

CLEARINGHOUSE REVIEW

JOURNAL OF POVERTY LAW AND POLICY



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Sargent Shriver National Center on Poverty Law

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Full implementation of the Patient Protection and Affordable Care Act must overcome these barriers: delays in income verification; conflicting information about how to note marital status on applications from domestic violence victims; unprocessed appeals of eligibility determinations; a “glitch” that prevents families who cannot afford employer-sponsored insurance from receiving premium tax credits; and preserving eligibility for a “special enrollment period” for individuals coming out of the Medicaid “coverage gap.”

HelpHub

Technology to Build a Community for Affirmative Advocacy

BY STEPHANIE ALTMAN, STEPHANI BECKER, AND BASEL MUSHARBASH



Affirmative advocacy to implement large federal and state public health programs, such as the Patient Protection and Affordable Care Act, requires detailed information about how the programs are working on the ground for their consumers.¹ One major goal of the Act is to offer subsidized private health insurance and expanded Medicaid coverage to low-income uninsured populations in order to increase health care insurance coverage and access. To see clearly how the law is being implemented and to measure its success, advocates must be able to gather the experiences of a critical mass of firsthand users to determine if the program works or, if not, to identify the policy, practice design, and implementation flaws.

In this first year of implementation of the Affordable Care Act, for example, advocates had to monitor whether the computer systems assessing household income accurately determine eligibility for premium tax credits and cost-sharing subsidies; whether the enrollment process accurately screens and refers applicants to Medicaid or the Marketplace; and whether subsidized health insurance offered to uninsured, low-income consumers through health insurance marketplaces is affordable enough to motivate them to purchase coverage.² Without such feedback from consumers,

policymakers may be creating ineffective programs or programs that do not reach an intended audience. Instantaneous and regular consumer feedback can be used by advocates to “build the case” to amend laws and fix programs and processes for the benefit of low-income populations.

Technology can help “spread the word” about an issue and be used as a teaching tool to allow others to engage in advocacy effectively and bring the experiences of low-income populations to policy leaders to advocate change. Building an online community of advocates can work in a bi-directional manner to disseminate expertise and information from technical experts and government agencies to advocates as well as to learn from advocates and case handlers if the policies and practices are working as designed to enroll low-income consumers into coverage. This model of an online community of experts, government workers, and frontline advocates was the idea behind the creation of HelpHub—a crowdsourced technical assistance site for frontline enrollment specialists in Illinois to provide expertise and feedback on the implementation of the Affordable Care Act in 2014.³

An Online Community to Foster Low-Income Consumer Enrollment Under the Affordable Care Act

On October 1, 2013, EverThrive Illinois, the Sargent Shriver National Center on Poverty Law, and Health & Disability Advocates partnered to launch HelpHub, an online technical assistance center where Illinois enrollment specialists could share their concerns about Affordable Care Act enrollment and have them answered in real time by policy experts and state and national policymakers. The site has proven very successful; it has drawn more than 1,300 members and, during the first open enrollment period (October 1, 2013–April 15, 2014), generated almost 16,000 visits and over 140,000 page views.⁴ Thousands of questions have been asked and answered by experts, including Shriver Center policy experts; up-to-the-minute policies posted; practice tips disseminated; resources distributed; and training events publicized. In dozens of in-person feedback sessions conducted in the spring of 2014, enrollment specialists consis-

1 [Patient Protection and Affordable Care Act](#), Pub. L. No. 111-148, § 2702, 124 Stat. 119, 318–19 (2010).

2 “Marketplace” refers to an online marketplace where individuals, if eligible, can purchase health insurance coverage and receive financial assistance through advanced premium tax credits or cost-sharing reductions or both. In the Affordable Care Act marketplaces are referred to as insurance exchanges. The term “exchange” was changed to “marketplace” in the implementation of the Act.

