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FOLLOW-UP EVALUATION OF THE

Covering Kids & Families Access Initiative (CKF-AI)

PHASE I FINAL REPORT:

Lessons from 18 CKF-AI Grantees

From the CKF-AI Project Directors:

"There's so much need... Being part of the AI project allowed us to uncover something that must not be left alone."

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I. Introduction

Grant-supported community-based programs, especially ones that address complex social problems, are sometimes just beginning to show results when their funding period comes to an end. What happens next, after the initial grant expires? Do the fledgling programs started through the grant move ahead, fulfilling the promise they showed during the grant period? Do their outcomes eventually get evaluated? Do they change focus as new sources of support come into play? How can we best judge their success as funded initiatives?

To shed light on these issues, in 2006-2007 the Robert Wood Johnson Foundation (RWJF) undertook a follow-up study of the *Covering Kids & Families Access Initiative* (CKF-AI), a program sponsored by RWJF during the period 2003 to 2005. The follow-up study is part of an ongoing RWJF-funded evaluation of CKF-AI's parent initiative, *Covering Kids & Families*, being done by Mathematica Policy Research, Inc., in collaboration with the Urban Institute and Health Management Associates. It builds on and extends an evaluation of CKF-AI funded in 2005 by the Center for Health Care Strategies (CHCS), a New Jersey-based research and development organization engaged by RWJF to manage CKF-AI during the project's funding period.

The present Phase I Final Report: *Lessons from 18 CKF-AI Grantees* summarizes what has been learned from the first part of the follow-up study, based on hour-length telephone interviews with each of the eighteen CKF-AI grantee teams carried out during the period of January through April 2007. In the second part of the follow-up study, five site visits are being carried out by staff of the Urban Institute during the summer and fall of 2007. Findings from the site visits will be presented in the follow-up evaluation's Phase II Final Report: *Case Studies from Five CKF-AI Grantees* in spring of 2008.

All figures mentioned in the present report appear in the Appendix section.

II. Background

The *Covering Kids & Families Access Initiative*

The program described in this report—the *Covering Kids & Families Access Initiative* (CKF-AI)—is part of a still-evolving long-term effort by the Robert Wood Johnson Foundation (RWJF) to solve problems of coverage and access in Medicaid and the State Children's Health Insurance Program (SCHIP).

In 1997, RWJF established the *Covering Kids Initiative* (CKI) with the goal of enrolling more eligible children into Medicaid and SCHIP through outreach, enrollment simplification and health insurance program coordination strategies. CKI coordinated programs in all 50 states and more than 170 communities nationwide. The *Covering Kids & Families* (CKF) program, introduced in 2002, was an expansion of this effort. CKF worked to reduce the number of uninsured children and adults who are eligible for public health care coverage programs but who are not enrolled. By providing funds and technical assistance to community-based initiatives in every state, CKF helped states expand outreach, coordinate activities and simplify application processes to enroll greater numbers of low-income children and families.

As gains have been made in coverage, it has become increasingly apparent that having health insurance does not in itself assure access to needed health care. A variety of access barriers—some obvious, others poorly understood—can prevent meaningful use of insurance coverage even after children and families are formally enrolled. In 2003, in order to learn more about the access problem and to find effective strategies for reducing access barriers, RWJF undertook CKF-AI as a special program within CKF.

Compared to its parent initiatives *Covering Kids* and *Covering Kids & Families*, CKF-AI's resources were relatively modest and its funding period very short. However, its goals were ambitious. The two-year initiative awarded grants of approximately $125,000 per site to eighteen community-based organizations already serving as local partners in CKF coalitions, all with strong track records of working successfully with medically underserved populations. Geographically, the CKF-AI grantees were located in fifteen different states representing every major region of the country. In the initiative's first year (Phase I) each grantee was to investigate access barriers by collecting data directly from affected families and health care providers in the local area. The grantees were then to move into a second phase in which each of them would select one or two barriers based on their Phase I findings; develop site-specific intervention strategies for addressing these barriers; and attempt to field the interventions as pilot programs. Intensively during Phase I and as needed during Phase II, the CKF-AI grantees were supported with technical assistance from consultants working for the Center for Health Care Strategies (CHCS).

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In the initiative's second year, CKF-AI also made available $20,000 per site to fund "state partners" to assist with the Phase II programs and help link the grantees' local interventions to state-level changes. One third of the CKF-AI grantees (6 of the 18) selected their state's CKF lead organization as the state partner. At the remaining 12 sites, grantees used the state partner awards to tap the skills of organizations or individuals with specific expertise related to the Phase II interventions. For example, the North Carolina grantee team wanted to improve access to health care by developing a system for training and certifying medical interpreters; as their state partner, they chose an expert on medical translation who could help develop a curriculum and lend credibility to certification efforts. The California grantee team, aiming to improve access for a large migrant population with limited English proficiency, chose a university professor with a strong research background in assessing service needs of rural Hispanic populations. In New Mexico, the Phase II project goal was to build support for a badly needed hospital; the grantee's choice for a state partner was the New Mexico Hospitals and Health Systems Association, an organization that could help with the financial and technical aspects of a detailed hospital development plan. The Phase II plans of the two grantees in Pennsylvania both involved legal analysis of service providers' contracts—focusing in one case on medical transportation and in the other case on enforcement of state contracts with managed care organizations—and both of them chose the Pennsylvania Health Law Project, a public interest law organization, as their state partner.

CKF-AI's Status at the End of the Grant Period

In 2005, CHCS sponsored a comprehensive evaluation of CKF-AI[1] covering in detail the following points:

- **Basic program information** describing how the eighteen grantee teams approached their Phase I data-gathering, how they used the technical assistance provided to them, how they decided which of many access barriers to focus on in Phase II, how they interacted with their state partners, what kind of pilot programs they designed, and what program effects were evident at the end of the grant period.
- **Examples of how grantee experience was affected by contextual factors** such as the state's economy and political climate; the status of managed care in the local area; strength or weakness of relevant networks and coalitions; rural versus urban location of the grantee site; size and history of the grantee organization; training and background of the project directors and state partners; etc.
- **Local grantee and state partner perspectives** on the initiative's design and management—what helped, what caused difficulty, and what they would recommend doing differently.
- **A number of "lessons learned"** that are potentially useful for other advocates working to reduce access barriers, as well as for future RWJF grantmaking.

Figure 1 (see Appendix A), borrowed from the earlier CHCS evaluation, gives a snapshot of where things stood at the end of the grant period. As this Figure shows, one of the initiative's hallmarks was its **extreme internal diversity**. After assessing local access barriers, typically through focus groups and small-scale interview studies, each grantee team designed its own

1 The Final Report from this evaluation and a related CKF-AI Toolkit are available from CHCS and can be downloaded or ordered online at www.chcs.org or by calling 609-528-8400. See Needleman C. *Covering Kids & Families Access Initiative, Final Evaluation Report*. Center for Health Care Strategies, March 2006. See also Redmond P (contributing author Needleman C, editor Martin L). *Reducing Barriers to Health Care: Practical Strategies for Local Organizations: Covering Kids & Families Access Initiative Toolkit*. Center for Health Care Strategies, January 2007.

customized approach to improving access. Some worked on language and cultural barriers, a major problem in areas with rapidly growing immigrant populations. Some addressed transportation problems. Some sought to help parents become more knowledgeable about how to use medical services for themselves and their children. In some cases, service providers rather than health care consumers were the intervention target; for example, better information resources were developed for local pharmacists who were reluctant to fill prescriptions because of uncertainty about Medicaid and SCHIP reimbursements. In general, the technical assistance staff at CHCS supported what each grantee proposed, although they did encourage grantees to plan projects that were "doable" within the initiative's resources and timeframe.

The diversity of CKF-AI's intervention projects posed some interesting challenges for the initiative's management and evaluation. However, it was clear at the end of the funding period that **CKF-AI's strategy of site-specific program design, coupled with active but very flexible technical assistance from CHCS, had unleashed a high level of energy and "outside the box" thinking**. Grantees as a group had done a remarkable job of gathering new and sometimes surprising front-line information about barriers that can prevent children and families from making effective use of health care coverage. They had designed a variety of innovative projects to help reduce barriers, and many of these projects showed great initial promise.

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However, the planned interventions were in most cases just getting started when the funding period ended. The 2005 evaluation found that, even with the three-month no-cost extensions that most sites requested and received, **two years had simply been too short a time period for grantees to move their work through all the steps originally envisioned for CKF-AI**. Despite high commitment and dedicated effort, they were not able to complete the full sequence of intended stages including research on access barriers, planning of appropriate interventions, and implementation of the program plans. Similarly, **the grant-supported link between local grantees and state partners was greatly valued by both parties, but these partnerships had not yet had enough time to produce system changes** as CKF-AI's program concept had envisioned.

The Follow-Up Evaluation

In 2006-2007, to gather more information on the development of the CKF-AI projects over a longer time period, RWJF undertook the present follow-up study. It is organized as a collaborative effort between the author of the earlier CHCS evaluation (Carolyn Needleman) and researchers from the Urban Institute (UI) (Ian Hill, Brigette Courtot, and Louise Palmer) who are associated with the ongoing evaluation of *Covering Kids & Families*.

While the follow-up study builds on the previous evaluation, it aims at a different set of questions:

- ***A year and a half after the end of the RWJF grant, what is the current status of the projects started through CKF-AI?***
- ***If these programs are still continuing, how are they being supported? What strategies for sustaining them have been used, with what results?***

- ***Do the programs seem to be having an impact on the access barriers they were meant to address? If so, how are their effects being documented and/or measured?***
- ***In the post-grant period, have there been changes in the programs' focus and/or structure? If so, what kind of changes, and why?***
- ***What lessons for program development and/or future RWJF grantmaking can be learned from these grantees' post-grant experience?***

The follow-up study's methodology has been exploratory and qualitative, more akin to ethnography than to survey research, because (as the previous evaluation found) the CKF-AI grantees do not really represent eighteen participants working on a shared endeavor within a common structure. Their site-specific projects are so diverse that it is more productive to think of the evaluation as a series of linked case studies, with all of the eighteen grantee teams working toward the broad goal of improving access but doing so independently in different ways tailored to local circumstances.

Data for the follow-up evaluation are being collected in two distinct phases:

Phase I (now completed) consists of telephone interviews about one hour in length with one or more key individuals from each of the eighteen CKF-AI grantee teams. These interviews have been arranged, scheduled, and conducted by Carolyn Needleman, with one or more Urban Institute researchers sitting in on each call. As an aid to accuracy and completeness, the participating evaluators have each taken detailed notes separately during the interviews, with all the notes being typed up and later consolidated for analysis.

