding of access barriers and realistic ways to reduce them, RWJF could build on CKF-AI in three ways (which could be combined):

- **Additional evaluation**. Follow-up work could be funded to assess all of the present CKF-AI grantees' programs after enough time (another six to twelve months) has passed, in order to reach firmer conclusions about impact and long-term sustainability. In effect, this would approximate adding the third year for assessment that the grantees suggested.

- **Renewal grants**. CKF-AI grantees (particularly the more successful ones) could be invited to apply for renewal grants of two or three years to continue and expand their interventions, providing momentum and additional time to further develop and assess their programs' system-wide implications.

- **Replication.** The CKF-AI initiative could be replicated with a new set of grantees to examine how well it works with a different group of states and under altered conditions related to the federal Deficit Reduction Act of 2005 and recent state Medicaid waivers.

Followups to CKF-AI could hardly be more timely or more important for protecting the health of vulnerable populations. Explicitly or implicitly, the federal DRA and some states' recent Medicaid waiver programs aim to cut costs by reducing Medicaid families' service utilization, which could translate into ignoring existing access barriers in ways that leave basic healthcare needs unmet. Some of the state waivers currently under consideration would actually intensify the access-blocking problems that CKF-AI grantees sought to solve, creating a real need for increased documentation and collaborative work to keep Medicaid coverage viable. Thus, ***in the present policy environment, meaningful healthcare access after enrollment seems likely to remain a central "hot spot" in the Medicaid under-coverage problem, urgently calling for further investigation and policy attention.***

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[1] See Figure 1 for a list of the 18 CKF-AI grantees. One additional award was made to an organization in New Jersey, but this grantee discontinued participation early in the program.

[2] Numerous recent publications describe growing access barriers for Medicaid/SCHIP enrollees. For example, see:

- Robert Hurley, Hoangmai Pham, and Gary Claxton. “A widening rift in access and quality: Growing evidence of economic disparities.” Health Affairs web exclusive, December 6 2005.
- Catherine Hoffman and Susan Starr Sared. “Threadbare: Holes in America’s Health Care Safety Net.” Washington, DC: Kaiser Commission on Medicaid and the Uninsured; November 2005.
- Teresa Coughlin, Sharon Long, and Yu-Chu Shen. “Assessing access to care under Medicaid: Evidence for the nation and thirteen states.” Health Affairs, July/August 2005; 24 (4): 1073-1083.
- Peter Cunningham and Jack Hadley. “Expanding care versus expanding coverage: How to improve access to care.” Health Affairs, July/August 2004; 23(4): 234-244.

See also two reports from the Robert Wood Johnson Foundation’s ongoing assessment of its Covering Kids and Families initiative, being carried out by Mathematica Policy Research, Inc. and its partners the Urban Institute and Health Management Associates:

- “Covering Kids and Families Evaluation – “What parents say about access to care and how it affects decisions regarding enrollment and renewal under Medicaid and SCHIP,” by Ian Hill, H Stockdale, M Evert, and K Gifford (undated).
- “Covering Kids and Families Evaluation – Highlight Memo #12: Access to care for SCHIP and Medicaid enrollees: Findings from site visits to ten states,” by Jennifer Sullivan and Embry Howell; February 1 2005.

[3] For example, see:

- Bill Wright, Matthew Carlson, Tina Edlund, Jennifer DeVoe, Charles Gallia, and Jeanene Smith. “The impact of increased cost sharing on Medicaid enrollees.” Health Affairs, July/August 2005: 24(4): 1106-1116.
- Peter Cunningham. “Medicaid cost containment and access to prescription drugs.” Health Affairs, May/June 2005; 24(3): 780-789.

[4] See Judy Solomon, “Helping families enrolled in Medicaid access prescription drugs,” Hamilton, NJ: Center for Health Care Strategies, Inc.; May 2004.

