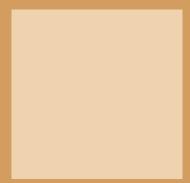
Reducing Barriers to Health Care: Practical Strategies for Local Organizations

Covering Kids & Families Access Initiative Toolkit









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CHCS Center for Health Care Strategies, Inc.

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Covering Kids & Families
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About the Center for Health Care Strategies

The Center for Health Care Strategies (CHCS) is a nonprofit organization dedicated to improving the quality and cost effectiveness of publicly financed care for people with chronic health needs, the elderly, and racially and ethnically diverse populations. CHCS works with state and federal agencies, health plans, providers, and consumers to design programs that better serve high-need and high-cost populations. Its program priorities are: improving quality, reducing racial and ethnic disparities, and integrating care.

The Covering Kids & Families Access Initiative, funded under the Robert Wood Johnson Foundation's Covering Kids & Families National Initiative, was designed to increase the number of eligible children and adults benefiting from public health care coverage programs. The initiative, managed by CHCS, awarded 19 grants to local pilot projects to identify and document barriers to the use of health care services for low-income children and adults enrolled in Medicaid and the State Children's Health Insurance Program¹ and to develop strategies to improve their access to health care services. This report highlights the successes and challenges of local community organizations working to improve access to health care services for low-income families.

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Activities in this toolkit relate to both Medicaid and the State Children's Health Insurance Program enrollees. To simplify text, Medicaid is used throughout the toolkit to represent both populations.

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Acknowledgments

The Center for Health Care Strategies would like to thank the many people who assisted with the Covering Kids & Families Access Initiative (CKF-AI) and with the production of this toolkit. We are especially grateful to the staff of the 18 local organizations who took this project from idea to reality and who devised the innovative solutions to problems that are described in these pages. CKF-AI grantees displayed both dedication to improving health care for low-income families and a willingness to work with the real complexities that emerged in their projects. Pat Redmond and Judith Solomon, from the Center on Budget and Policy Priorities, served as the expert advisors and guided program design and direction for our 18 grantees. We greatly appreciate the encouragement provided by Carolyn Ballard and others at CHCS, as well as Barbara Barr, Lori Grubstein, and others at the Robert Wood Johnson Foundation who supported this project through its implementation. Our evaluator, Carolyn Needleman, provided tremendously useful insights about the project during the course of her evaluation and in her final report. And finally, we recognize the hundreds of families who participated in surveys, focus groups, and telephone calls and helped to chisel away the barriers to much-needed health care services not only for themselves, but for many others.

FOREWORD:

SUPPORTING MEANINGFUL ACCESS TO HEALTH CARE



Access to health care means much more than having an insurance card in hand. Unfortunately, simply providing insurance coverage does not automatically guarantee the delivery of vital health care services. A myriad of barriers contributes to this problem, including lack of health care providers, language barriers, and transportation issues, as well as the intricacies of navigating a complex health care system.

Covering Kids & Families, a national initiative of the Robert Wood Johnson Foundation (RWJF), opened the door to health coverage for millions of children and adults across the country. The Covering Kids & Families Access Initiative (CKF-AI) was developed by the Center for Health Care Strategies, with RWJF support, to go one essential step farther: to ensure that children and adults enrolled in publicly funded health care programs receive the health care they need.

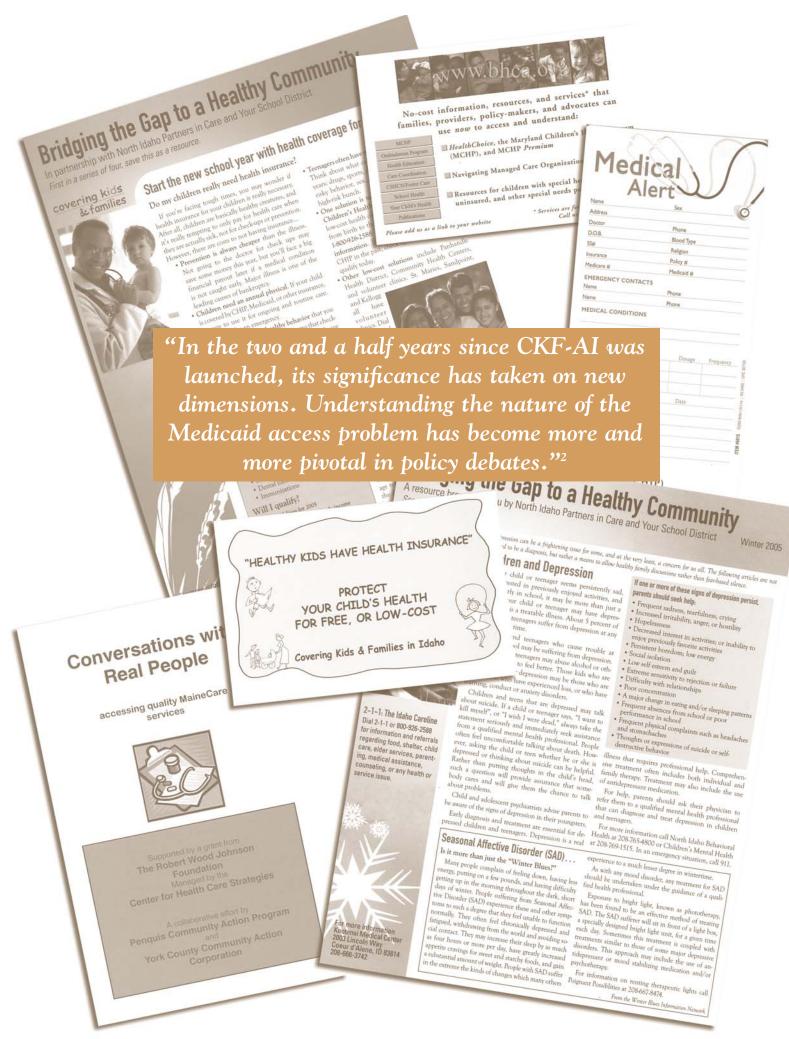
Through targeted technical assistance and key linkages with state partners, CKF-AI demonstrated a successful locally-based approach to improving access to care for families enrolled in Medicaid. The 18 grantees, all locally-based organizations with strong community ties, did not dive headfirst into solving access issues. First, they put assumptions aside and carefully listened to what families with children enrolled in Medicaid were telling them. Through surveys, telephone calls, focus groups, and one-on-one conversations, the grantees identified many of the multitude of barriers that impede access to health care. Organizations received expert help in narrowing the broad range of problems to one or two key focus areas, and in designing low-cost interventions to address the highest-priority issues.