3 Crowdsourcing is the use of contributions from a large group of volunteers to achieve a particular shared goal.

4 Web analytics such as numbers of visits and page views are available upon request from [Stephani Becker](#).

tently highlighted how valuable HelpHub has been to their work in the field.⁵

Besides nongovernmental policy experts who launched the site and have answered enrollment specialists' policy and practice questions, state and federal partners—including the Centers for Medicare and Medicaid Services (CMS) Region V; the Illinois Governor's office and the Get Covered Illinois Marketplace Team; and the Illinois Department of Healthcare and Family Services (the Illinois single state Medicaid agency)—have joined HelpHub to get feedback from the field and resolve enrollment issues. Through this “feedback loop,” advocates can quickly voice on-the-ground enrollment questions to government, state or national advocacy, and private-sector partners.⁶ This has prompted federal and state partners to change systems and policies; they have provided new questions and answers on HealthCare.gov for legal permanent resident enrollment; extensions for difficult cases; and waivers for victims of domestic violence to receive financial assistance in buying insurance. The accessibility of state and federal partners on HelpHub has also allowed hundreds of individual Medicaid and Marketplace cases to be resolved into enrollments in affordable health care coverage.⁷

5 Focus groups were conducted during spring 2014 training and feedback sessions under a Centers for Medicare and Medicaid Services Children's Health Insurance Program Reauthorization Act of 2009 (CHIPRA) grant, a Blue Cross Blue Shield of Illinois Building Refugee and Immigrant Community (BRIC) grant, and the In-Person Counselor Learning Institute, a two-day continuing-education event for enrollment specialists (also known as In-Person Counselors) held in June 2014 in Chicago and Springfield, Illinois. Results are not open to the public but are available from [Stephani Becker](#).

6 “Feedback loop” is a generally used term for soliciting feedback from users of a forum, course, product line, and such. A feedback loop may take on different shapes in different contexts, but the essential characteristic of an institutional feedback loop is that it facilitates responsive, evidence-based decision making by “feeding” information about field outcomes “back” into the decision-making process.

7 Individual stories are available from [Stephanie Altman](#) upon request.

For Illinois's health advocacy community, HelpHub has been particularly effective in implementing the Affordable Care Act and moving Illinois toward universal health care coverage.

As HelpHub administrators, we built trust with government agencies by meeting with agency staff before we launched the site. We explained that the purpose of the website was not to foster complaints about government implementation of the Affordable Care Act but rather to troubleshoot and prevent problems before they were made “public.” The site is controlled as to the users and does not have a “public” facing front; this helped convince state agency staff that the staff could communicate freely on the site. Moreover, we invited government staff to participate as HelpHub members only after confirming user opinions that their participation would not have a “chilling effect” on the sharing of information.

Long after the initial Marketplace open enrollment period, HelpHub continues to demonstrate its usefulness for the Affordable Care Act community in Illinois. HelpHub supports enrollment specialists as they file Medicaid applications, Marketplace applications under special enrollment periods, exemptions, and appeals. HelpHub experts continue to respond to information requests, elevate cases to government partners where necessary, and monitor for signals of policy shortcomings. In the next Marketplace enrollment period (beginning on November 15, 2014), we expect to add to the online community hundreds of newly certified navigators.

Genesis

The idea for HelpHub first came about through two 2013 funding opportunities: “Connecting Communities to Coverage,” a federal CMS Children's Health Insurance

Program Reauthorization Act of 2009 (CHIPRA) grant, and an Outreach, Education and Enrollment (OEE) grant from Community Catalyst and the Robert Wood Johnson Foundation. The feedback loop contemplated in both of these funding opportunities was to build upon the original platform of Illinois Health Matters, an online outlet for news, data visualizations, webinars, and other resources about health care reform in Illinois.⁸ The goal of the proposed site was to provide those working on outreach and enrollment a virtual platform to share ideas, troubleshoot, and use Q&As among network users.

Since the purpose of both the CHIPRA and OEE projects was to disseminate information through in-person and Web-based training, HelpHub was meant to provide the outreach and enrollment network with a way to stay connected, especially since so many navigators, certified application counselors, in-person counselors, and other enrollment specialists were scattered throughout the state. The site was initially populated with essential resources and upcoming events, as well as some initial questions. Initial users were imported from attendees of “Connecting Communities to Coverage” outreach and training events held in the fall of 2013. In collaboration with the University of Illinois at Chicago (UIC) School of Public Health and the Illinois Get Covered Illinois Marketplace Team, an announcement was made on UIC's Public Health Learning website so that all certified enrollment

8 [Illinois Health Matters](#) is powered by Health & Disability Advocates in partnership with a collaborative of Illinois health policy and community-based organizations.

specialists would learn about HelpHub when they received their state navigator certification.⁹ After the launch, hundreds of enrollment specialists requested to join HelpHub. This demand suggested a welcome forum for information.