Generally speaking, the telephone interview respondents have been the original CKF-AI project directors and/or key consultants who were interviewed previously in the initial evaluation. In some cases the interviews have included additional individuals who took over active management of the CKF-AI local projects after the grant expired. Unlike the earlier evaluation, telephone interviews for the follow-up evaluation have not included systematic input from the CKF-AI state partners, because at this point most of the state partners are only distantly involved with the local projects that got started through CKF-AI. However, in two cases where the original project directors have left and the local CKF-AI programs have been discontinued, interviews were held with the grantee team's state partner as the next best source of information.

We initially attempted to use a detailed protocol for the telephone interviews, but it quickly became obvious that forcing responses to fit a highly structured instrument would be counterproductive. Because many site-specific topics could not be known in advance, a simpler and more flexible interview guide was needed. A copy of the simplified protocol used for most of the interviews is attached as Appendix B. In practice, this brief interview guide was used primarily as an agenda/checklist to make sure that important points were not skipped. The calls took the form of "conversational interviewing"—a relaxed, rapport-building method of data collection commonly used in ethnographic research.[2] The resulting data are less neat and more challenging to analyze than responses to a pre-structured survey would be, but also much richer and better able to serve the study's exploratory purpose.

2 See Patton MQ, *Qualitative Research & Evaluation Methods, 3rd Edition*, Sage Publications, 2002.

Analysis of data from the telephone interviews followed established methods for qualitative social science research.[3] First, for each interview, the detailed notes taken by each participating researcher during the call were typed up as narratives of about six to ten single-spaced pages, and compared with each other so as to fill in any missed information and identify any disagreements about what the respondent(s) had said. Fortunately, discrepancies turned out to be rare and easily resolved. As the body of consolidated interview narratives grew, while the data-gathering was still going on, a process of "open coding" and "constant comparison" was begun in which patterns of meaning were identified, checked and refined against more data, and then applied systematically to the entire body of data. That is, the available interview narratives were read and re-read for meaning numerous times and marked up thickly with marginal notes to flag important points. During this process, tentative categories were developed to describe what seemed to be underlying themes in the experience of these widely different CKF-AI project sites. The categories and themes were revised and elaborated repeatedly as more interview narratives became available. Initially the emerging interpretive framework changed drastically with each new interview, but eventually began to stabilize with fewer new categories being added. At this point of "data saturation," toward the end of the data collection, all of the interviews were re-analyzed systematically so that the parts of each interview related to particular themes could be selected out. The relevant sections of the interviews were then grouped theme by theme, and considered together to develop cross-cutting "lessons."

The analysis approach used here did not involve quantifying the interview data, because quantification would not have contributed much for evaluating an exploratory, internally diverse initiative such as CKF-AI.[4] The goal was not to tally the distribution of responses as might be done in a survey of comparable projects, nor to measure program outcomes and relate them to specific variables as might be done in a field experiment to test the effectiveness of a predetermined program approach. Instead, the purpose of the analysis was to mine the interviews for new insights about the process of reducing access barriers and to highlight useful lessons that could be learned from the grantees' collective experience—whether the lessons came from one site or many.

Phase II (to be completed over the summer and fall of 2007) consists of five site visits by Urban Institute staff to provide fuller information on selected CKF-AI programs of special interest, located in Connecticut, Maryland, Minnesota, North Carolina, and Washington State. Two to three UI researchers will spend approximately two days at each of these sites, gathering data through interviews and observation with a wide range of stakeholders. The Phase II methodology and findings will be discussed in detail in the evaluation's Phase II Final Report: *Case Studies of Five CKF-AI Grantees.*

3 See Strauss A and Corbin J, *Basics of Qualitative Research*, Sage Publications, 1998; Miles M. and Huberman AM, *Qualitative Data Analysis: An Expanded Sourcebook, 2nd Edition*, Sage Publications, 1994.

4 See Needleman C and Needleman M, "Qualitative Methods for Intervention Research," *The American Journal of Industrial Medicine* 1996, 29(4):329-337.

III. Descriptive Findings

As noted above, the CKF-AI grantees chose to focus on a variety of different access barriers in their Phase II interventions, depending on what their Phase I data collection had revealed as urgent problems for consumers in their local areas. They were encouraged by the CHCS technical assistance staff to concentrate on barriers that could realistically be addressed within a short time frame. Thus, while almost all of the grantees identified provider shortages and inadequate dental care as serious problems in their communities, none chose these deeply entrenched access barriers as a primary program focus.

To give an idea of the wide range of the CKF-AI interventions,[5] grantees' project goals included:

- **Reducing administrative barriers related to policies of state agencies, managed care organizations, hospitals, or providers**—a major focus of 6 grantees, secondary focus for 15 others
- **Educating consumers about system navigation**—a major focus for 6 grantees, secondary focus for 5 others
- **Improving families' "health literacy" about common illnesses and preventive care—**a major focus for 4 grantees, secondary focus for 1 other
- **Educating providers about benefit systems, reimbursements, and existing barriers to care—**a major focus for 2 grantees, secondary focus for 7 others
- **Helping consumers find alternatives to hospital emergency rooms as a better way of obtaining non-emergency medical services**—a major focus for 2 grantees, secondary focus for 4 others
- **Outreach to individuals and families officially enrolled but not connected with the health care system**—a major focus for 2 grantees, secondary focus for 4 others
- **Addressing delivery system problems such as a lack of medical facilities, unaffordable cost-sharing measures, and provider non-compliance with mandated standards of care**—a major focus for 2 grantees, secondary focus for 4 others
- **Reducing language and literacy barriers to care**—a major focus for 2 grantees, secondary focus for 3 others
- **Reducing barriers to getting prescriptions filled by pharmacies**—a major focus for 2 grantees, secondary focus for 2 others

5 The CKF-AI grantees' project choices and the programs they developed are briefly summarized for each grantee in Figure 1 of this report, and discussed at more length in the earlier CKF-AI Final Evaluation Report and CKF-AI Toolkit sponsored by the Center for Health Care Strategies; see footnote 1. The in-depth case studies to be reported in the follow-up evaluation's Phase II Final Report, forthcoming in spring 2008, will give a detailed picture of five grantees' program efforts during and after the funding period.

- **Reducing medical transportation barriers**—a major focus for 1 grantee, secondary focus for 2 others

To meet their goals, the grantees used a variety of program approaches such as recruiting and training medical translators and community health workers; developing and disseminating culturally appropriate consumer information about medical services and disease symptoms; distributing factsheets to providers to help clarify confusing benefit and reimbursement requirements; starting dialogs with decision-makers at the state level or in hospitals and managed care organizations; advocating for expanded medical facilities; and seeking to strengthen enforcement of regulations mandating specific benefits. As shown in Figure 1, most of the CKF-AI programs were just moving into implementation at the end of the CKF-AI funding period and had not yet had time to yield results.

One purpose of the follow-up telephone interviews was simply to learn how the CKF-AI programs had fared during the year and a half that had passed since the end of the RWJF grant. Were these programs still operating? If so, how were they being supported? Were they by now showing tangible results? Did CKF-AI's working relationships between local organizations and state partners continue, and if so, were they productive?

Highlights of the follow-up study's descriptive findings are summarized here as background for the interpretations that follow.

- **The majority of the CKF-AI projects were continuing in some form, although some were struggling and a few had ended**. At the time of the follow-up telephone interviews, five[6] of the eighteen grantee sites had succeeded in establishing robust barrier-reducing programs that had gotten their start through CKF-AI; these programs were thriving and in some cases expanding. Another five sites[7] were keeping their CKF-AI project plans going in a more limited form, in some cases folding their access work into related service programs. Four sites[8] had temporarily suspended their CKF-AI projects pending new sources of funding or developments in state policy, but planned to resume their access work in the future building on the groundwork laid through CKF-AI. At the remaining four sites[9] the original CKF-AI programs were no longer active and the project directors had left; in three of these cases, the state partners or other organizations continued to make positive use of the CKF-AI access work. **Figure 2** (see Appendix A) briefly describes the present status of the grantees' CKF-AI programs.

- **Grantees with still-active projects had generally been successful in locating alternative sources of program support after the RWJF grant expired**, although their strategies varied and in many cases the funding was significantly lower. Several of these grantees were seriously strapped for resources to keep their access work going. But, as shown in **Figure 3** (see Appendix A), about half of them had been able to obtain some level of funding from other private foundations. In a few cases, they were successful in tapping public sources—local or state tax systems or special state and federal programs. In one very interesting case (**North Carolina**[10]), the grantee team successfully established a fee-for-service business model for the medical interpreter bank they had developed through CKF-AI; they expect this service to become self-supporting.

6 Connecticut, Maryland, Minnesota (Olmsted County), New Mexico, North Carolina.

7 California, Maine, Texas (Rio Grande Valley), Washington state, West Virginia.

8 Minnesota (Minneapolis), Oregon, Pennsylvania (Philadelphia), Texas (Houston)

9 Arkansas, Idaho, Pennsylvania (Pittsburgh), Virginia

10 The Phase II Final Report will contain a fuller description of the North Carolina project's current status, based on the Urban Institute's site visit.

- **When the grant ended, some CKF-AI grantee organizations found it necessary to move the management of their projects to a collaborating organization better equipped to continue the effort**. Of the eleven CKF-AI grantees whose projects were still continuing at the time of our follow-up interviews, five had experienced post-grant program relocation to a different organization, usually under different leadership. **Figure 4** (see Appendix A) shows these patterns.

- **Very little systematic analysis has been done by the grantees on the effects of their CKF-AI projects**. The reasons are discussed later in this report. A majority of grantees say they feel their projects are having a positive impact and they wish they could document the effects with something more than anecdotal evidence. Grantees' experience with evaluating their own programs is briefly summarized in **Figure 5** (see Appendix A).

- **Collaboration between the local grantees and their state partners has tended to become less active during the post-grant period**. This is unfortunate, since in the earlier CHCS evaluation, this linkage was highly praised by both the grantees and the state partners as a major strength of CKF-AI. **Figure 6** (see Appendix A) shows the current status of the local/state partnerships.

IV. Interpretive Findings

Because the eighteen sites are non-comparable in terms of program focus and circumstances, the grantees' current differences cannot be understood by seeking correlations with variables such as rural/urban location or size of the grantee organization. However, the telephone interviews offer a number of qualitative insights into what may have contributed to variation in their post-grant experience.

1. ***The strength and promise of CKF-AI projects at the end of the grant period turned out to be fairly poor predictors of how well these projects would be doing a year and a half later. A more powerful factor in their long-term success or difficulty appears to have been their external policy context.***

During the post-grant period, some of the projects that had seemed most promising based on preliminary results were stopped dead in their tracks by some external event. A good example of this occurred in **Houston, Texas**, considered by CHCS's technical assistance and evaluation staff to be one of the initiative's "stars." Shortly after the CKF-AI funding ended, the grantee organization in Houston (Children's Defense Fund) had to put aside its programs for reducing prescription drug barriers in order to deal with a crisis that followed the state's decision to change vendors for Medicaid/SCHIP enrollment. As the CKF-AI project director in Houston put it, the private contractor newly hired by the state was not up to the task and the system "just imploded," with thousands of children and families being abruptly disenrolled. All of CDF's current efforts have for the moment been channeled into damage control, helping eligible children and families obtain or retain coverage. It would be inaccurate to view this grantee's CKF-AI prescription drug programs as failures, because a great deal of groundwork has been laid and can be activated again in the future—but the fact remains, the programs that started through CKF-AI are temporarily on hold.