This toolkit lays out a roadmap to help other local organizations, states, and health plans identify priority areas and to develop programs that effectively confront barriers to care. In particular, local funders can refer to this toolkit to effectively guide their own use of limited resources to support organizations that can catalyze important improvements in access to health care.

Through our ground-level work at CHCS, we know that the best-laid policies are meaningless if individuals, particularly those with chronic health care needs, face obstacles that deter them from getting necessary health services. We hope the lessons in this toolkit can help focus local community efforts to uncover, address, and, ultimately, reduce the barriers that limit the effective delivery of vital health care services to low-income families.

Stephen A. Somers, PhD

President, Center for Health Care Strategies



Introduction



The Covering Kids & Families Access Initiative (CKF-AI), supported by \$4 million in Robert Wood Johnson Foundation (RWJF) funding, was a national effort to improve access to health care services for children and families enrolled in Medicaid and the State Children's Health Insurance Program. Launched in 2003, the two-year initiative demonstrated a successful, locally based approach to a problem often considered intractable: the inability of many families enrolled in public coverage programs to obtain meaningful health care access. This toolkit is designed to highlight the lessons from the program.

CKF-AI was designed as part of the much larger Covering Kids & Families program, a \$150 million nationwide initiative by RWJF to increase the number of children and adults benefiting from health care coverage programs. The Center for Health Care Strategies (CHCS) provided program direction and technical assistance for CKF-AI. Local organizations participating in the larger Covering Kids & Families program were invited to apply for grants of up to a total of \$125,000 in two years. Eighteen local organizations in 15 states participated in the project from start to finish. The program's goals were intentionally broad, with the expectation — which was largely met — that grantees would develop specific, feasible projects appropriate to their local context. CKF-AI grantees were asked to aim for sustainable improvements in access to health care for low-income families.

Covering Kids and Families Access Initiative Participants



² C. Needleman. Covering Kids & Families Access Initiative, Final Evaluation Report. Center for Health Care Strategies, March 2006. Available at www.chcs.org.

How To Use This Toolkit

This toolkit is designed for local organizations and funders interested in improving access to health services for people enrolled in Medicaid. It draws upon the successes and challenges in the CKF-AI program to offer realistic, practical approaches that can help organizations to:

- Identify and document specific barriers that prevent children enrolled in Medicaid from receiving effective, necessary health care.
- Understand what kind of technical assistance is most useful for local organizations seeking to make concrete improvements in access to health care.
- Gauge the likelihood that a particular barrier to health care can be addressed through the intervention of a local organization working in partnership with other stakeholders.
- Test specific interventions for improving access to specific health care services.

How This Toolkit is Organized

This toolkit draws upon discussions conducted throughout the course of the grant with the 18 CKF-AI grantees, written grantee reports, and a formative evaluation of the program conducted by Carolyn Needleman, PhD.³ The evaluation provided tremendous insight into the elements of the program design and aspects of each grantee's work that led to success or, in some cases, impaired progress. The first section of the toolkit provides a description of the CKF-AI program, focusing on the program elements that proved to be critical to its success. The next sections discuss lessons about four action steps critical to the success of the project:

- Identifying barriers;
- Using technical assistance;
- Determining whether a particular barrier or combination of barriers can be effectively addressed by the local organization; and
- Assessing the potential of an intervention.

The appendices include contact information for CHCS, consultants, and the CKF-AI grantee organizations.

CKF-AI: Program Design Elements

The CKF-AI program was designed with three premises:

- 1. That a grounded, in-depth understanding of the reasons some covered families miss out on health care is a prerequisite for developing feasible strategies for change.
- 2. That local organizations are well-positioned to understand health access problems from the family's perspective, and can have a significant impact on barriers to health care, if they strategically choose the problems they address.
- 3. That access to state and federal policymakers might be necessary to bring about changes in the way that health care is delivered; and that, for the most part, local organizations do not have such access.

³ Needleman, op. cit.



Phase I of the CKF-AI program provided resources to help grantees identify and document barriers to health care access. Grantees could devote up to one year to these initial identification activities. Grantees were encouraged to use methods that they deemed appropriate to identify access problems in their communities, and to continue with Phase I until they had "gotten underneath" the surface of the problem.

"Getting underneath" entails understanding the issue from multiple points of view—those of families, health care providers, managed care organizations, and policy-makers. It also involves questioning assumptions and being willing to analyze, objectively and in great detail, what happens when a family on Medicaid attempts to obtain a particular service (for example, a prescription drug).