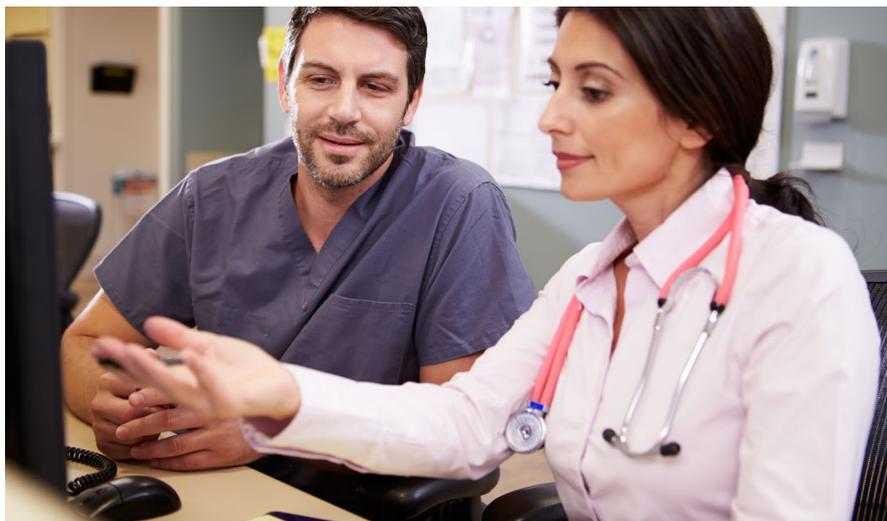
Throughout the enrollment period and beyond, we have kept in close connection with a national version of HelpHub called “In the Loop,” which is run by Community Catalyst and the National Health Law Program.¹⁰ We use In the Loop mainly (1) to post questions that require national expertise and perspective and (2) to talk with enrollment and policy specialists in other states. In turn, information from HelpHub is used to help answer questions from the national policy experts who run In the Loop.

Usage and Effectiveness Survey

As HelpHub rolled out, its leadership team implemented a review and feedback process to understand HelpHub’s members better and to identify opportunities for improvement. The team has been conducting in-person feedback sessions regularly in order to achieve a qualitative appreciation of members’ experiences. The team surveyed 1,204 HelpHub members on May 12, 2014, to obtain a profile of their work and their organizations; the quality of their experience on HelpHub; their rate of HelpHub usage; and what improvements they might consider most helpful. The team received 152 responses, or a 12.6 percent response rate. The team also analyzed the site’s data to chart HelpHub usage by geography and topic.

9 PublicHealthLearning.com (PHL) is a widely used training resource for the public health community, particularly in Illinois and the Midwest. Supported by the MidAmerica Center for Public Health Practice (MCPHP) and the Great Lakes Centers, PHL offers continuing education and professional development courses for public health professionals, such as Affordable Care Act enrollment specialists.

10 See [In the Loop](#) (n.d.).



Our quantitative findings indicate a diverse membership, high overall satisfaction, and a likelihood that HelpHub members will continue to use HelpHub and recommend HelpHub to others. Although almost 6 out of 10 survey respondents worked for health care or social service providers, 41 percent worked for various other institutions, such as legal services organizations, food pantries, advocacy outfits, and local health departments. A majority of respondents (93 percent) had an “excellent” (54 percent) or “good” (39 percent) overall impression of the site. More than 9 out of 10 rated the quality of answers to questions as “good” or “excellent,” and nearly 8 out of 10 rated the enrollment resources offered as “good” or “excellent.”¹¹ There were several signals for targeted improvements, however, especially in the search function and tagging system (32 percent rated those features as “decent” or “could be better”). Respondents heavily recommended creating or expanding features such as links to federal rules and regulations, more fact sheets on more issues, and more enrollment resources

11 Enrollment resources are any tools that enrollment specialists can use to facilitate consumer assistance and outreach, e.g., health literacy presentations, promotional banners, and helpful consumer intake forms.

during the next open enrollment period. Some 90 percent of respondents said they were likely to use HelpHub during the next enrollment period and that they were likely to recommend HelpHub to others.¹²