As another example, in **Virginia**, the CKF-AI project director (a consultant working for the Radford University Foundation) had started a variety of promising programs including a mechanism for providing urgent care at a new facility across the street from the university hospital's badly overcrowded emergency room. At the end of the grant period, this plan was just moving into implementation and seemed likely to relieve overcrowding at the ER and at the same time improve access and quality of care for health consumers—a win-win situation. Unfortunately, with very little notice, the University's trustees decided to close the clinic that had been the project director's base of operation, essentially dropping the floor out from under the CKF-AI program plan. In the process, the project director's own employment was also scheduled to be terminated. The project director has not abandoned the effort and is working

to put together a funding package to support a private urgent-care clinic, which he hopes to head by the time his university consulting position is phased out.

The reverse also sometimes happened. That is, some of the grantees whose projects had been deemed unpromising at the end of the funding period have been able to achieve startling levels of success during the post-grant period. For example, in **New Mexico**, the grantee team at Youth Development Inc. had decided—against the strong advice of CHCS's technical assistance staff—to work on a seemingly overambitious goal: getting a full-service teaching hospital built in their large rural county, which had a rapidly growing population, no hospital of any kind, and virtually no mass transit to nearby cities. While a hospital was clearly needed to improve health care access, this goal seemed an unrealistic match with the resources of CKF-AI's lightly-funded one-year Phase II intervention period. However, the New Mexico grantees could not be dissuaded from their plan. Now, a year and a half later, what the project director calls a "miracle" has happened. An unusual convergence of interests created a window of opportunity, and the grantees seized it. They were able to enlist support from a diverse group of local stakeholders including realtors and the Chamber of Commerce as well as the area's health providers. They put together a sophisticated, well-researched hospital development plan and mounted a successful public information campaign to increase the local property tax mill rate, providing a steady base of funding to finance the new hospital. By now, bonds have been floated, bids have gone out, contractors and providers have been selected, and construction is scheduled to start by the end of summer 2007 on a hospital complex costing approximately $10 million, expected eventually to be self-supporting. Meanwhile, inspired by unexpected signs of dynamism in this neglected rural county, state officials have improved the area's bus and rail services in ways that make transportation to the city of Albuquerque (some forty miles away) easier for families seeking medical services. So in this case, a CKF-AI project that seemed wildly unrealistic to outside observers has yielded impressive results. Full results must await physical completion of the hospital, still years away, but ultimately the positive impact on access should be major.

A lesson from this finding is that the success of grant-funded projects cannot be understood in isolation from their social and political context. Success or lack of success is not a matter of program strength alone, but depends also on how the grantees' activities fit with opportunities and constraints in the policy environment—before, during, and after the funding period. While favorable circumstances will not necessarily turn a weak program into a success, unfavorable circumstances can certainly overwhelm a strong program. This needs to be taken into account when evaluating what "works" as an intervention and what does not.

This lesson is unfortunately very timely. As the present report is being written, an intense debate over reauthorization of the SCHIP program is raging in Washington, with Congressional Democrats working to expand the program and President Bush's administration vowing to keep the program from growing. Twice during the fall of 2007, reauthorization legislation expanding SCHIP has been sent forward; twice it has been vetoed. "Out of concern that money is running short," Congress finally sent forward legislation extending the SCHIP program in its present form through March 2009, and President Bush signed this short-term extension into law on December 29, 2007.[11] However, the debate is hardly over, since the

11 Kaisernetwork.org; November 28, 2007. See also "Bush Signs Child Health-Care Extension into Law," Washingtonpost.com; December 30, 2007.

present program provides benefits to only 6 million individuals and the Democrats are pledged to expand it to cover 10 million. Meanwhile, in August 2007, the federal Centers for Medicare & Medicaid Services (CMS) announced new and extremely restrictive federal requirements for SCHIP eligibility. At least eight states plan to file or join lawsuits against the administration for "arbitrary and capricious" rulemaking procedures related to these new requirements.[12] Children's health advocates in many states, including the CKF-AI grantees, are bracing for the hard-to-predict outcome of these policy struggles, which potentially could undercut even the most successful state-level coverage and access-improvement efforts.

A useful conceptual framework for thinking about the policy environment and its implications is John Kingdon's model of system change, developed in the 1980's.[13] Kingdon's work focuses on the idea of "windows of opportunity," how they emerge, and how they can be used in advocacy efforts. It seems highly relevant to foundation-sponsored efforts to improve health care coverage, access, and quality.

2. ***While convinced that their interventions are having a positive impact, most of the CKF-AI grantees have been unable to gather hard data on the direct effects of their projects on access. Their organizations are stretched too thin to undertake systematic data gathering and analysis in the absence of dedicated funding for evaluation purposes.***

This inability to document their projects' impact is extremely frustrating to the grantee teams themselves, since hard evidence of program effectiveness would help in promoting their access-improvement activities. In a number of cases, relevant quantitative data sources already exist in the form of hospital records and medical claims databases being kept for other purposes. These could be useful for evaluating of the impact of CKF-AI programs, if only the staff time could be found to extract and analyze the appropriate information.

Wherever even small amounts of quantitative or qualitative data have been systematically collected and presented as outcome evaluation, the findings have been compelling. For example, in **West Virginia**, the CKF-AI grantee's Phase II intervention consisted of giving Medicaid/SCHIP families information on how to deal with non-emergency childhood illnesses at home when medical providers are unavailable, as is often the case in this rural area. The grantees set up a pilot project in which the participating parents or other caregivers received a free copy of a book entitled *What to Do When Your Child Gets Sick*, written by two nurses.[14] Participating families also received a minimum of five monthly home visits from a community health worker to discuss how to use the book. The WV state partner evaluated this pilot program, comparing pre- and post-intervention self-reported data from 92 participating families concerning their level of knowledge and confidence about health care access. The findings from the evaluation study were so positive that a regional foundation decided to fund replication of the program in two additional West Virginia counties. In **Washington State**,[15] the Phase II intervention was a program of multi-disciplinary assessment, counseling and referral for "heavy ER users" who had been relying on emergency room services for non-emergency long-term management of chronic pain. The grantees evaluated the experience of their first four participating "heavy ER users" and found not only greater patient satisfaction following the intervention, but also an annual savings in ER costs of $15,000 per patient.

12 Kaisernetwork.org; October 02, 2007.

13 See Kingdon J, *Agendas, Alternatives and Public Policies, 2nd Edition;* New York: Harper-Collins College, 1995.

14 Available from the Institute for Healthcare Advancement, www.iha4health.org.

15 The Phase II Final Report will contain a fuller description of the Washington State project's current status, based on the Urban Institute's site visit.

A few additional small-scale participant satisfaction surveys have been carried out by other grantees. But most have not been able to collect outcome data, although they strongly feel that systematic evaluation would show positive effects. The problem seems to be that funding for the specific purpose of outcome evaluation is difficult to obtain. As one grantee explained, "It's hard to get funding for that kind of thing… Foundations love to help people. They want to fund services." Exactly for this reason, a number of grantees suggested adding an evaluation component to the initial grant itself.

The lesson here is that research on program effectiveness will not happen on its own. The effects of projects like those developed through CKF-AI are unlikely ever to be systematically assessed by grantees unless the necessary resources (along with a requirement for evaluation and technical assistance where appropriate) are either included in the grant itself or made available as a post-grant supplement. Potentially, this is an area where sponsors of an initiative like CKF-AI could achieve high added value at relatively low added cost.

3. Some important effects of CKF-AI have been indirect ones such as building skills, strengthening advocacy networks, and changing the framework of policy discussion. These indirect effects should be taken into account in assessing the initiative's value for improving access over the long term.

In the telephone interviews, grantees frequently mentioned the following indirect effects of CKF-AI—all of which might be considered necessary building blocks for developing interventions to reduce access barriers over the long term. As they see it, the initiative succeeded impressively in:

- **Capacity building.** It provided new skills and strategies of permanent value for both the grantee organizations and the program staff as individuals. For some of the CKF-AI grantees, this initiative was their first experience with external funding. As a result of their projects and the technical assistance they received, they now have increased confidence in collecting data, developing programs, and seeking additional funding. Other grantees already had extensive experience and sophisticated skills, but still say that CKF-AI expanded their capacities in ways that will be useful in their future healthcare improvement efforts.

- **Network development.** It strengthened local advocacy coalitions and positioned the grantee's community-based organization as an issue leader on the access aspects of Medicaid and SCHIP. As one grantee put it, "This project made us the 'go-to' organization for access issues in the community." The prestige of getting funding from RWJF lent a new level of credibility to the grantee organizations, and energized their local coalition efforts in ways that created a stronger base for future advocacy.

- **Broadening the base of institutional support.** It helped establish broad-based stakeholder buy-in to the goal of reducing access barriers, by linking the grantee's community-based organization with providers, city officials, state officials, and other important stakeholder groups. A majority of CKF-AI grantees report that during the grant period they had entrée with state agencies and professional associations that were previously closed to them, and

in some cases (although not all), these connections are surviving the grant. Several grantees have secured positions on ongoing planning bodies, giving them a continuing voice in access improvement.

- **Reframing perceptions.** It began to correct misconceptions about access and cause a gradual change of perspective within power systems such as managed care organizations and state agencies, as key decision-makers in these systems became more aware of how access barriers affect real children and families. CKF-AI's case examples from the field appear to be particularly effective in making a personal impact. For example, an executive of a managed care organization, hearing that a family was denied an emergency supply of prescription drugs to control a child's post-surgical pain, told the CKF-AI state partner that he now recognized how serious his plan's prescription access problem was and would try to get it corrected. He added, "If this ever happens again, here's my number—please call me at home even if it's late."

- **Strengthening ties with wary service populations.** It increased the grantee organization's level of recognition, acceptance, and trust among hard-to-reach service populations in the community—a slow process often requiring time-consuming recruitment and training of community health workers and other intermediaries from the neighborhoods themselves. A good example is the project in Minnesota (Olmstead County) where, after many growing pains, the grantees have built a cadre of community health workers who are trusted by the area's large population of new immigrants. By working through community residents, the grantees have succeeded in reaching even refugee families from war-torn Somalia and Bosnia, who have endured extreme hardships and tend to shrink from contact with authorities.

In the view of most grantees, these indirect effects were a large part of CKF-AI's value—less visible than the immediate results of the specific intervention projects they developed through the initiative, but at least equal in importance.