[5] See:

- Leighton Ku and Matthew Broaddus. “Out-of-pocket medical expenses for Medicaid beneficiaries are substantial and growing.” Center on Budget and Policy Priorities; May 31 2005.
- Sharon Long and John Graves. “What happens when public coverage is no longer available?” Washington, DC: The Urban Institute, for the Kaiser Commission on Medicaid and the Uninsured; January 2006.
- J Hadley. “Consequences of the Lack of Health Insurance on Health and Earnings.” A report for the Missouri Health Care Foundation. Washington, DC: The Urban Institute; 2005.

[6] For example, see:

- Vernon Smith, Kathleen Gifford, Eileen Ellis, Amy Wiles, Robin Rudowitz and Molly O’Malley. “Medicaid Budgets, Spending and Policy Initiatives in State Fiscal Years 2005 and 2006: Results from a 50 state survey.” Washington, DC: Health Management Associates and Kaiser Commission on Medicaid and the Uninsured; October 2005.
- Teresa Coughlin and Stephen Zuckerman. “Three years of state fiscal struggles: How did Medicaid and SCHIP fare?” Health Affairs web exclusive, August 16 2005.

- Ian Hill, Brigette Courtot, and Jennifer Sullivan. "Ebbing and flowing: Some gains, some losses as SCHIP responds to third year of budget pressure." Washington, DC: The Urban Institute; May 2005.
- Robert Pear. "States Proposing Sweeping Change to Trim Medicaid," New York Times, May 9 2005.

[7] See:
- "Issue brief: Deficit Reduction Act of 2005: Implications for Medicaid." Washington, DC: Kaiser Commission on Medicaid and the Uninsured; February 2006.
- Leighton Ku. "The Slowdown in Medicaid Expenditure Growth." Center on Budget and Policy Priorities; March 16 2006.

[8] See:
- Robert Pear. "Measure would hurt poor on Medicaid, report says." New York Times, January 30 2006.
- Edwin Park. "New Congressional Budget Office estimates indicate millions of low-income beneficiaries would be harmed by Medicaid provisions in budget bill." Washington, D.C., Center on Budget and Policy Priorities; January 29 2006.
- Congressional Budget Office Cost Estimate, S. 1932, Deficit Reduction Act of 2005. Washington, DC: Congressional Budget Office, January 27 2006.

[9] Richard Kreuger. Focus Groups: A Practical Guide for Applied Research, Third Edition. Thousand Oaks, CA: Sage, 2000.

[10] See:
- Carolyn Needleman and Martin Needleman, "Qualitative methods for intervention research," American Journal of Industrial Medicine 1996, 29(4): 329-337.
- Michael Quinn Patton, Utilization-Focused Evaluation. Thousand Oaks, CA: Sage, 1997.

[11] Roger Fisher, Bruce Patton, William Ury. Getting to Yes: Negotiating Agreement without Giving In. New York: Houghton Mifflin Company; 1981, 1991.

[12] A more complete discussion of these conceptual models can be found in "Nursing advocacy at the policy level: Strategies and resources," by Carolyn Needleman, pp. 253-259 in Nursing, Health and the Environment: Strengthening the Relationship to Improve the Public's Health, edited by Andrew Pope, Meta Snyder, and Lillian Mood; Washington, DC: National Academy Press, 1995.

[13] The importance of connecting demonstration programs with a "window of opportunity" in the political environment has been noted by numerous theorists of public policy. See, for example:
- J W Kingdon. Agendas, Alternatives, and Public Policies. New York: Harper Collins Publisher; 1984. Kingdon describes two kinds of opportunity – (1) a "problem window" that opens when an issue becomes pressing and politicians reach for a policy solution to solve it, and (2) a "policy window" that opens when a politician takes a stand on an issue and needs a problem to support that stand. He notes that these windows of opportunity *"open infrequently and do not stay open long."*
- Richard Nathan, Social Science in Government: The Role of Policy Researchers; New York: The Rockefeller Institute Press, 2000. Nathan observes, "*In selecting the subjects for both demonstration and evaluation studies, priority should be given to situations in which three conditions apply: first, that policymakers and government officials are genuinely interested in the questions being asked; second, that they are uncertain about the answers; and third, that they are willing to wait for them."*