The qualitative responses received highlighted how HelpHub users utilized the site to advocate on behalf of their clients. Most respondents said that they used HelpHub to answer questions to assist them in enrolling clients into coverage; to network with other enrollment specialists on advocacy topics; and to find out policy information unavailable elsewhere. Some sample qualitative responses: “HelpHub often had answers [to policy questions] before others did”; “HelpHub provided timely information on problems enrolling immigrants and allowed me to help the client and not turn them away”; HelpHub gives “direct, concrete ... answers”; and “I use HelpHub as my go-to... [T]his is the only place I can get consistent information.”¹³

12 HelpHub Survey 2014 (available from [Stephani Becker](#)).

13 *Id.*

Impact on Advocacy and Systemic Change

By facilitating enrollment specialists' access to policy experts and policymakers (creating a "feedback loop"), HelpHub has allowed Illinois enrollment specialists to conduct more effective outreach while pressing the problems they identified on the ground to the front of the policy agenda, both in Springfield, Illinois, and in Washington, D.C. Affordable Care Act enrollment specialists have used HelpHub to crowdsource answers to their questions from policy experts as well as fellow specialists. Enrollment specialists also frequently share best practices; indicate persisting information gaps; and, most significant, call attention to consumer cases that demonstrate substantive policy problems and present advocacy opportunities.

For instance, when legal permanent residents faced problems enrolling in Marketplace insurance, HelpHub members were among the first in the nation to identify specific cases of flawed identity verification systems denying legal permanent residents the chance to purchase subsidized health insurance. Armed with substantiated cases drawn directly from enrollment specialists and their experiences with consumers, advocates from the Shriver Center, EverThrive Illinois, and the National Immigration Law Center, among others, successfully lobbied the U.S. Department of Health and Human Services to attend to the barriers that noncitizens faced in enrolling through the Marketplace.¹⁴

Another example concerns victims of domestic violence. In order to be eligible for Marketplace subsidies, married couples

14 "HelpHub has helped NILC (the National Immigration Law Center) raise important issues to the national stage about the barriers non-citizens have faced in enrolling in coverage through the Marketplace—thereby pressing the issue to the front of the policy agenda" (E-mail from Jenny Rejeske, Health Policy Analyst, National Immigration Law Center, to Stephani Becker (Feb. 9, 2014)).

have to file taxes jointly. Domestic violence victims, estranged from their spouses but still legally married, were unable to apply for the subsidy they needed to purchase health insurance. Trustworthy HelpHub cases, voiced by enrollment specialists with reliable documentation, again allowed advocates to demonstrate the policy gap to policymakers and advocate redress. As a result, victims of domestic violence were allowed extra time to apply for health insurance coverage through the Marketplace with a special provision to mark that they were unmarried—without fear of penalty for misreporting marital status—and still be allowed to receive tax credits.¹⁵

HelpHub also provided key information to advocate, on a state level, changes in Illinois Medicaid policies and the ABE (application for benefits eligibility), a new Web portal used to apply for Medicaid and Supplemental Nutrition Assistance Program and cash assistance. Through HelpHub,

Due to HelpHub's constructive role in state and federal advocacy, HelpHub has been recognized as significant and replicable in the Affordable Care Act's implementation.

advocates learned about problems with some MAGI (modified adjusted gross income) eligibility determinations, delays in Medicaid application processing, and a multitude of erroneous decisions and terminations on Medicaid renewals.¹⁶ This information was in turn relayed to state officials and resulted in a legislative policy change on renewals; meetings with state

15 See generally [Center for Consumer Information and Insurance Oversight, Centers for Medicare and Medicaid Services, Victims of Domestic Abuse](#) (March 31, 2014).