The lesson here is that strong indirect progress might plausibly be counted as a program success, even if tangible results from the attempted intervention are meager. Indirect outcomes such as organizational capacity building, network development, gaining community trust, and slowly changing decision-makers' perceptions seem like valid goals for an initiative like CKF-AI. Especially where the infrastructure for intervention was previously lacking—for example, at the **Texas (Rio Grande Valley)** site—these indirect outcomes may well be essential as prerequisites for developing specific intervention projects to improve access.

4. ***The end of the CKF-AI grant sometimes caused organizational relocation of the project and/or a change of project leadership. However, because of past successes in coalition-building and networking within the health care advocacy community, this did not seem to have negative effects on CKF-AI project continuity.***

Shutting down a project at the original grantee organization looks drastic on the surface, appearing to signal the end of the effort. However, in the cases where transfers to a different

setting occurred, the new organizational home had typically been involved with the project throughout the grant period. Good working relationships had already been established between new leadership and the original CKF-AI project directors, and these tended to continue after the organizational changes. While transfers of this sort sometimes required staff retraining and administrative adjustments, they did not necessarily disrupt project continuity.

For example, in **North Carolina**,[16] the Buncombe County Department of Social Services transferred the management and leadership of its innovative interpreter bank to a close colleague on the project's advisory board, who was working at the Buncombe County Medical Society. Similarly, at the end of the grant period, **Olmsted County in Minnesota**[17] moved the management of their community health worker program out of the county's Department of Social Services and into a collaborating local organization, the Intercultural Mutual Assistance Association.

Sometimes the organizational setting stayed the same, but the project's staff turned over completely. For example, in **Maryland**,[18] when the CKF-AI grant ended, the original project director's position was de-funded and she left to take a position in an allied agency. Post-grant management of Maryland's CKF-AI community information activities was taken over temporarily by the grantee organization's CEO, who had been only distantly involved up to that point. At the time of the telephone interviews, a "new person" was being hired to direct the access project, which meant that it would eventually be continued by someone with no direct connection to the RWJF grant. Yet with all this change of personnel, the projects started in Maryland through CKF-AI have continued and expanded.

The lesson here is that these projects can move around organizationally without necessarily losing their identity and purpose. The CKF-AI grants were given to specific local organizations, but those organizations were typically operating within a complex network of collaborators who in various ways supported the initiative's goals (which is, in effect, the fruit of the successful coalition-building accomplished over the years through RWJF's Covering Kids and Families initiative).

5. *"Sustainability" is a more complicated concept than it first appears, since the shift to a new funding source after a grant ends can involve considerable reshaping of project goals.*

Sustainability was much on the minds of the CKF-AI grantees at the time of the CHCS evaluation, since the end of the RWJF grant was imminent. A few were trying to get their programs adopted by school systems, hospitals, or managed care organizations. One team (**North Carolina**) had developed an innovative business model to finance their CKF-AI project. Most typically, they were seeking grants from other foundations to keep their intervention programs going once the RWJF money stopped.

The follow-up telephone interviews found that, in general, grantees have been fairly successful in finding alternative funding (see **Figure 5** in Appendix A). However, the support was not without strings attached, especially when the new sponsor was a private foundation with its own priorities and agenda. The CKF-AI grantees sometimes found they needed to adapt their original project plans to fit new grant requirements. For example, in **Connecticut,**[19]

16 The Phase II Final Report will contain a fuller description of the North Carolina project's current status, based on the Urban Institute's site visit.

17 The Phase II Final Report will contain a fuller description of the Minnesota (Olmsted County) project's current status, based on the Urban Institute's site visit.

18 The Phase II Final Report will contain a fuller description of the Maryland project's current status, based on the Urban Institute's site visit.

19 The Phase II Final Report will contain a fuller description of Connecticut's current access-improvement activities, based on the Urban Institute's site visit.

the efforts to reduce prescription drug barriers that began through CKF-AI are now being funded in part by the Universal Care Foundation, whose mission is to build support for a Connecticut state plan for universal coverage. The new grant has a very different set of grant objectives, constraints and reporting requirements that necessarily absorb the CKF-AI grantee team's current attention. Those who worked on CKF-AI have found creative ways to weave prescription drug access considerations into their new grant activities, so that the previous work on this issue has not been lost. However, the original CKF-AI project no longer occupies the central position it did while the RWJF grant was active.

The lesson here is that when a grant like CKF-AI ends and the grantee organizations start to work with other sponsors, the connection with the original sponsor's agenda grows weaker. As time passes, it becomes more ambiguous whether some grantee teams' current access-related activities should still be viewed as "CKF-AI projects." They were started with RWJF funds and still reflect the broad goals of CKF-AI, but in some cases they seem to be gradually morphing in response to new funding requirements.

6. ***Policy change is not a one-shot effort. After policy makers have formally agreed to make a system change, implementation of the change needs to be regularly monitored and/or periodically reviewed, to check whether the change is actually being made.***

In some cases grantees have been successful in convincing state agencies, managed care organizations, hospitals, and/or provider associations to undertake access-improving system-level changes. For example, in **Connecticut,** several of the state's health plans agreed in principle to adopt a best practice that will improve families' access to prescribed medications. However, the CT grantees say that, based on their past advocacy experience, this apparent victory is just the beginning of real system change. Making sure the changes "stick" will require monitoring and periodic reinforcement over a period of at least several years. Without such reinforcement, the change may not actually happen.

The lesson here is that some system-level changes take considerable time to unfold. Because initial formal agreements may not be honored, assessing such changes also requires a long timeframe.

7. ***Although highly valued by both sides, the link between local grantee organizations and their state partners has proved hard to sustain during the post-grant period. The reason is not lack of interest, but difficulty in finding time to continue the working relationship once the connection is no longer required as a condition of funding.***

In the earlier evaluation, CKF-AI's local grantees and state partners were virtually unanimous in identifying the linkage of community-based organizations with state partners as a major design strength of CKF-AI. Both sides cited many advantages to the relationship. Local grantees felt that it helped them become aware of what was happening at the state-policy level, and it also helped in gaining entrée to policy-making bodies that had previously been closed to them. For their part, the state partners greatly valued having a source of "real-life" case material from the front lines, useful in their policy change efforts as dramatic examples

of the human suffering caused by access problems. Some state partners also felt they learned about new dimensions of the access problem from their local partners, causing refinement of their assumptions and policy positions. From the final reports filed by the local grantees and their state partners in December 2005, it was clear that, in most cases, strong and productive working relationships with mutual benefits had been established. Both sides expressed interest in maintaining contact after CKF-AI ended.

Unfortunately, this linkage has not always fared well in the post-grant period. At most of the eighteen sites, the CKF-AI local project directors and their state partners no longer have close or frequent contact. Because of work overload, it appears difficult for both parties to find time for staying in touch once regular contact is no longer a grant requirement. Interest in working together is still high if the time could be supported and justified, but the partnership has simply been crowded out by other urgent activities that have more reinforcement.

At those sites where the CKF-AI state-local partnerships have remained strongest during the post-grant period, part of the explanation seems to be that the relationships pre-dated the access initiative. They may have become less active once CKF-AI ended, but they are part of a well-established advocacy network built through more than a decade of working together in the past, largely through *Covering Kids & Families*.

The lesson here is twofold: (1) state-local partnerships initiated through grants can become permanent, but the process takes considerable time; and (2) when a short-timeframe grant ends, newly established partnerships that were part of the initiative will not necessarily survive on their own without continued dedicated funding. New partnerships must compete for staff time with many other pressing priorities, and are fragile in their early stages. They need a period of reinforcement to become established and self-sustaining. Encouraging new partnerships to continue could potentially be a high-payoff focal point for a small amount of ongoing foundation support after a short-timeframe initiative like CKF-AI ends.

8. In retrospect, CKF-AI grantees continue to give the initiative very high ratings. They have a number of practical suggestions for reinforcing its gains.

A year and a half after the grant's expiration, CKF-AI's grantees continue to express high enthusiasm for the initiative, even in cases where their specific intervention projects are struggling. In terms of how well the initiative helped them work on understanding and reducing access barriers, the "grades" given by the group were as follows:

Grade	*Number of Grantees*
A+	3
A	2 ("For taking it on." "Thanks, and send more money!")
A-	1
B+	5 ("Would have been A, if the funding period was longer.")
B	4
B-	2 (One of these suggested a grade of "incomplete.")
C+	1

Median grade = B+

As in the earlier evaluation, grantees were unanimous in noting that the initiative's two-year timeframe was very short, considering its stated goals. Several suggestions were offered for improving the match:

- **Keep the present design but lengthen Phase II from 1 year to 2 or 3 years of funding (possibly in declining amounts) in order to give projects more development time.**
- **Keep the present design with 1 year for Phase I and 1 year for Phase II, but add a third year with additional funding to allow for evaluation of results.**
- **Keep the present 2-year design, but add an option allowing grantee teams to apply for continued funding if their projects showed promise but needed additional time to mature**.

In hindsight, grantees offered the following thoughts on the question of what had encouraged success with their intervention projects:

- **Pre-existing long-term coalitions were essential as groundwork for CKF-AI's access-improvement efforts.** In particular, the initiative relied heavily on the relationships built over many years through Covering Kids and Families. It would be a mistake to think of CKF-AI as a stand-alone effort. It could not have been successful without CKF.
- **The information-gathering stage of CKF-AI was indispensable.** The Phase I investigations brought to light important information that surprised even those grantees who were convinced they already understood access barriers in their communities.
- **In a short-term initiative like CKF-AI, grantees advise: "Don't invent new local networks—work with the ones you already have in place."** Otherwise, much of the grant period will need to be spent in developing infrastructure for the effort, rather than setting up intervention projects.
- **An especially productive strategy for focusing access-improvement intervention efforts has been to identify and target areas of interest overlap among diverse stakeholders.** Many barriers to care—for example, those related to medical transportation and low English proficiency—are open to "win-win" interventions that can benefit not only consumers but also providers, hospitals, health plans, and even the local business community. Because some stakeholders may not initially recognize the potential for mutual benefit, raising awareness and redefining the problem are important early steps in such interventions.
- **"Stories from the front line" have been an especially useful tool for influencing policy makers.** In their system change efforts, the state partners have been able to make active use of the case examples provided by CKF-AI grantees. Several grantees have compiled booklets of case examples and are circulating them with apparent high impact. For example, the **Maine** grantees have distributed a colorful book of "Conversations with Real People" to state legislators, and the grantees in **Houston, Texas** have compiled a book of "Family Profiles" (which has gotten national press coverage) to show the disastrous consequences of recent access-restricting changes in Texas state policies.

- **Some materials and websites developed by the grantees are permanently useful. Others have a limited shelf life and need periodic updating, which takes resources.** Consumer information describing symptoms and appropriate care for common diseases of childhood does not usually need updating. On the other hand, material providing consumers and/or providers with system-navigation information must be kept current with policy changes. Otherwise, it ceases to be useful and much of the original investment's value is lost.

