CONSUMER HEALTH ASSISTANCE & NAVIGATION FOR THE AGE OF REFORM

Design Considerations & Recommendations for Utah

(Discussion Draft for Partners)

"Though my doctor said the procedure was medically necessary, Medicaid insisted that the only appropriate course of treatment was the life-threatening invasive surgery! " UHPP worked with Sandra, her doctors, and a Disability Law Center attorney through the months of appeals, during which Sandra's condition declined rapidly. Finally the judge ruled in Sandra's favor.

–Sandra, Medicaid Enrollee & Grandma of 25

In 2009 Clark had a liver transplant. He then needed a bone marrow transplant, for which doctors said he was a good candidate. After 3 denials from (insurer), Clark lost his fight. He returned to his heavenly father(s) on June 11, 2010. *"If his story brings inspiration, strength, light, and knowledge into your life, then this travesty will not be in vain."*

-Kristin Purles, Sister of 'Super Clark' Kimble

UTAH HEALTH POLICY PROJECT

Quality Health Care Coverage for All Utahns

www.healthpolicyproject.org

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EXECUTIVE SUMMARY

Across the land Utah is known for its delivery of high-quality, cost-effective health care. Life is good for those whose health care coverage gives them access to this excellent care: They can sleep better at night knowing they will get good care when they need it. Yet, too many Utahns are not able to benefit from our community's state-of-the-art health care. Some feel pretty healthy now, so why should they enroll in their employer's health plan? They have better things to spend their money on than their part of the premiums. Others may be one diagnosis or accident away from financial ruin, without even knowing it. Low-income families eligible for Medicaid may not be in a place in their lives where they can appreciate the benefits of coverage. They may have so much stress in their lives that they will risk going without.

The new federal health reform law changes all of this—and, we think, for the better. It begins with the fundamental premise that everyone should have affordable health care coverage, and not only for their benefit, but for the benefit of the entire society. Covering all Americans is the only way to avoid the staggering cost, not to mention waste, of delaying care until folks show up in the emergency room, at which point their treatment options have often become frightfully limited. Last year CHIPRA (Children's Health Insurance Program Reauthorization Act) started us down this path by giving states every possible incentive to cover most of their kids.[i]

Like CHIPRA which came before it, the federal reform law will bring just about every American into the system by making decent coverage affordable on the private market; expanding Medicaid for those without a reasonable offer of coverage at work; and mandating a minimum level of coverage for those who can afford it. But implementation of the new expansions and mandate will be tricky in places like Utah, where so many are not enrolled in plans for which they *already* qualify now. *An estimated one-third of our uninsured are currently eligible for public programs but not enrolled*; another one-third are the so-called 'young immortals:' they could possibly afford coverage but nonetheless choose to go without. How can we bring newly eligible Utahns into the system when we can't even cover those eligible now? And once they are in the system, how do we know they will get the care they need? The reforms will bring new consumers into a system riddled with difficulties, for example:

- Denials of care, treatment, and services;
- Delays in getting care;
- Lack of access to specialty care or primary care providers;
- Inappropriate or inadequate care;
- Lack of understanding about how the health care system or coverage works.

Now is the time for a coordinated effort around eligibility and consumer health assistance, and navigation in Utah. Right now this capacity is weak and disjointed, to say the least. Fortunately, most of the coverage expansions do not happen until 2014; but before we kick back, we must consider that we stand a better chance of getting these new expansion groups covered if we puzzle out the enrollment and navigation challenges now, for those currently eligible.

This report proposes a public-private sector partnership dedicated to helping all Utahns make sense of and navigate their choices for coverage and care. What we need is a "no wrong door' approach: Human service agencies need proven tools and incentives to help their clients get and keep coverage. Consumers need a specialized, independent helpline to help them navigate coverage choices and assist with appealing denials of claims.

Finally, and perhaps most importantly, Utah's CHAP must do more than assist individual consumers, a "bottomless task;" it must analyze broad trends in consumers' problems in order to identify and fix systemic weaknesses for the eventual benefit of *all* consumers.[ii] These and other recommendations are based on best practices around the nation and on an assessment of current capacity and strengths here in Utah.

PART 1 BACKGROUND ON THE NEED

FEDERAL HEALTH CARE REFORM BRINGS NEW URGENCY FOR CONSUMER ENGAGEMENT

It is a bright new day for all American health care consumers, but particularly for the uninsured, the under-insured, or those who are not well situated to take charge of their health. In March of this year President Obama signed into law The Patient Protection and Affordable Care Act. Over a number of years, the law will contain health care costs improve quality of care, and guarantee access to affordable health care coverage. Reforms have been underway here in Utah for more than two years, albeit at a slower and more deliberate pace aimed at controlling costs and improving efficiency as a first step, before expanding access to health insurance.