16 All states and the federal government use modified adjusted gross income (MAGI) as a measure of income to determine eligibility for lower costs in the Marketplace and for Medicaid under the Affordable Care Act. Generally MAGI is a person's adjusted gross income plus any tax-exempt social security, interest, or foreign income.

officials; and the issuance of frequently asked questions and other guidance. Individual cases referred from assisters through HelpHub were brought directly to the state level (without filing formal appeal) and resolved in the client's favor.¹⁷

A Best Practices Model to Be Replicated

Due to Help Hub's constructive role in state and federal advocacy, HelpHub has been recognized as significant and replicable in the Affordable Care Act's implementation. In the initial open enrollment period, national advocates, such as Community Catalyst, lauded the information received from HelpHub online members as useful for their advocacy as well as a national "best practice" model for creating an Affordable Care Act implementation feedback loop.¹⁸ HelpHub was also featured in a panel presentation at Enroll America's State of Enrollment: Getting America Covered 2014 national conference.¹⁹

We believe the success of HelpHub exhibits an effective use of technology to improve the lives of low-income Americans—not only with more agile customer service but also with enhanced responsiveness from state and federal agencies, national advocacy organizations, and private partners to the concerns of low-income

17 Individual stories are available from us upon request.

18 [Community Catalyst, Connecting Consumers to Coverage: Mobilizing for Enrollment 20](#) (June 2014).

19 Stephanie Altman was one of three speakers on a panel, "Connecting Consumers to Coverage: Is There a 'Better Door'?" at Enroll America's first national conference, State of Enrollment: Getting America Covered, Washington, D.C., June 16–18, 2014 (see [State of Enrollment: Getting America Covered, Conference Program 13](#) (June 16–18, 2014)).

HelpHub experts continue to respond to information requests, elevate cases to government partners where necessary, and monitor for signals of policy shortcomings.

and underprivileged communities. We also believe that the HelpHub model need not be limited to the health care community. Similar online crowdsourcing platforms that connect on-the-ground advocates, experts, and government institutions together have been created in other policy and social contexts to achieve positive systemic results. Whether in terms of affecting government policy, improving service delivery, or empowering advocacy networks, initiatives similar to HelpHub are facilitating outcomes in varied contexts. Two other initiatives using crowdsourcing technology to provide increased access to public benefits and services are described below.

STREAMLINING INFORMATION SHARING AND SERVICE DELIVERY: ILLINOIS LEGAL AID ONLINE

For more than a decade, the Illinois legal aid community has been a model for judicious use of technology to facilitate intracommunity information sharing, deepen advocacy networks, and enhance public access to legal resources.²⁰ Through its trio of websites, Illinois Legal Aid Online broadens access to justice by streamlining the delivery of free and pro bono legal services to the poor and providing easy-to-understand legal resources and assistance to the public. Each website caters to a particular audience:

(1) IllinoisLegalAid.org offers a platform where members of the general public can ask questions about their legal problems and receive localized, personalized responses, such as

relevant legal information, forms, and references to local aid organizations.²¹

(2) IllinoisLegalAdvocate.org provides training and practice support to legal aid organizations, attorneys, and staff. The site offers webinars and online curricula on a wide variety of issue areas; moderates a discussion board where members can obtain answers from one another as well as from field experts; gathers frequently used legal forms; and crowdsources legal briefs to facilitate advocacy. Legal aid organizations may advertise job and volunteer openings.²²

(3) IllinoisProBono.org connects Illinois attorneys, law students, paralegals, and legal secretaries interested in pro bono service to mentorship, case pairing, and volunteer opportunities, as well as to public interest fellowships and internships. The site provides pro bono service guides for specific groups (such as corporate counsel or government attorneys) and facilitates participation in special initiatives (such as JusticeCorps and the Nonprofit Legal Assessment program), which attend to particular social needs.²³

In broad terms, Illinois Legal Aid Online builds capacity for a connected, streamlined legal aid community that is accessible for its clients and effective in advocating on their behalf. While IllinoisLegalAid.org connects clients with

legal services organizations, stressed providers can reach out for support from pro bono lawyers and other partners. Disparate organizations pool their expertise in different legal fields in updating Illinois Legal Aid Online's resources for the public and for legal staff. Public interest and pro bono lawyers can pursue opportunities for service; connect with one another on difficult cases; and find mentors and training materials to develop skill and expertise. The three websites together received nearly 1.9 million visits in 2013.²⁴ Through its three websites, Illinois Legal Aid Online systemically enhances low-income Illinoisans' access to law, courts, and justice.²⁵

COMMUNITY-BASED URBAN PLANNING: ENVISION SAN JOSE 2040

In developing the latest general plan, Envision San Jose 2040, of San Jose, California, city officials were committed to creating an extensive and community-based planning process.²⁶ The City of San Jose used Wikiplanning, an online charrette service, to solicit input from a broader, more representative segment of city stakeholders.²⁷ On the city's Wikiplanning website, residents, community representatives, experts, and City of San Jose employees were able to learn about city issues and share and discuss varied priorities for city development. The website

²⁴ Illinois Legal Aid Online, *Our History* (April 29, 2014).