- **Where the goal is changing service providers' negative stereotypes or consumers' erroneous health beliefs, grantees advise: "To change mindsets, small steps may be best."** Grantees found that packing their consumer and/or provider education materials with too much information or too many different issues could be counterproductive. If kept simple and focused, the materials were more likely to be used.

V. Conclusions

Many unknowns were unavoidably left hanging at the time that CKF-AI's funding period expired. At that point, it was hard to say whether or not the initiative had been a "success." But now, from the vantage point of a year and a half after its end as a formal grant initiative, what can we conclude about CKF-AI?

The answer depends on the type of evaluation question posed. One way to look at funded initiatives is to view them as field experiments to pilot specific intervention strategies and test their effectiveness. Evaluation would then focus on the question:

> ***What measurable outcomes and long-term impact can the grantees demonstrate from their funded efforts?***

Looked at this way, the descriptive findings summarized in Appendix A of this report paint a rather discouraging picture. Only about a third of the original CKF-AI intervention projects are really thriving. Some have been put on hold, overwhelmed by external circumstances. Some have adapted so much to the priorities to new funding sources that it is questionable whether they should still be thought of as "CKF-AI projects." The impact of those that appear successful is still documented mainly with impressions. Some desirable program elements (such as close and frequent contact between grantees and their state partners) have lapsed, and some hard-won policy agreements (such as formal adoption of best practices by managed care organizations and changes in state contract language) are in danger of slipping away for lack of reinforcement over time.

However, a broader set of evaluation questions may be more appropriate for initiatives like CKF-AI, where the target is a very large, ongoing, multifaceted social problem; uncertainty exists about the nature of the problem itself; the various grantees' activities are heterogeneous and site-specific; the pace of the grantees' work is unpredictable and fits awkwardly into the funding timeframe; and the funded projects are greatly affected by external developments in the state and federal policy context. For CKF-AI, and for any initiative with these characteristics, it seems more productive to ask:

> ***What new information and insights have resulted from the initiative, after as well as during the grant period?***

> ***Did the funding significantly strengthen grantees' ability to work toward the initiative's underlying long-term goals, after as well as during the grant period?***

Looked at in this broader way, CKF-AI has succeeded admirably in:

- **Producing new information about the nature of access barriers, bringing to light many aspects of the problem that had not previously been well understood**.[20] Some barriers seem to be more widespread and serious than had previously been appreciated—in particular, problems related to cultural difference, problems getting prescriptions filled, and problems locating providers willing to take Medicaid/SCHIP patients. Equally important, some ways in which diverse stakeholders can find common interests in reducing barriers have become much clearer through the initiative.

- **Stimulating a variety of innovative intervention projects, providing models for other advocates seeking to reduce access barriers**. The participating grantees say they have benefited greatly from talking with each other about their strategies and materials. In addition, the Center for Health Care Strategies has posted the earlier evaluation, a related toolkit, and grantee contact information on the internet,[21] which has attracted interest and inquiries from health advocates even in states that were not among the original CKF-AI participants. The Urban Institute's Phase II Final Report: *Case Studies of Five CKF-AI Grantees* will give a detailed description of five successful CKF-AI projects that can serve as program models.

- **Laying a foundation firm enough for most grantees to succeed in finding alternative funding sources to sustain their access projects in some form after the initial grant expired**. In addition to the funded projects themselves, grantees say that the prestige of receiving a grant from RWJF has given them added leverage in finding alternative support. (Planned collaborative giving by multiple funders to nurture access improvement efforts over time would greatly smooth the path for grantees who need a long timeframe for their projects to mature.)

- **Building capacity in the grantee teams, better equipping them and their organizations to address access barriers over the long term.** Even where external events have put the access projects temporarily on hold, grantees say they now have in place many more building blocks for change when the time is right.

- **Refining strategies for communicating with decision-makers to correct information gaps and misconceptions about healthcare access.** Many insights have been gained concerning what kinds of information gaps exist for various stakeholder groups, and how to get the attention of decision-makers with "real stories from real people."

- **Generating a number of lessons potentially useful for the program sponsor's future grantmaking**. Hopefully progress will eventually be made on expanding insurance coverage in the United States, but reducing access barriers seems likely to remain an important focal point for improving the nation's health care, no matter what form the health care delivery system takes. What has been learned from CKF-AI remains highly relevant to future RWJF funding initiatives.

In terms of the broader evaluation questions, the present study finds that CKF-AI has been a remarkably fruitful investment.

20 The CHCS evaluation gives a more detailed account of grantees' findings on access barriers; see footnote 1.

21 At www.chcs.org

Appendix A: Brief Summaries of All Grantees' Post-Grant Experience

FIGURE 1: CKF-AI Grantee Organizations and Their Projects

(Grantees in bold type are scheduled for site visits)

Grantee	Primary Project Focus	Project Status at the End of the Grant Period (Based on Grantee's Final Reports)
ARKANSAS (Texarkana) Our Children First Coalition	The state Medicaid system was not informing consumers about federally mandated EPSDT services.	The state had agreed to include information on EPSDT in the next Medicaid benefits manual (not yet implemented).
CALIFORNIA (Fresno) Multicultural Community Alliance	Rural families (especially SE Asian immigrants) were unaware of local care options such as FQHCs. Pharmacists were scarce and some would not fill Medicaid/SCHIP prescriptions. FQHCs could not fill prescriptions without a waiver.	Planned efforts to inform families about FQHCs and to educate pharmacists about benefit requirements were just getting started as the grant ended. The state's Medicaid waiver request had not yet been acted on.
CONNECTICUT (Bridgeport) **Bridgeport Child Advocacy Coalition; East CT Health Network ("East of the River")**	**In both project sites (urban Bridgeport and rural East-of-the River), local pharmacists were confused about health plans' reimbursement rules. They sometimes would not fill prescriptions unless families paid out-of-pocket, even in emergency situations where the rules allowed a temporary 30-day supply without prior authorization.**	**Fact sheets had been distributed to 30,000 parents and 650 pharmacists. Six MCO contract changes were recommended to DSS. Some MCOs had agreed to adopt a "best practice" on emergency supplies. A computer screen alert for pharmacists at the point of billing was under discussion, and a toolkit for pediatric office staff was ready for distribution.**
IDAHO (Coeur d'Alene) Kootenai Medical Center	Consumers lacked information about Medicaid/SCHIP resources and the importance of a "medical home." Providers lacked cultural sensitivity in dealing with low income patients.	Public information was given out through 172,000 school newsletter inserts; 5,000 education packets; and local media ads. A sensitivity training CD-ROM for providers was in production.
MAINE (Bangor, York) Penquis Community Action Program, York Community Action Coalition	MaineCare consumers were unaware of the program's full range of benefits such as speech therapy, chiropractic care, and hearing exams. In particular, most did not know that benefits included transportation for medical care. Both consumers and pharmacists reported problems with using the system's prescription drug benefits.	1,000 "MaineCare Benefits" cards went out to consumers in a three-county area. 1,000 benefits factsheets went to pharmacists. DHHS agreed to improve their website benefit information. A compilation of case examples ("Conversations with Real People") was distributed to state-level policy makers.
MARYLAND (Baltimore) **Baltimore Health Care Access**	**Newly arrived Hispanics (specifically, pregnant Latinas and their newborns) faced many language and cultural barriers to adequate care and needed help to negotiate the health care system. Providers were hard to reach on weekends and evenings. Providers were confused about Hispanic naming customs, leading to lost medical records. New state policies threatened to drop coverage for thousands of women and children.**	**A number of area hospitals had partnered with the grantee to offer cultural competency and language training for their staff. Information on how to use health services, including print materials and a bilingual video with a soap-opera format ("Senora de La Cruz"), was designed, pretested, and widely distributed in the community.**
MINNESOTA (Olmsted County) **Olmsted County Health Care Access Initiative**	**The area's rapidly growing immigrant population had great difficulty with paperwork/ billing and communication issues in health care, as well as problems related to cultural differences and trust. Outreach posed special challenges due to the target population's diverse backgrounds (including Somali, Sudanese, Cambodian, Hmong, Bosnian and Latino). The state was developing a new web-based billing system ("HealthMatch") that would be highly relevant to the grantees' planned intervention, but this was proceeding very slowly.**	**A Community Health Worker program was established allowing trained CHWs from the community to assist families in their homes and/or drop-in centers. After some early growing pains and many lessons learned, the CHW program was on a firm footing and well accepted in the community. Grantees developed a matrix showing the huge volume of paperwork going to clients—an eye-opener for health plans and state-level policy makers. The state's HealthMatch system had not yet materialized.**
MINNESOTA (Minneapolis) Minneapolis Dept of Health and Family Support	New immigrants faced multiple barriers related to using health services, billing, scheduling appointments, finding interpreter services, medical transportation, etc. New state-level cost-sharing policies were a problem for many. The state was developing a new web-based billing system ("HealthMatch") that would be highly relevant to the grantees' planned intervention, but this was proceeding very slowly.	A "system navigator" was hired to give one-on-one assistance. Informational materials in a variety of languages were widely distributed, including cards on the right to an interpreter; "I've been helped" cards to avoid duplicate assistance; a health plans resource list and Community Resource Directory; and an Access Folder. A state commission on translation/ interpreting issues was established. Meanwhile, the state's planned HealthMatch system had not yet materialized.