To assist grantees in choosing their individual areas of focus, the call for proposals limited Phase II interventions to no more than two of the issues identified in Phase I and stressed that projects funded by CKF-AI must have "a significant impact on access to care" and "should be feasible to address within a limited budget and time-frame." Technical assistance was especially useful in this phase of grantee work, as some local organizations had to winnow a broad range of problems to find the one or two that might prove feasible. Others needed assistance with designing low-cost interventions that could actually ameliorate serious problems.

Access to and expertise in working with policymakers is not a given for many local organizations. The program allowed grantees to obtain this expertise by partnering with statewide groups of their choice. A special pool of technical assistance funds was set aside for CHCS to purchase, on behalf of each grantee, technical assistance and/or collaborative activities with a statewide organization with expertise in policy issues and access to decision makers. The role of the state partner was broadly defined so that grantees, working with the technical assistance team, could customize the state partner's activities to meet their needs.

North Carolina: Buncombe County Department of Social Services

The Buncombe County Department of Social Services (BCDSS) in North Carolina was concerned about over-use of hospital emergency departments. After reviewing Medicaid claims data and identifying families defined as potential over-users, BCDSS interviewed a sample of these families to better understand why they turned to the emergency department for primary care. BCDSS also conducted focus groups with community leaders.

Two issues emerged: first, families with limited English were using the emergency departments and the county health clinic for care because these were the only places that provided medical interpreter services around the clock. Second, it was clear from the Phase I research that many parents were unsure about how to deal with routine childhood illnesses, such as when a fever should be treated at home with Tylenol and when the child should receive immediate medical attention.

Two strategies were designed to address the two issues. To help parents with a sick child and unsure what to do, the BCDSS developed, pre-tested, and widely distributed (in English and



Spanish) a packet of materials containing a thermometer, a laminated checklist of signs and symptoms of common childhood illnesses, and information on what to do when a child is sick. Because the county had a network of nurses who made home visits, these materials were often presented to parents along with in-person education. The materials were also provided by clinicians to families during sick-child appointments at the community health clinic and by community health nurses to all parents of newborns in the Medicaid program.

BCDSS interviewed a sample of parents before and after the materials were presented, and found an increase in parents' ability to manage children's conditions. Health care providers were impressed with the materials, and planned to assist BCDSS in finding additional funding to ensure continued distribution. A review of Medicaid claims data found some reduction in the use

of the emergency department, and BCDSS planned to determine whether the reduction was statistically significant.

To address the complicated problem of lack of interpreter services (an issue that many communities have struggled with and failed to solve), BCDSS recruited and trained a cadre of Spanish-language interpreters, using a curriculum designed by a specialist in medical translation. Interpreters were recruited through an advertisement in a local newspaper. Ten individuals who had volunteered their services in the community, but had never been trained, were selected to participate in the Western North Carolina Interpreter Network. BCDSS marketed the interpreter services to the community's four urgent care centers, and developed a series of regular meetings to help the interpreters exchange information and find peer support.

The Interpreter Network is an ongoing success, applauded not only by providers and families, but also by the interpreters themselves, who have found fulfilling employment with flexibility and decent wages. BCDSS is currently seeking long-term sustainability for the network by working to get Medicaid reimbursement for interpreter services and by establishing a business model. The network now has its own website (www.winbcms.org), where it promotes stressfree and culturally competent medical interpretation services in Spanish, Russian, Moldovan (Romanian), Chinese, and American Sign.

Practical Strategies to Improve Health Care Access



The CKF-AI program provides a replicable model of a successful approach to improving access to care for families enrolled in Medicaid. In this section, specific lessons gathered during program implementation and evaluation are outlined for grant makers and local organizations interested in conducting similar work.

Identification and Documentation

How can a local organization reliably identify and credibly document specific barriers that prevent children enrolled in Medicaid from receiving effective, necessary health care?

One of the most important lessons from CKF-AI was that reliable information about barriers to health care does not require expensive survey research or statistical analysis. After some trial and error, and technical assistance from CHCS, most grantees found effective ways to investigate how families actually experience health care access problems. Although there is no formula for obtaining detailed information about the barriers the families face, local organizations and grant makers need to be able to listen closely to families' experiences, pinpoint where the problems are occurring, and question their own assumptions. CKF-AI grantees often uncovered problems that were different or more complicated than they had assumed, and in the process they developed an appreciation for the difficulty some families faced in getting care.

One grantee, for instance, explained that "because of our rural location, we expected transportation to be a major problem." The grantee learned through focus groups with families that it wasn't. "People had ways of getting where they needed to go. But prescription drugs were a huge problem, and one that we hadn't known about. People were being given prescriptions, but they couldn't get them filled." Another grantee in a rural community was concerned about reports from hospitals that families were using emergency departments for primary care. The grantee initially focused on the need for family education, but learned through a survey of primary care practices that systemic issues were in play: families were routinely referred to emergency departments by their own doctors' offices or answering services on evenings and weekends, because there was no coverage for primary care at these times.

Focus groups are an excellent method of collecting information about barriers directly from parents of children enrolled in Medicaid. In-depth, one-on-one interviews with parents also work well for this type of research. Focus groups and one-on-one interviews were found to be far more effective than written surveys, which in the CKF-AI program generally had a low rate of return and lacked the rich, anecdotal detail provided by surveys and focus groups. Table 1 displays the research strategies used by the grantees.