²⁵ Ross, *supra* note 20.

²⁶ Every city or county in California is required by state law to prepare and adopt a comprehensive and long-range general plan for its physical development. The general plan serves as an adopted statement of policy and "represents the City's assessment of the amount, type, and phasing of development needed to achieve its social, economic, and environmental goals [for the long-term future].... It is designed to be used by all members of the community as the policy framework for decision-making on both private development projects and City capital expenditures" (CITY OF SAN JOSE, *ENVISION SAN JOSE 2040: GENERAL PLAN 3* (2011); see *id.* at 29–30 for more details).

²⁷ A "charrette" is an intensive, collaborative workshop in which a group of designers drafts a solution to a design problem. It has become a particularly popular technique in urban planning, where it is used to invite consultation from a broad array of stakeholders and promote joint ownership of urban initiatives.

²⁰ Teri Ross, program director, Illinois Legal Aid Online, contributed to this section in a written interview (July 1, 2014).

²¹ See *Illinois Legal Aid: Helping Illinois Residents Solve Their Legal Problems* (2014).

²² See *Illinois Legal Advocate: Training and Practice Support for Legal Aid Advocates* (2014).

²³ See *Illinois Pro Bono: Training and Practice Support for Volunteer Attorneys* (2014).

allowed online participants to sign in with their e-mail address and zip code and directed them to their community's online forum, where they could view an elected community leader's video welcome and an activity guide introduced by the project's team leader. Activities included online surveys with instantaneous results, a blog or message board, a mapping exercise, a page where pictures could be posted and commented upon, and background materials such as maps, plans, and recorded and video presentations on city issues.²⁸

The Envision San Jose Wikipanning site attracted almost 4,500 participants between August and November 2009, and online participants posted over 100 images, completed 2,784 surveys, and wrote 240 pages of posted comments.²⁹ By contrast, the accompanying traditional outreach process, encompassing 51 Envision task force meetings and more than 125 outreach meetings over a two-year period, attracted only 600 people.³⁰ More significant, by implementing an extensive and targeted invitation strategy that employed the contacts of community organizations, affinity groups, and arts and culture associations, the online charrette process engaged communities that had largely been underrepresented in planning efforts—especially 18- to 25-year-olds and people of color.³¹ Thus, depending on political will and actual implementation over the next three decades, the published Envision San Jose 2040—which emphasizes job creation, tax base development, environmental stewardship, and public transit extension—may incorporate more productively the interests

and concerns of young and minority San Joseans into city development.³²

For Illinois's health advocacy community, HelpHub has been particularly effective in implementing the Affordable Care Act and moving Illinois toward universal health care coverage. HelpHub is a model, used in a variety of other settings for providers, advocates, and consumers and can be replicated and scaled to a wider membership. Similar crowdsourcing platforms that close the gaps among advocacy communities, citizens, and government institutions have been tested and have proven useful for a variety of causes and in disparate communities. The range of applications suggests that crowdsourcing platforms are agile enough to complement diverse advocacy conditions.

With the second Affordable Care Act open enrollment period on the horizon, HelpHub will continue to provide a forum for state and federal advocacy as well as a model for affirmative advocacy in the ongoing implementation of the Act. As other states now request information on the HelpHub model, other "HelpHub" models will likely take form across different states, social settings, and policy fields; they will create feedback loops, strengthen advocacy communities, and bring the concerns of underserved communities to the attention of policymakers.

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28 [Matt Leighninger, IBM Center for the Business of Government, Using Online Tools to Engage—and Be Engaged by—the Public](#) 18 (2011).

29 *Id.*

30 *Id.*

31 *Id.*

32 CITY OF SAN JOSE, *supra* note 26, at 15; see also [Tracy Seipel, San Jose's Updated General Plan Emphasizes "Smart Growth," Healthier Communities](#), SAN JOSE MERCURY NEWS (Oct. 31, 2011).

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