Grantee	Primary Project Focus	Project Status at the End of the Grant Period (Based on Grantee's Final Reports)
NEW MEXICO (Albuquerque) Youth Development Inc.	The grantees' largely rural county had no hospital and poor transportation links to urban centers. Many covered families lacked a "medical home" and were out of touch with the health care system.	A school-based immunization program had been established as a "hook" to link families with providers. Grantees were developing plans and financing strategies to build a hospital complex—a long-term goal, still uncertain as the grant ended.
NORTH CAROLINA (Asheville) Buncombe County Dept of Social Services	Covered families lacked "health literacy" and did not understand when and how to access services other than the ER for non-emergency health needs. Because medical translation resources were in short supply, non-English speaking families sometimes could not communicate with providers and turned to the ER as the only place to get interpreters. Providers did not understand patients' right to an interpreter, and did not know how to obtain medical translators when needed. There was no state-level certification or reimbursement for medical interpreter services.	The grantees had developed and widely distributed (along with counseling) a health information packet containing a thermometer, information on how to interpret fever, information on care for common illnesses, and a laminated checklist of symptoms. Major effort went into developing a community bank of Spanish-speaking medical interpreters and making them available at nearby Urgent Care centers. At the end of the grant, the interpreter bank was operating well and seemed headed toward sustainability through a business model. Many generalizable lessons had been learned about how to set up this kind of service. State certification and reimbursement of medical interpreters had not yet been achieved.
OREGON (Portland) Outside In	Existing practices at Portland's inpatient drug treatment programs were discouraging addicted homeless youths from accessing needed health services, despite coverage. This medically needy, hard-to-reach population was often completely out of touch with health care services of all kinds.	Grantees worked with the area's largest detox center to expedite access, and succeeded in placing 88 addicted youths in detox with a high completion rate (82%). Unfortunately, during the grant period, state policy changes essentially eliminated insurance coverage for this target population. At the grant's end, the state partner was preparing a white paper on system barriers for addicted youths in need of detox and other health care.
PENNSYLVANIA (Philadelphia) Philadelphia Citizens for Children and Youth	The state's Medicaid Managed Care Organizations were failing to provide adequate interpreter supports. The state's private contractor for medical transportation was providing inadequate and culturally insensitive service, especially for migrant workers. Families needed help with navigating the health care system.	The state's new MCO contract included some of the grantees' recommendations on interpreter services. Several well-attended "know your rights" community workshops were held. The grantees participated in developing the RFP for a new medical transportation contractor and got several changes made in the state's contract language.
PENNSYLVANIA (Pittsburgh) Consumer Health Coalition	The city of Pittsburgh has the highest maternal smoking rate in the nation—yet the state's Medicaid Managed Care Organizations were failing to deliver mandated smoking cessation services to pregnant patients. The state agency responsible for enforcing compliance was not correcting this situation.	The grantees analyzed MCO's contractual responsibilities and produced a white paper with recommendations to the state agency. They participated in a state-level workgroup on smoking cessation that brought together state officials and MCO managers. At the end of the grant, no changes in enforcement had yet been made.
TEXAS (Houston) Children's Defense Fund of Texas	Access to prescription drugs was being blocked by confusing preferred drug lists and prior authorization provisions in the state's new CHIP/Medicaid Vendor Drug Program. Families were not able to get prescriptions filled by local pharmacists, who lacked clear guidance on what drugs were reimbursable. Families often received incorrect information about cost-sharing, paid out-of-pocket, or went without the prescribed medications.	The grantees partnered with the Texas Medical Association and the Houston Association of Pharmacists to offer CEU workshops on the state's new drug program. A Power Point presentation was developed for policy makers, and a town-hall meeting was sponsored by the state's largest children's health plan to present CKF-AI findings on Rx access. Educational materials were distributed to both consumers and providers, including a laminated formulary list for pharmacists.
TEXAS (Rio Grande Valley) Migrant Health Promotion Inc.	Language and literacy barriers often prevented the area's largely Spanish speaking residents from using health care services. Providers lacked knowledge of health care mandates and requirements, and had many negative stereotypes. Families' awareness about system navigation and preventive care was low.	The grantees' community health workers (promotoras) worked with families to increase awareness of health care options. Case examples were provided to the state partner for use in informing policy makers. The grantees developed a colorful, highly portable medical records folder for storing medical information—a boon to migrant families who move frequently.

Grantee	Primary Project Focus	Project Status at the End of the Grant Period (Based on Grantee's Final Reports)
VIRGINIA (Radford) Radford University Foundation	Consumers lacked confidence and information for system navigation. With a serious shortage of providers willing to take Medicaid patients and no convenient urgent care center, families found the ER their only alternative, especially for evenings and weekends.	Information booklets were distributed to 1,500 families and personnel of local schools, Head Start programs, and Early Childhood Intervention programs. A provider database was developed. Plans were developing to open an Urgent Care Center near the ER to provide more options for families in need of health services.
WASHINGTON (Olympia) **CHOICE Regional Health Network**	**Shortage of Medicaid providers was seen as the most serious problem, but the grantees found it was not amenable to solution through their original plans. They switched to lowering ER use for a small subpopulation of users—chronic pain patients who sought help there frequently (sometimes several times a month) because they were unaware of better alternatives. The care received at the ER was not well suited to their medical needs.**	**The grantees established interdisciplinary hospital-based teams to help heavy ER users find a primary care provider and obtain more appropriate care. While the number of patients served by the program was fairly small at the time the grant ended, the cost savings and the improvement in patient satisfaction were impressive.**
WEST VIRGINIA (Charleston) United Way of Central West Virginia	This rural area lacked health care facilities and services. Especially during evenings and weekends, families were often unable to find professional health care without traveling long distances. They had little understanding of common diseases of childhood, and did not know what required emergency service and what could be handled at home. In the absence of better alternatives, they "overused" the ER, fueling negative stereotypes.	Because the scarcity of services left families to cope on their own, the grantees focused on giving parents information about how to care for common childhood diseases at home (and how to recognize a true health emergency). Working through "Parents As Teachers" home visitors, they gave 500 local organizations and 128 families copies of a book titled *What To Do When Your Child Gets Sick*, developed by two nurses in California. This resource was received enthusiastically by the participating families, who reported feeling more confident of their ability to give appropriate home care. Efforts to interest the state in adopting the project were underway, although not yet successful.

FIGURE 2: Status of CKF-AI Grantees' Projects At the Time of Follow-Up

(Grantees in bold type are scheduled for site visits)

Grantee	Current Project Status	Reported Post-grant Progress on Access Goals
ARKANSAS	Discontinued as a specific project when the grantee organization closed and the project director left.	According to the state partner, information produced through CKF-AI continues to be useful in informing policy makers and has furthered new interventions (see Figure 3). DHS did issue a new manual with improved information on EPSDT.
CALIFORNIA	Now blended with other efforts through the grantee's ongoing promotora program.	Grantees feel they have succeeded in raising community awareness and changing negative stereotypes about existing but underutilized health clinics (FQHCs). Some clinics have agreed to extend hours into evenings and weekends, though not all have yet followed through. No significant progress yet on the Rx goals.
CONNECTICUT	**Continuing and expanding in Bridgeport. (The East-of-the River part of the project was discontinued when grant support ended.)**	**The parent flyers, pharmacy fact sheet and provider toolkit were all well received and are still in use, but it is now clear that they need regular updating; resources for this are a problem. One large health plan had adopted the computer screen alerts (a major victory) but another health plan that agreed to do so had not yet followed through. Plans were underway for improving in-service training at two especially problematic local pharmacies. The state had not yet made the recommended changes in MCO contracts.**
IDAHO	Discontinued as a specific project when the parent institution withdrew support after the grant ended.	The school newsletter information inserts were well received but are not continuing. The sensitivity training CD-ROM for providers did get completed and distributed, with some minor technical flaws due to rushed production. Meanwhile, some grant-supported spin-off projects were undertaken by the state's CKF organization.
MAINE	Now merged into broader social service assistance.	The project focus has shifted to comprehensive counseling not only on how to obtain health benefits, but also help with fuel, housing, etc. The CKF-AI consumer and pharmacist factsheets are still available but need updating; resources for this are a problem. The booklet on "Conversations with Real People" is still being used for informing policy makers about access barriers, although policy change efforts have slackened.
MARYLAND	**Continuing and expanding.**	**Informational materials are still being widely distributed. The video (which has attracted national attention) is particularly popular with consumers, and reportedly some providers are now using it to train their office staff. Work continues on improving provider awareness about Latino naming conventions. Through a spin-off program, Spanish/English printed resources on health care access are now being made available in kiosks set up in eight locations, including a large grocery store that 30,000 Latinos pass through annually.**
MINNESOTA (Olmsted County)	**Continuing and expanding.**	**The community health worker program developed through CKF-AI is actively delivering help not only with basic access concerns but also with health literacy ("They need to know, 'Why do I need to keep getting treated for diabetes, why can't they just cure it?' You can't just say, 'Take a bus and go to the doctor.' They need to know what is a bus and how to ride it.") The program has become slightly smaller but much more sophisticated in terms of recruitment, training, and management. CHWs are now required to go through a state certification program, which in principle would qualify them for third-party reimbursement if some currently proposed state legislation goes through. Meanwhile, the state's HealthMatch system is still not established.**
MINNESOTA (Minneapolis)	Temporarily suspended. Seeking funds to continue work on access barriers.	The grantee is in the process of teaming with Family Resource Centers through the school system to continue assisting families with access problems. Meanwhile, the state commission on translation/interpretation services died without results, and the state's HealthMatch system is still not established.
NEW MEXICO	Continuing and expanding.	The immunization program is continuing through the school system and might expand to other counties or even statewide, although whether it actually functions to give families a medical home is unclear. The real breakthrough has been in getting a hospital built. The grantees succeeded beyond their own expectations, and ground will be broken in 2007 for a new full-service teaching hospital that will greatly expand access.

NORTH CAROLINA	**Continuing and expanding.**	**CKF-AI health literacy materials are still being distributed – mainly through the grantee's large clinic, less so through other pediatric practices. The West North Carolina Interpreter Network (WIN) has grown into a self-supporting service with about 30 trained interpreters providing services in 7 languages (Spanish, Russian, Moldavian, Chinese, Korean, American Sign Language, and Portuguese). Translator appointment requests have increased ten-fold. Besides serving 65 medical practices, the interpreter bank donates services to a program called Project Access, which provides specialized health care to the uninsured through volunteered provider services. Meanwhile, CKF-AI's state-level policy change goals are still "on hold."**
OREGON	Temporarily suspended, pending developments at the state level.	The grantee's focus of effort shifted to service interventions (needle exchange, "Road Warriors" outreach program) in response to state policy changes that caused many in the target population to lose insurance coverage. Groundwork has been laid for a return to work on access issues when the context allows.
PENNSYLVANIA (Philadelphia)	Temporarily suspended. Seeking funds to continue work on access barriers.	Contract changes were made for the state's new medical provider, but the grantee organization has not been able to monitor whether this has actually improved service. They "have not done much on LEP since the funding ended." It's uncertain whether their partner Congreso will continue to organize community workshops.
PENNSYLVANIA (Pittsburgh)	Discontinued, stalled by state inaction. The project director has left.	The state has not moved ahead on enforcement of contract requirements. The state's workgroup on smoking cessation has been disbanded without issuing a report.
TEXAS (Houston)	Temporarily suspended, pending developments at the state level.	The grantee's focus of effort shifted to enrollment outreach in response to state policy changes that caused many in the target population to lose insurance coverage. Groundwork has been laid for a return to work on access issues when the context allows.
TEXAS (Rio Grande Valley)	Struggling, very short of resources. Unable to "wrap up" everything they had planned.	The promotora program continues, but is no longer year-round; it has been scaled back to a migrant and seasonal basis. The pharmacist survey data has not been analyzed, but doing the survey built relationships and raised pharmacists' awareness about barriers. The supply of medical record folders has been exhausted and no funds are available for producing more, despite their low cost ($1 each). The grantee still occasionally contributes case examples to the state partner for advocacy use.
VIRGINIA	Discontinued when the parent institution withdrew support after the grant ended.	The Urgent Care clinic opened briefly, but was closed by the University. The project director, whose position has been de-funded by the University, is hoping to open a new clinic and make use of some CKF-AI products (e.g., the educational materials and provider database).
WASHINGTON STATE	**Continuing, but on a smaller scale due to slim resources.**	**While the number of ER clients being referred is increasing, only one part-time staff member is now available to actually see clients. A list of providers willing to take Medicaid/SCHIP patients is maintained and updated daily – "not that small of an intervention, because nothing like it existed before, as a resource for clients."**
WEST VIRGINIA	The original program no longer exists, but was "reincarnated" as a broader social service program. Meanwhile, the original program concept is being replicated elsewhere in the state.	The original program "dissolved for unique reasons" and the project director left, but a new program has replaced it – a broad intervention through community health centers, aimed at a wide variety of child development issues that go "beyond helping with the sick child." The original project attracted the attention of a local foundation ("they really liked the access work we did"), and is now being replicated in two additional counties. The annual Child Health Conferences started through CKF-AI are continuing, and insights from CKF-AI are being used actively by the state partner in policy discussions related to WV's recent "Medicaid redesign."