Table 1: Grantees' Data-Gathering Methods

Grantees	Information Sources and Methods Used
ARKANSAS Our Children First Coalition	Families — Initially planned large survey, downsized to 96 interviews; five focus groups (not well attended due to conflict with working hours). Providers — Five interviews with family and pediatric nurses/nurse practitioners.
CALIFORNIA Multicultural Community Alliance	Families — Four focus groups; 200 bilingual interviews with Hispanics, Southeast Asians. Providers — Stakeholder meetings.
CONNECTICUT Bridgeport Child Advocacy Coalition and Eastern Connecticut Health Network/ East of the River HUSKY Collaborative	Families — Nine focus groups in English/Spanish, 28 one-on-one interviews. Providers — Eleven telephone interviews with pediatric offices; four in-person interviews pediatricians; one focus group with community-based providers; surveyed 12 pharmacists.
IDAHO Kootenai Medical Center	Families — Data from 61 Medicaid families (subgroup in a related survey); two focus groups with 16 participants, follow-up individual interviews.
MAINE Penquis Community Action Program and York Community Action Coalition	Families — Mailed survey (1,198 = 30% return rate); 64 one-on-one interviews. Providers — Mailed survey (247= 36% return rate).
MARYLAND Baltimore HealthCare Access	Families — Two focus groups (eight participants); six bilingual individual interviews; 50 interviews with Hispanic women with newborns. Providers — Discussions with hospital and with clinic administrators.
MINNESOTA Minneapolis Department of Health and Family Support	Families — Chart review for representative sample (N=88) of DHFS' "new families." Four focus groups in clients' native languages. Providers — Survey of 12 clinics used by DHFS clients.
MINNESOTA Olmsted County Community Services	Families — Survey administered by bilingual interviewers to 220 Medicaid-enrolled recent immigrants; contacts at 14 community-wide events.
NEW MEXICO Youth Development Incorporated	Families — Focus groups (10 participants); community discussions; information on access barriers from clients being enrolled (average 110 per month). Providers — Meetings with coalition including MCOs; physician survey planned.
NORTH CAROLINA Buncombe County Department of Social Services	Families — Interviews with 62 parents from sample lists based on claims data. Other — Three group interviews with key stakeholders and professionals; interviews with community leaders; community meetings.
OREGON Outside In	Families — Staff interviews with homeless addicted youth in community settings. Providers — Discussions with treatment center directors and staff.
PENNSYLVANIA Consumer Health Coalition, Inc.	Families — Mailed surveys (278 =30% return); focus groups. Providers — Survey of 106 providers in Healthy Beginnings Plus. Other — Legal review of managed care contracts and practices.
PENNSYLVANIA Philadelphia Citizens for Children and Youth	Families — Focus groups in English and Spanish; survey of 50 clients through Spanish-speaking community organizations. Providers — Informal discussions with providers at professional forum.
TEXAS Children's Defense Fund	Families — Eleven bilingual focus groups (112 participants); survey of 48 parents. Providers — Survey of eight pediatric offices by computer and fax; 37 pharmacists surveyed (survey form hand-delivered/faxed back).
TEXAS Migrant Health Promotion	Families — Four focus groups (51 participants); ~1,000 contacts by promotoras. Providers — Individual contact with 75 pediatric/family doctors, dentists (planned roundable discussions declined by providers due to no time).
VIRGINIA Radford University Foundation	Families — Mailed surveys, telephone follow-up (77 = 38% return); four group sessions through Job Readiness Program (23 participants). Providers — Telephone survey of 200 physician offices and 40 dentists. Other — Analysis of 9,390 pediatric ER visit reports from 2003.
WASHINGTON CHOICE Regional Health Network	Families — Four focus groups in English and Spanish (52 participants); 18 in-depth interviews with Hispanic clients; accompanied 26 Spanish-speaking clients to provider visits and observed barriers. Providers — Provider survey planned for Phase II, scaled back as focus shifted.
WEST VIRGINIA United Way of Central West Virginia	Families — 101 in-depth interviews through Parents as Teachers program.

Source: C. Needleman, Covering Kids & Families Access Initiative, Final Evaluation Report.



Focus groups and one-on-one interviews were found to be most fruitful if:

- A reasonable sample of parents with children on Medicaid attended (or were interviewed);
- The focus group was facilitated by an expert so that issues were explored in depth;
- Information was taped or otherwise captured for later use (with participants' consent); and
- Information was analyzed so that issues could be followed up with more research if needed.

Leaders of focus groups should have some training in the method and should follow established protocols. The most successful focus groups and interviews taught grantees that access problems were often rooted in unrecognized system malfunctions. This was largely because the only people who knew about the problems were the families involved. Individual stories from families were, after investigation, often found to reflect common problems.

Once a pattern is identified, and a group of similar stories is collected, a local organization can investigate the problem and present the analysis to the relevant decision makers. In collecting and presenting this type of information, balance is key: groups need to assess common themes; provide detailed stories that represent common problems; and be careful to communicate to other stakeholders that focus group or interview material is meant to bring issues to the surface that often require further investigation.

Focus Group: Connecticut

The following story from a Connecticut focus group illustrates the problem that the grantee decided to tackle.

A child with chronic asthma and who was in foster care was taken by her foster mother to her primary care physician because of a persistent cough. The child's primary care provider diagnosed bronchitis and prescribed Biaxin for the infection and a stronger dose of her asthma medication.

Despite the persistent efforts of the foster mother, the child was unable to get the prescription she needed immediately, and spent the weekend without the medication. The local pharmacy told the foster mother that Medicaid would not pay for the Biaxin, and then called the managed care company to inquire further. The pharmacist did not offer the mother a temporary supply of the medication.

By gathering a number of similar stories, the Connecticut grantee was able to identify patterns and pinpoint systemic problems such as the lack of a uniform computer alert to inform pharmacists that a temporary supply of medication should be dispensed, and widespread frustration among providers regarding prior-authorization requirements.

Technical Assistance

What type of technical assistance is most useful for local organizations seeking to make concrete improvements in access to health care?