FIGURE 3: Resources Supporting the CKF-AI Grantees' Access Efforts At the Time of Follow-Up

(Grantees in bold type are scheduled for site visits)

Grantee	Current Program Support
ARKANSAS	While the original project has ended, a spin-off program consisting of nine pilot projects to improve EPSDT services is being funded by the Arkansas Foundation for Medical Care.
CALIFORNIA	Their community-based access work continues at a reduced level through ongoing projects supported by other grants.
CONNECTICUT	**The grantees are able to continue their access work (although with a somewhat changed focus) through support from the Universal Health Care Foundation, an organization hoping to see Connecticut adopt a state-level plan for universal coverage similar to the one in Massachusetts.**
IDAHO	The project was housed within a large hospital complex that in principle might have been able to continue the access work as community service, but chose not to do so. As a spin-off, Idaho's CKF coalition undertook some school outreach programs related to CKF-AI (although with a different focus), funded by the Paul G. Allen Foundation.
MAINE	The project has been absorbed into the grantee organization's broader social service interventions, funded by a combination of foundation grants and the community service penalties paid by the Anthem health care system when it went private.
MARYLAND	**The grantee organization is 90% supported by the Department of Health and Mental Health, giving it permanent core funding.**
MINNESOTA (Olmsted County)	**Current funding, effectively substituting for the RWJF grant, comes through a five-year support commitment from United Way which overlapped with CKF-AI but extends three years beyond the RWJF funding period. A smaller amount of support comes from the BlueCross/BlueShield Foundation and the Mayo Clinic. The shift to United Way funding meant a broadened program scope (help with citizenship, housing etc as well as medical access) and required some retraining for the community health workers.**
MINNESOTA (Minneapolis)	Sustainability is a major problem. They are actively seeking grants, hoping to continue the access project. Reimbursements from school-based immunizations, interpreters and nurse services provide 1/5 of their funding. They get some support from the Health Department, but "protecting the safety net" has to compete with 5 other identified health priorities: youth violence, preparation for emergencies, obesity, sexual health of adolescents, and health needs of young mothers/early childhood.
NEW MEXICO	The project director's position has received continued funding from the grantee organization's other grants from non-profit institutions. Program costs for the immunization program are being picked up by the school system, and costs for the hospital ($10 million) are being supported through an increase in local property taxes which allowed the county to float bonds.
NORTH CAROLINA	**Minor costs associated with the CKF-AI health literacy materials are being absorbed by the grantee organization. Further development of the medical interpreter bank is being supported by a two-year grant from the Mission Foundation, with a business model used to cover costs of the service itself (physicians request the service and pay a fee of $40 per hour, lower than competing private interpreter services). The interpreter bank is expected to become entirely self-supporting.**
OREGON	Not applicable, since the CKF-AI project is on hold.
PENNSYLVANIA (Philadelphia)	No replacement funding. "We have looked at possible funding sources to continue work on this. No luck. Doing systems work isn't sexy to foundations. It's not going to result in a product with their name on it. We had already done the fun part, researching the problem." "It's hard to keep doing access programs when the money runs out…We're all still interested and committed, but for all of us, there are so many priorities."
PENNSYLVANIA (Pittsburgh)	Not applicable, since the CKF-AI project is now inactive.
TEXAS (Houston)	Not applicable, since the CKF-AI project is on hold. The grantee organization has funding from multiple sources and plans to resume access improvement efforts once the current enrollment crisis has passed.
TEXAS (Rio Grande Valley)	Community outreach continues through their existing promotora program, but resources are so slim that the medical record folders can no longer be produced despite their low cost. "We haven't found anyone who will fund it. The funding sources out there are very narrow, they have a specific focus and are always looking for innovation, so maybe they want to move on to new things…If you happen to see anything, an RFP, please let me know!"
VIRGINIA	The project director got a one-year carryover from an existing HRSA grant, and is seeking funding for the new clinic from the Virginia Healthcare Foundation and also from RWJF Local Initiatives. Funding discussions are underway with a large health plan, Virginia Premier. "We're in crisis here in this local area, but it's a local setback. The state as a whole is moving ahead. Radford University did not stay with us, but we're still on the same road…There are other ways to skin a cat!"

Grantee	Current Program Support
WASHINGTON STATE	**The grantee organization is absorbing some ongoing costs, but is currently "in a low spot for funding." Application has been made for state funding through a program called "Communities Connect" which would build on the CKF-AI project, although the focus would broaden to include social service as well as medical needs. At the time of the interview, this application was still pending.**
WEST VIRGINIA	United Way absorbs some continuing costs as part of a broader child development intervention. Funding for replication of the original access project in two other counties comes from a regional foundation, the Claude Worthington Benedum Foundation, that has a special interest in West Virginia. The state partner has donated her time and most of her CKF-AI state-partner grant to see that access efforts continue. She says, "I ask everyone for money."

FIGURE 4: Organizational Changes among CKF-AI Grantees At the Time of Follow-Up

(Grantees in bold type are scheduled for site visits)

Grantee	Projects' Current Organizational Status
ARKANSAS	The original grantee organization has closed—"not as a result of the grant ending, it just came to the end of its life cycle." The original project director left the area when her husband took an out-of-state job.
CALIFORNIA	The grantee organization oversees a coalition of numerous partners whose roles shift depending on the project. These relationships were strengthened by collaboration on CKF-AI and continue as a base for access-improvement efforts.
CONNECTICUT	**The grantee organization in Bridgeport is broad-based with multiple grants for housing, education, and other service areas in addition to health care. This has allowed the project director's position to continue after CKF-AI ended. By contrast, the project director's position at the East of the River site was entirely funded by RWJF and did not continue past the grant period, and access efforts there have ceased due to lack of staff.**
IDAHO	When the project director left at the end of the grant period, the job description for her replacement was redefined and the focus on health care access was lost.
MAINE	The original project director has left. Her work on access issues has been picked up by a staff member originally hired as a case manager for a variety of services, who joined the CKF-AI work fairly late in the grant period.
MARYLAND	**The original project director left the grantee organization at the end of the grant period, and management of the CKF-AI project was taken over by the organization's CEO, who had not previously been directly involved with CKF-AI. However, the original project director is still in close touch with the project because she now works in a grant-supported position at one of the grantee organization's long-term partners. A new staff member is currently being added to help manage the project.**
MINNESOTA (Olmsted County)	**The project has been transferred completely to the IMAA, a close collaborator with the grantee during CKF-AI. The current project director is still in close touch with the original project directors.**
MINNESOTA (Minneapolis)	During the CKF-AI funding period, the original project director was appointed Health Commissioner and the project management was taken over by a staff member, who has continued the effort. Both project directors have been beset by many competing priorities related to the state's deep budget cuts in health and human services.
NEW MEXICO	The project director served as consultant to the grantee organization rather than as direct staff. Since sufficient funding continued to be available, this arrangement allowed program continuity.
NORTH CAROLINA	**When CKF-AI ended, the original project director moved to a different position in the grantee organization and management of the interpreter project was shifted to the Buncombe County Medical Society (which has helped strengthen its acceptance in the medical community). The "new" project director at BCMS was closely associated with CKF-AI throughout the grant period, and continues to collaborate closely with the original project director.**
OREGON	The original CKF-AI project director is still at the grantee organization and still concerned about access barriers, but currently working on other projects.
PENNSYLVANIA (Philadelphia)	The original CKF-AI project director is still at the grantee organization and still concerned about access barriers, but currently working on other projects.
PENNSYLVANIA (Pittsburgh)	The original CKF-AI project director has left the grantee organization. Her replacement is working on other issues. "It's not just us affected when a grant ends, but all of our cooperating groups. We still have the relationships, but they aren't active in the way they had been."
TEXAS (Houston)	The original CKF-AI project director is still at the grantee organization and still concerned about access barriers, but currently working on other projects.
TEXAS (Rio Grande Valley)	The original CKF-AI project director is still at the grantee organization and still working on access issues despite a lack of resources. "We do everything we can to make a dent….This is my passion, my life."
VIRGINIA	The project director served as consultant to the grantee organization rather than as direct staff. When the grantee organization abruptly decided to close some services and discontinue this position, program continuity was jeopardized. The project director hoped to keep the effort going through personal advocacy and alternative organizational arrangements.
WASHINGTON STATE	**The original CKF-AI project director is still at the grantee organization and still concerned about access barriers, but currently working on other projects. Available staff resources have been redeployed within the organization to keep the project going. "You have to be creative."**
WEST VIRGINIA	The original CKF-AI project director has left the grantee organization. The driving force behind access work in WV is currently the state partner.

FIGURE 5: Grantees' Assessments of Their CKF-AI Project Effects At the Time of Follow-Up

(Grantees in bold type are scheduled for site visits)

Grantee	Evaluation of Original CKF-AI Projects	Grantee Comments on Evaluation
ARKANSAS	Not systematically evaluated. A related spin-off program may be showing positive effects.	The nine pilot projects on EPSDT that followed as spin-offs are being assessed through that separately funded program. The CKF-AI state partner thinks the preliminary findings are positive, but says "we haven't had time to look at it."
CALIFORNIA	Not systematically evaluated, although relevant data are being tracked for other purposes.	The integration of multiple efforts makes evaluation more complicated. "It really is difficult for us to identify results from specific grants…It's hard to say that something resulted from CKF-AI, in and of itself."
CONNECTICUT	**Not systematically evaluated, although complaints about Rx access seem to have dropped off in current focus groups.**	**"We just don't have the staff time to do any of this data gathering… It's very hard to break loose staff time when we're all working on other things as well, and need to be writing grants as well because we're grant-dependent."**
IDAHO	Not systematically evaluated.	"One way to [assess effects] would be to go back to the school nurses and other partners and ask them: Were the pieces helpful, did you use them? We never had the opportunity to go back to ask."
MAINE	Not systematically evaluated.	"It would have helped to have a line item for that."
MARYLAND	**As a city-funded agency, they are required to keep numbers for various activities (contacts, referrals, etc), but no impact data.**	**"We think there may be an increase in earlier prenatal care…but the raw numbers won't really tell you much, because of the continued influx of immigrants."**
MINNESOTA (Olmsted County)	**United Way requires twice-yearly reports on numbers of families helped, but no impact data. A survey of 87 clients, carried out by the community health workers, showed high satisfaction with the program.**	**"Would we be collecting these data if not required to do so [by United Way]? Probably not. We really don't have the capacity… We are not funded for tracking. We get paid to provide services."**
MINNESOTA (Minneapolis)	Not systematically evaluated.	"In terms of evaluation, our in-house research is driven by grants, so we were not looking at this [because assessment of program effects was not required].
NEW MEXICO	Not systematically evaluated.	"It would take a special study to really document [the immunization project], working with providers. We don't have the resources for that." "[For the hospital], it would probably be possible to track the effect on access through hospital records, because they'll be keeping records on everything. They're required to. They'll have lots of data. As to who would pore through it and analyze what it means for access, that would take a special study. At the moment we have no resources for that."
NORTH CAROLINA	**Not systematically evaluated. A subsequent grant from the Mission Foundation has required an interim report on numbers of participants served, but no impact data.**	**"We would have liked to evaluate more, but don't have the resources… It takes staff time, is the problem." "We do know that it [the health literacy material] has reached a lot of people and was well received by the small group we talked to." "On the interpreter network, we haven't continued to track it. It could be, though—it's just waiting to be tracked." "How do you get measurable data that shows what the interpreters prevented from happening, such as a misdiagnosis? It's virtually impossible to show that kind of effect."**
OREGON	Not systematically evaluated.	The enrollment crisis put the CKF-AI activities on hold, precluding evaluation of CKF-AI results. "The context changed. The population we were aiming at [homeless addicted youths who had insurance coverage] more or less disappeared."