One of the premises of CKF-AI — that local organizations had to choose issues strategically in order to have the greatest impact on reducing access barriers — prompted CHCS to invest considerable resources in technical assistance. Technical assistance was essential because some grantees were new to this type of work, and had a short timeline to influence concrete changes. Grant makers and local organizations considering this work should bear in mind that most of this technical assistance was individualized, although conference calls and two annual meetings were

Connecticut: Bridgeport Child Advocacy Coalition and Eastern Connecticut Health Network/East of the River HUSKY Collaborative

When the Connecticut CKF-AI groups held focus groups with parents, they learned of a common, very distressing problem: families often had problems filling prescriptions, particularly on the weekends and in the evenings. Systemic problems — largely unrecognized except by families on Medicaid — resulted in some parents leaving pharmacies without necessary prescriptions for their children. One parent explained in a focus group that because his daughter's prescription cost so much, and Medicaid would not pay for it, he had to choose between paying his utility bill and filling his daughter's prescription.

In order to research the problem from all angles, the CKF-AI groups interviewed pharmacists, pediatricians and pediatric office managers, and were able to identify a number of causes. Among the issues: each of the four managed care plans providing services to Medicaid beneficiaries required doctors to use a different formulary, and each plan had a different procedure for prior authorizations. The plans also relied on different time lines and after-hours services for



providers and pharmacists. The CKF-AI groups also learned that pharmacists were, for the most part, unaware of Medicaid managed care contractual safeguards that provide for a temporary supply of prescription medications for beneficiaries in urgent or emergency situations.

The CKF-AI project undertook a multi-pronged and very successful effort to correct the system problems and provide user-friendly information to families. With technical assistance from Connecticut Voices for Children, the state partner, the project asked the state Medicaid agency to convene a series of meetings with CKF-AI groups and the four managed care organizations. Presentations and discussion at these meetings quickly revealed some of the underlying flaws in the existing policy and MCO-specific procedures. Using case narratives from families in touch with the Bridgeport Child Advocacy Coalition (BCAC) or Eastern

Connecticut Health Network (ECHN)/East of the River (EOTR), the CKF-AI groups were able to shed light on the nature of the problem and to identify a "best practice" in use by one of the managed care organizations. The work led to a number of important and specific improvements in pharmacy practice and procedure, including changes in the electronic messaging between managed care organizations and pharmacists, replication of one organization's best practice, and statewide dissemination of information on providing Medicaid beneficiaries with temporary supplies of medication.

The local organizations also took on the task of educating both parents and the staff in provider offices regarding specific Medicaid policies and procedures on prescriptions, eligibility, and other issues. A parent-friendly fact sheet on navigating managed care was distributed through the BCAC and EOTR networks to the statewide *Covering Kids & Families* Coalition and the Women Infants and Children program. The group also wrote and published a provider toolkit for office managers, in order to give private pediatric offices the tools they needed to better manage the Medicaid system for their patients.



held for the entire group. The technical assistance consultants hired by CHCS devoted considerable time to individual discussions regarding the initiative.

The CKF-AI evaluation confirms the usefulness of this investment in expert technical assistance. According to the evaluation, "the importance the CKF-AI grantees placed on the technical assistance they received can hardly be emphasized enough. Without exception, they say that the customized individual support they received was indispensable." Technical assistance generally took place by email and phone. Grantees and their technical-assistance advisors developed close partnerships, working together to understand the results of focus groups and interviews or to develop new approaches to getting necessary information. Technical assistance was designed and provided by a team of two consultants with expertise both in Medicaid policy issues and in how access issues can be addressed at the state and local level.

Technical assistance was especially important in helping grantees choose their one or two interventions. Finding the right issues — problems that were important and could be addressed within the CKF-AI project format and timeframe — called for more technical assistance than any other aspect of the project, and often required the help of the program's consultants, who drew upon their own extensive work experience at the state and local level, as well as their knowledge of Medicaid policy and public health issues.

Selecting Issues for Interventions

How should a local organization gauge the likelihood that a particular barrier to health care can be ameliorated through an intervention?

Families, providers, grantees, and grant makers can have significantly different ideas about what constitutes an access barrier and what can be feasible to take on as a project. The CKF-AI evaluation points out that grantees' early research typically identified access barriers occurring on very different levels. These barriers fell roughly into three categories, which are termed in the evaluation Type A, Type B, and Type C (Table 2, page 14). Type A and B barriers are more amenable to change influenced by a local organization working in concert with a state partner. Type C barriers generally require much more investment and political capacity than is possible in this kind of project. This typology of barriers can be used to guide local organizations and grant makers in maximizing their time and investment.

⁴ Needleman, op. cit., pages 18 - 20.

Texas: Children's Defense Fund

The Houston-based Children's Defense Fund (CDF) of Texas administered surveys to parents, conducted community focus groups, and surveyed local providers and pharmacists. They uncovered the following problems for families enrolled in public health insurance: (a) access to care after hours; (b) access to high-quality information through nurse help lines; (c) difficulty in choosing an appropriate provider and health plan; (d) language barriers; (e) lack of access to prescription drugs; (f) cost-sharing caps on services; and (g) difficulties obtaining prescription drugs.

Given the number of issues that surfaced, technical assistance efforts helped CDF determine the appropriate focus for Phase II. Prescription drug access was chosen as the target issue — through help from a local advisory committee, CHCS, and the state partner organization, the Center for Public Policy Priorities in Texas. All advisors agreed with CDF that prescription drug access posed a significant problem, that there were opportunities to improve access, both locally and at the state level, and that CDF was in a good position to conduct the work.

CDF, with the assistance of its state partner, examined the systemic issues that were behind many parents' inability to get the prescriptions their children needed. One of the primary factors identified was a lack of provider knowledge on how to use the



state's new vendor drug program. Phase II work focused on a series of provider and pharmacist training sessions, developed in partnership with the Houston Association of Pharmacists and the Texas Medical Association. More than 160 pharmacists and providers participated in the forums, which provided continuing education unit credits, and garnered rave reviews. Hospitals, health clinics, and other stakeholders were informed about how to address prescription access problems through educational materials and trainings. More than 730 key stakeholders in children's health were trained. The cooperation of the Texas Health and Human Services Commission was essential in the effort, and the state partner was critical in securing the cooperation of the Commission.

As a result of the training sessions and widespread publicity about the problem, the City of Houston Health Department adopted the pharmacy education initiative and assigned the city's chief pharmacist as the CKF-AI project liaison. The Health and Human Services Commission's Regional Advisory Committee created a provider-access subcommittee to monitor access barriers in Harris County. In addition, English and Spanish materials on prescription drug access were developed by CDF and incorporated into the managed care health plan manuals and mailings to all members. The Texas Children's Health Plan, the largest children's health plan in the state, added a question on pharmacy access to its standard member survey.

CDF plans to continue work on the pharmacy education initiative, holding at least three additional continuing education credit sessions on the vendor drug program, developing new educational materials for members and providers, and conducting further research on the implementation of the vendor drug program.

Table 2: Typology of Access Barriers Addressed by CKF-AI Grantees in Phase II

	Type A							Тур	е В	Туре С				
	1	2	3	4	5	6	7	8	9	10	11	12	13	14
ARKANSAS Our Children First Coalition							1			Χ				1
CALIFORNIA Multicultural Community Alliance	√			1		Χ	Χ	/	1		1			
CONNECTICUT Bridgeport Child Advocacy Coalition and Eastern Connecticut Health Network/East of the River HUSKY Collaborative	X					1	1		Χ	1				
IDAHO Kootenai Medical Center						Χ	•							
MAINE Penquis Community Action Program and York Community Action Coalition	1					X	X			1				
MARYLAND Baltimore HealthCare Access		1	1		Χ	1	/		1					
MINNESOTA Minneapolis Department of Health and Family Support			Χ	1	•	Χ	1	Χ	1	Χ			•	
MINNESOTA Olmsted County Community Services			/	/		Χ		1						
NEW MEXICO Youth Development Incorporated		1			Χ	1		/	1		Χ			
NORTH CAROLINA Buncombe County Department of Social Services		1	Χ		Χ				1	Χ				
OREGON Outside In								Χ	1				1	
PENNSYLVANIA Consumer Health Coalition, Inc.										Χ				Χ
PENNSYLVANIA Philadelphia Citizens for Children and Youth			/	Χ					1	Χ				
TEXAS Children's Defense Fund	Χ					1	1		1	1				•
TEXAS Migrant Health Promotion						Χ	1	1						
VIRGINIA Radford University Foundation		Χ			1	1	1		1	1	1		•	•
WASHINGTON CHOICE Regional Health Network		Χ			Χ				1	1		•		
WEST VIRGINIA United Way of Central West Virginia		1			X							•		

X = major focus

√ = supplemental focus • = explored but not selected

Type A Barriers

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

Type B Barriers

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

Type C Barriers

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

West Virginia: United Way of Central West Virginia

The CKF-AI project at the United Way of Central West Virginia conducted in-depth interviews with 128 families with children enrolled in Medicaid. Like other grantees, the United Way staff were surprised by what they learned. As a rural state, they expected to find transportation problems, but families did not mention transportation as a major concern. Staff also expected to find problems with families not having a "medical home" — a regular health care provider — for their children, but learned that this was not the case. The interviews showed that 94% of the children had a health care provider who was their usual source of care. For the most part, the grantee learned, families on Medicaid in West Virginia "are treated well, promptly and respectfully by their health care providers."

What was surprising — and a concern — was that 42% of the families interviewed reported that they did not have access to their doctors after regular business hours or on weekends, and that one-third were told to go to the emergency department when their doctors were not available. CKF-AI staff realized that families were in a bind: they were seen as using services irresponsibly, but the families themselves often felt — understandably — that they had no choice.

The CKF-AI project, the state partner, and the technical assistance advisors agreed that it would be difficult to change provider hours within the grant's short time frame. After much discussion, another approach emerged: the interviews with families had revealed that many parents did not know what to do when their children were sick, and did not have the basic health care information they needed. Parents were actively seeking more information about how to take care of their children's health care needs.



The United Way learned from a technical assistance call conducted by CHCS that a simple guide for parents, called "What to Do When Your Child Gets Sick," had been shown in a California study to be effective in reducing unnecessary emergency department visits. The United Way decided to test this tool in West Virginia by having a trained home visitor present the book to families and to provide a basic orientation about well- and sick-child care.

As a result of the project, parents reported that they were better able to deal at home with minor issues such as fever, rash, diarrhea, and vomiting. Parents said that they did not feel as compelled to leave home at night to visit the emergency department. After receiving the book and the orientation, more than half of the parents said that they would first consult a health book when their children were ill. Most parents also reported that they felt

more confident in taking care of their children's minor medical needs and that their use of the emergency department declined.

Another outcome of the project: The West Virginia Healthy Kids and Families Coalition, the state partner organization, obtained a \$75,000 grant to disseminate the project to other sites. A rural child care center and a rural community health center are currently replicating the project.