Grantee	Evaluation of Original CKF-AI Projects	Grantee Comments on Evaluation
PENNSYLVANIA (Philadelphia)	Not systematically evaluated.	"We did get the contract language changed…but we haven't actually monitored whether they've been complying. If I were still working on this, I would be calling them, asking questions….That piece—evaluation—doesn't just happen. Someone needs to be really engaged in it. We were having numerous conversations with DPW [about evaluation], but now our network and relationships are not as active."
PENNSYLVANIA (Pittsburgh)	Not systematically evaluated.	"It's important to be simply monitoring…we have been trying to remind [the health plans] to tell their pregnant patients that smoking cessation support is available."
TEXAS (Houston)	Not systematically evaluated.	The enrollment crisis put the CKF-AI activities on hold, precluding evaluation of CKF-AI results.
TEXAS (Rio Grande Valley)	Not systematically evaluated.	"We get lots of positive feedback from families through the promotoras. Also, I have seen families taking the medical record folder with them when they go to the doctor. The folders are bright yellow, so you can't miss them—you know it's our tool."
VIRGINIA	Not systematically evaluated.	During the brief time the new urgent care center was in operation, the project director feels that the patients who were referred to it "went from using it for episodic care to using it as a primary care provider. This was a good thing. Before, all they had was the ER. Now they had a medical home."
WASHINGTON STATE	**Initial small-scale analysis showed dramatic results: sharp cuts in ER use, greater patient satisfaction, and an average annual savings to the hospital of about $15,000 per patient.**	**Subsequent information has been gathered on ER visits and costs, and is being analyzed by the project's small staff ("they're passionate about it.") The cost savings are impressive and would seem of interest to hospitals. However, hospitals tend to feel that the savings are going to Medicaid, so Medicaid should help foot the bill for the project. The grantee says "We've shown enough, through this pilot program. Now we're waiting… It's the next step that matters now."**
WEST VIRGINIA	Evaluated with self-reported pre- and post-data for the three pilot counties. The CKF-AI state partner donated her own time and used her part of the CKF-AI grant to defray costs of this evaluation.	"Every legislator got a copy of the pilot study." "The pilot study… suggests the program is effective, but what you really need is an analysis of claims data. We do have that data through Medicaid but I don't know what it would cost to analyze it." "It's hard to get funding for that kind of thing. Foundations love to help people. They want to fund services."

FIGURE 6: Grantees' Relationships with their CKF-AI State Partners At the Time of Follow-Up

(Grantees in bold type are scheduled for site visits)

Grantee	Current Working Relationship	Apparent Explanation
ARKANSAS	None.	The original project director has left, without replacement.
CALIFORNIA	Ongoing.	The relationship pre-dated CKF-AI. The state partner remains on the grantee organization's team of consultants for a variety of projects.
CONNECTICUT	**Available but contact is infrequent.**	**The relationship pre-dated CKF-AI. The state partner is still sometimes consulted on specific questions concerning access issues. However, without the grant, time is lacking for regular collaboration.**
IDAHO	None.	The original project director has left, without replacement.
MAINE	None.	The original project director has left. The access work now being done by her replacement is focused entirely at the local level and does not involve the state partner.
MARYLAND	**Ongoing.**	**The relationship pre-dated CKF-AI. The state partner remains a resource for the grantee organization on a variety of projects.**
MINNESOTA (Olmsted County)	**Available but contact is infrequent.**	**The relationship pre-dated CKF-AI. The state partner's work is largely completed for the local project (although her work continues on related state-level policy changes).**
MINNESOTA (Minneapolis)	Available but contact is infrequent.	In the absence of grant requirements, competing priorities and lack of time make regular collaboration difficult.
NEW MEXICO	Available but contact is infrequent.	The state partner's work on hospital planning is largely completed for the local project.
NORTH CAROLINA	**Available but contact is infrequent.**	**The state partner's work on interpreter training is largely completed for the local project (although her work continues on related state-level policy changes).**
OREGON	Available but contact is infrequent.	The state partner still arranges meetings between the CKF-AI project director and state legislators to "put a face on the crisis." She says, "CKF-AI changed what I pay attention to in policy work."
PENNSYLVANIA (Philadelphia)	Available but contact is infrequent.	In the absence of grant requirements, competing priorities and lack of time make regular collaboration difficult. "Working with the state partner was wonderful [during the grant period]…We did work with them before, but there's nothing like a formalized partnership, a reason to be getting together on an issue."
PENNSYLVANIA (Pittsburgh)	None.	The original project director has left and her replacement is working on different issues.
TEXAS (Houston)	Available but mainly on coverage issues.	The enrollment crisis caused by changes in state policy has temporarily diverted attention away from access issues. The relationship between the grantee and the state partner remains strong and both parties intend to work together actively on access issues when the time is right.
TEXAS (Rio Grande Valley)	Available but contact is infrequent.	In the absence of grant requirements, competing priorities and lack of time make regular collaboration difficult. "She tried, and I tried, to get together—but time just passed. We're still reporting to each other now and then."
VIRGINIA	Available but contact is infrequent.	When the university decided to close the project clinic, it put the grantee under a temporary gag order. As soon as this order was lifted, the SP was consulted—"but she's in the state capitol, and not very close to this." The SP does plan to advocate for some of the applications needed for an alternative clinic.
WASHINGTON STATE	**None with the original SP.**	**The original SP became seriously ill part way through the project, and this link was not fully developed. However, the SP's organization was instrumental in advocating for the state program through which this grantee now hopes to get funding.**
WEST VIRGINIA	None.	The project director has left and is now working as a school principal. Leadership of work on access issues has essentially been assumed by the state partner, who was a strong program champion throughout the grant period.

Appendix B: Statement of Study Purpose and Interview Guide

Purpose of the CKF-AI Evaluation Interviews, 2007

Thanks very much for scheduling an interview! Here's some information by way of informed consent.

The purpose of the interview, sponsored by the Robert Wood Johnson Foundation (RWJF), is to get an update on what's happened with your CKF-AI team's access-improvement work. There are no implications for any past or future funding, and your participation is completely voluntary. We hope to learn from your experience so the Foundation can better understand the successes, potentials, and challenges of this grant initiative.

Interviews with all of the CKF-AI grantee teams are being carried out jointly by:

- Carolyn Needleman, working as a consultant to RWJF. She conducted last year's evaluation of CKF-AI for the Center for Health Care Strategies.
- Staff of the Urban Institute (UI) in Washington—Ian Hill, Brigette Courtot, and/or Louise Palmer. UI is part of the team that's doing the evaluation of *Covering Kids & Families*, in collaboration with Mathematica Policy Research, Inc., and Health Management Associates, and they proposed that some additional evaluation of the *Access Initiative* should be included in Phase II of the overall CKF evaluation.

There aren't any "right" or "wrong" answers to the questions we'll ask. We just want to get your individual perspective and opinions.

As in the earlier evaluation of CKF-AI, we're hoping to get ideas and examples that can be used in various reports and issue briefs. However, the interview is confidential in the sense that none of what we discuss will be attributed to you as an individual without your permission. If anything comes up that you feel is especially sensitive or you prefer not to discuss, just let us know.

A rough agenda is attached, but we don't have to stick to it exactly. You should feel free to raise anything at all that you feel would be important to understanding your experience with improving access both during and after the CKF-AI grant.

There's no need for you to do any elaborate preparation and no need to respond to this memo in writing.

Looking forward to talking with you!

Agenda for the CKF-AI Evaluation Interviews, 2007

At the beginning of the interview:

- Do you have any questions about the interview's purpose, as explained in the statement sent to you?
- Do we have your permission to go ahead with the interview?

From the earlier CKF-AI evaluation and the project's final report, we have some idea of the Phase II implementation projects you were working on as the RWJF grant ended. As a starting point, we'll very briefly summarize what we think we know, in order to confirm or correct it.

Then we can discuss the following topics (not necessarily in order), plus anything else you think is important.

A. Activities Related to CKF-AI

- Update on projects started through CKF-AI
- Any continued information gathering related to access?
- Any new interventions (actual or planned) related to access?
- Sources of support for continued work on access issues
- Strategies for sustaining the projects after the end of RWJF funding
- Any organizational shifts involved in continuing your access work?
- Major successes
- Major challenges

B. Implementation Impact

- Do you see any direct effects from the work started through CKF-AI?
- Do you see any indirect effects?
- Your thoughts on data collection and measurement of effects
- Your thoughts on scalability and spread
- Any outcome data available that we could request?

C. Lessons Learned from the CKF-AI Initiative

- Re: Designing and implementing interventions to improve access
- Re: Documenting and measuring these interventions' effects
- Re: Sustainability of projects developed through CKF-AI

D. Advice for RWJF

- Based on your experience as a grantee, what grade would you give CKF-AI as a grant program, in terms of how well it enabled you to work on access issues?
- Any specific suggestions for RWJF?
- In addition to yourself, is there anyone else we should interview in order to get a complete picture?

Robert Wood Johnson Foundation

Our Commitment to Evaluation

The Robert Wood Johnson Foundation is committed to rigorous, independent evaluations like this one. Evaluation is the cornerstone of our work and is part of the Foundation's culture and practice. Our evaluation efforts often include varied approaches to gather both qualitative and quantitative data. These evaluations are structured to provide insight, test hypotheses, build a knowledge base for the field, and offer lessons learned to others interested in taking on similar efforts.