Type A barriers appeared to exist primarily because of unrecognized or neglected needs. These barriers were unintentional, in that multiple stakeholders agreed that the barrier should not exist and felt that removing it would be in everyone's best interest in terms of improving quality and perhaps even providing cost savings. Within these "win-win" areas of goal and interest convergence, a broad range of stakeholders (including professional and provider associations, managed care organizations, consumers, and consumer advocates) would potentially support the grantees' interventions once all parties were convincingly informed about the problem and a realistic, affordable solution. Typical Type A barriers included:

- Problems with getting drug prescriptions filled.
- Families making inappropriate use of emergency department services because they were not well equipped to use better alternatives.
- Language and literacy barriers due to shortage of, and poor organization of, medical interpreter services.
- Problems with medical transportation due to cultural insensitivity, unnecessary restrictions, and misuse of the transportation system by providers.
- Families needing greater health literacy on common illnesses and preventive care.
- Lack of understanding among consumers concerning Medicaid benefits and system navigation.
- Lack of understanding among health care providers and pharmacists concerning allowable benefits and access barriers faced by families.
- Enrolled families being unconnected with the health care system.

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

- Certain barriers to care in managed care and hospital practices. For example, unrealistic policies on prior authorization for prescription drugs or barrier-creating emergency room and treatment policies.
- Certain barriers to care in state-level policies. For example, poorly drawn state contracts with providers of medical transportation, which could be revised to reduce access barriers.



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

- Shortages of health care facilities due to lack of resources.
- Inadequate provider availability due to low reimbursement rates.
- Increased cost-sharing and exclusion of certain benefits so as to cut state Medicaid costs. For example, higher co-pays, caps on service utilization, or no coverage for dental or mental health services.
- Provider noncompliance with federally mandated standards of care. For example, failure to provide required EPSDT, vision, or prenatal services; poor after-hours callin services; no emergency prescription drug supply; no recognition of patients' right to have an interpreter.

Some CKF-AI grantees initially found themselves taking on Type C problems, but ended up changing direction when they realized that they were unlikely to achieve the desired results. One of the lessons of CKF-AI is that Type C problems — although in some ways the most serious access barriers — should be avoided in planning local projects, unless special consideration has been given to how to make progress on the problem. Type A and B problems can be productively addressed within these constraints, although success will depend on the local organization's ability to diagnose the issue, communicate the complexity of the issue, and mobilize the appropriate stakeholders to resolve the problem.

Even after determining that a Type A or Type B problem is the most appropriate target for its work, some local organizations were lost when deciding how to prioritize the many issues that surfaced in family focus groups or interviews. A strong partnership with an influential state policy organization can be particularly useful at this stage. CKF-AI grantees benefited from the insights of state partner groups regarding state policy discussions to help determine overall direction, as well as specific next steps. State-specific policy expertise and access were essential. In CKF-AI, state partners were able to provide timely assessments of grantee plans and work with them to find the individuals and government bodies necessary to implement them.

In Pennsylvania, for example, a local community organization determined that parents and children were often unable to manage a needlessly complicated transportation system. The state partner organization took these findings to the committee charged with writing a new transportation contract. Together, the state partner and local organization worked to design ways to improve the transportation system, and the state issued a new request for proposals incorporating CKF-AI recommendations.

Pennsylvania: Philadelphia Citizens for Children and Youth

Philadelphia Citizens for Children and Youth (PCCY) identified two significant, and serious, access barriers for families during its Phase One research. One issue (which did not come as a surprise to the organization) was the whole constellation of problems in accessing medical care encountered by families who did not speak English. This issue was part of the difficulties many families had in navigating the managed care system. The other issue was transportation. In both the city and the surrounding suburban areas, families on Medicaid reported problems with using the state's contracted medical transportation system. PCCY decided to tackle both of the issues, working in a coalition of community partners in two areas of the region with large numbers of Spanish-speaking residents.

Working with the Maternal and Child Health Consortium of Chester County, the CKF-AI project offered two medical interpreter training courses to Chester County health providers. In response, five local health care organizations developed interpreter service protocols. In partnership with Congreso de Latinos Unidos, a Philadelphia-based agency, educational workshops on navigating managed care and getting an interpreter were provided to 108 Spanish-speaking

families. PCCY, in conjunction with The Children's Hospital of Philadelphia, also developed "I Speak" cards, which indicate that the person carrying them needs an interpreter. PCCY then held a public forum on the problem of language access, with 125 people attending, including representatives from the Pennsylvania Department of Public Welfare, the Pennsylvania Department of Health, and representatives from three children's hospitals in the city.

After airing the language access issue in a public forum, PCCY looked into the systemic issues underpinning both language access and transportation, working closely with its state partner organization, the Pennsylvania Health Law Project (PHLP). PCCY discovered early on that the issues were linked: by simply placing a call to the medical transportation provider to test customer



service, PCCY found out that there was no Spanish-speaking prompt on the automated message. After PCCY and PHLP communicated this concern to the state, Spanish-speaking prompts and schedulers were added to the service, and work to improve the system continued.

Ultimately, PCCY and PHLP's work resulted in a series of recommendations to the state on improving language access, several of which were incorporated into new contracts with managed care organizations. The work also resulted in a new transportation provider being chosen for Philadelphia County, with both organizations being asked to serve on the new provider's consumer committee to monitor the program.



Designing an Intervention

How should local organizations assess the potential of particular intervention?

Picking the right problem to address is only the beginning. Determining how best to intervene is the most challenging aspect of any program built on the CKF-AI model.

Successful CKF-AI interventions were diverse. Some grantees took on fairly large-scale system change efforts, pulling together key Medicaid stakeholders, including state officials, managed care executives, large provider systems, and organizations representing families. Others looked to build pilot projects or infrastructure (such as community health worker networks or interpreter services) that could be replicated or supported by other funding sources once CKF-AI funding expired. Most grantees found an information gap of some sort, and produced videos or other material for people with low literacy to explain the Medicaid delivery system to families.

What elements made an intervention successful? The CKF-AI evaluation provides insight into why some grantees achieved spectacular success and others made more modest progress. The most successful projects had five characteristics in common:⁵

- Pragmatic choice of program focus. Successful grantees typically targeted Type A and Type B barriers, took advantage of some specific policy window in their state or locality, and chose an intervention focus that was consistent with the project staff's particular strengths and expertise. These successful grantees showed what might be called "constructive opportunism," matching interventions, focusing on perceived opportunities, and choosing mid-range interventions that could realistically make a difference.
- Reliance on collaborative strategies that emphasized convergent interests. Successful grantees typically formed advisory boards made up of diverse stakeholders including plans, providers and consumers (or consumer representatives) who met regularly to discuss access problems. In these meetings, all parties sought win-win solutions. This did not necessarily mean avoiding difficult discussions, but when issues arose that could have turned confrontational, the successful grantees found creative ways to redefine them as mutually beneficial. Two areas in particular getting prescriptions filled and appropriate use of emergency services were defined as win-win, since many agendas could be served by addressing these areas. Successful grantees gained broad support for other access concerns for example, consumer and provider education on system navigation, improved medical transportation, community health education, and improved medical translation services by linking them to these two central themes.

⁵ Needleman, op. cit., pages 27 - 29.

- Targeting Both Providers and Consumers. Successful grantees typically designed interventions to involve health care providers as well as Medicaid families. For example, consumer education on the differences between various health plans' drug coverage was complemented by a laminated one-page form that pharmacists could post next to their computers for easy reference. Development of medical translation services for limited-English-proficiency families was matched with training of (initially resistant) urgent care clinic staff on how to use the service effectively. An outreach program that helped families effectively answer doctors' questions about symptoms was matched with a continuing medical education course for physicians on how to effectively obtain information from families.
- Ability to humanize the access problem. Successful grantees achieved enormous mileage from vivid stories that came out of focus groups, and made frequent use of these personal accounts of Medicaid beneficiaries. In one meeting, the administrators of five managed care plans were almost in tears over reports from the field, saying, "We had no idea this was happening." It is apparently one thing to know abstractly that access barriers exist, and another thing entirely to hear that last Tuesday Mrs. Gonzales was unable to get the medicine prescribed for her son's ear infection, leaving him screaming in pain all night. Real accounts of real families dealing with access problems cut through a lot of denial and resistance.
- An enthusiastic program champion. The more successful projects all seemed to have one person who took ownership of the project and was ready to "eat, breathe, and live it," putting in weekends and evenings out of sheer commitment. In most cases the champion was the project director, but not necessarily. In some cases the role was played by the state partner, and sometimes by a consultant hired through the grant who functioned as the de facto project director or state partner. Once a primary champion was in place, secondary champions sometimes emerged in the form of highly committed volunteers, student interns, or organizational partners not funded through this grant.

Minnesota: Minneapolis Department of Health and Family Services

Staff of the New Families Center, a project of the Minneapolis Department of Health and Family Services, sought to use CKF-AI resources to improve access to health care services for immigrant families in the community. Through a chart review of families using the center's services, a survey of the 12 health clinics used by clients, and focus groups with families, a number of barriers to care were identified. For example, families had difficulties finding and using appropriate interpreter services; problems arranging for supportive services such as transportation and child care; and trouble paying for health care (co-pays and premiums) as well as difficulty understanding invoices. Families also needed help understanding the need for preventive care.

The New Families Center decided to focus on the issue of interpreter services as a systemic problem, and to offer one-on-one assistance to families needing help with the other identified



problems. The New Families Center developed an informational card for non-English-speaking families to give to providers. The card identifies the need for an interpreter and describes the legal rights to these services. Working with their state partner organization, the Children's Defense Fund of Minnesota, the New Families Center staff met with the Minnesota Council of Health Plans to identify the problems that enrollees were having securing interpreter services and to brainstorm solutions. The health plans responded by creating a comprehensive health plan guide that details available interpreter services, as well as information on transportation, mental health, and other services. The state partner also worked to engage state policymakers in the problem, which led to a legislative initiative calling for the establishment of a commission on improving interpreter services.

Throughout the initiative, one-on-one assistance was provided to many immigrant families, and informational materials were produced in Spanish, Hmong, and Somali. Due to the success of the one-on-one assistance, the Children's Defense Fund of Minnesota and the New Families Center are seeking funding partners to support ongoing outreach services for immigrant families. The two organizations are also seeking to expand the program by collaborating with school-based programs.

Conclusion



Medicaid provides health care coverage to many of the most vulnerable families and individuals in the nation. The goal of the program is access to necessary health care services. In the changing Medicaid environment, it is critical that policymakers understand the on-the-ground barriers to services that these people face. As the CKF-AI groups and the stakeholders working with them learned, the apparent problems are not always the real ones. Any attempt to improve access to health care services for people enrolled in Medicaid needs to be based on an in-depth understanding of what is really happening at the local level. This information can be hard for policymakers to obtain, and solutions can seem elusive.

By getting underneath and identifying the pressing needs of families, CKF-AI successfully generated a number of specific rapid-cycle interventions that show promise as win-win strategies for reducing Medicaid access barriers and gaining broad-based support from stakeholders who had not previously recognized that they might have common interests with Medicaid families seeking care. These interventions have considerable potential to serve as models that others could adopt or adapt.

Those seeking more information about specific materials that the CFK-AI grantees used for gathering information and educating consumers are encouraged to contact grantees directly, using the contact list on the following pages. As a group, CKF-AI grantees are eager to share their experience and tools with others who are working to reduce barriers to health care access for children and families on Medicaid.

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