Federal health reform will fill in many of the gaps in the state's current reforms, particularly in two respects:

1. the emphasis on affordable, quality coverage options;
2. the responsibility to obtain health care coverage.

The ultimate aim of reform *must* be nothing less than to bring everyone into the coverage system—willingly. Right now, however, too many Americans, especially the young and healthy, are opting out of coverage altogether to cut their own living expenses. Yet this creates an enormous financial burden for the rest of the nation. First, it leaves only the sickest individuals in the overall risk pool, which increases costs for everyone in the pool. Second, when these young, healthy, uninsured individuals show up in the emergency room, we all pay a staggeringly inflated cost for their care. In fact, an estimated 17% of private market premiums currently reflect the cost of caring for the uninsured, often in the emergency room.[iii]

This is why it is so critical to require consumers to obtain health care coverage. Federal reforms will achieve this aim, making approximately 260,000 Utahns newly eligible for coverage (either through Medicaid or through premium subsidies) by 2014. Yet many of these consumers will find this new requirement onerous or bewildering, especially those that have no experience navigating the health care system. We need to provide them with targeted assistance aimed at helping them understand and navigate their choices. Those with access to the internet will find the federal government's new navigator tool (http://www.healthcare.gov/) helpful as a starting point, but so many of the currently insured are not accustomed to accessing information on the internet.

Spearheaded by Speaker Clark, the state health reform process has several promising initiatives underway: a new Exchange marketplace where businesses and employees can shop for and compare available insurance products; a solid investment in electronic health records and other delivery system initiatives designed to limit cost growth and improve quality and efficiency of care; and a *risk adjuster* to even out the risk assumed by insurers across the small group market. These are excellent initiatives with respect to cost containment. But they leave aside the question of basic, affordable coverage. In particular, the state's current reforms contain no affordability or benefit standards, which are necessary in order to avoid or minimize the dreaded mandate. . Small business owners may be grateful for the shift to a *defined contribution* market, where they can limit how much they spend on premiums. But their employees may be left holding the bag, paying higher deductibles for less and less of the benefits and care they will need. In short, it does little good to increase the efficiency and quality of care if consumers still have no access to it.

Utah has clearly decided that cutting costs should come *before* expanding access. The architects of federal health care reform have taken a different approach, arguing that the way to bend the cost curve is *through* coverage, not around it. Toward this end, federal reforms devote significant resources not only to affordability options but also to outreach and navigation assistance, with the goal of helping consumers make the most of their new options and responsibilities.

Our task, to strengthen Utah's health care navigation infrastructure, has been made easier and more urgent by the signing into law of The Patient Protection and Affordable Care Act. This act provides for a more robust office of consumer health assistance and funds the creation of health care navigator programs which

will help meet the broad goals of reform. Through an amendment to the Public Health Service Act, each state would establish offices of consumer assistance or ombudsman programs with the following duties:

- Assist consumers with enrollment by providing information, referral and assistance;
- Educate consumers on their rights and responsibilities with respect to insurance coverage;
- Assist with filing complaints or appeals, in both the health insurer's internal appeal or grievance process and the external appeal process;
- Resolve problems with the new tax credits;
- Collect data and track types of inquiries and problems.[iv]

The role of Navigators is spelled out under Sec. 1311 (Affordable Choices of Health Benefit Plans). Among its many duties, the Navigator would…

- Conduct public education to raise awareness of availability of qualified health plans;
- Distribute fair and impartial information concerning enrollment, availability of tax credits and cost-sharing reductions;
- Facilitate enrollment;
- Provide referrals to the office of health insurance consumer assistance or ombudsman, or other appropriate state agency for grievances, complaints or questions.[v]

The role of navigator *can* be contracted out to a nonprofit—to the CHAIN, as we will recommend. Adding to the already complex health care system will be new rules, regulations and formulas that will dictate eligibility for tax credits or premium subsidies. Thus reforms will present a need for streamlined access to help consumers manage the new requirement to purchase coverage. While enrollment should be a top priority, to achieve the broader goals of reforms, a health care navigator program must reach further to create a culture of "coverage and personal responsibility:" consumers must have tools and supports to navigate the health care system and take charge of their health to the extent possible.

In Utah the enrollment and retention challenges may prove even more daunting. Today an estimated one-third of our uninsured are already eligible for Medicaid or the Children's Health Insurance Program (CHIP) but not enrolled. Even worse, Utah has significant *churning* (where people fall off the program for invalid reasons) in public programs serving children. This confirms what we have learned from states ahead of Utah on the reform front: it is not enough to make coverage affordable, much less to mandate it, though these are critical first steps. The state should take advantage of known *simplification* measures like removing the asset test and *presumptive eligibility* (where the applicant is automatically eligible until or unless they are found ineligible, thus minimizing interruptions in coverage) in order to capture hard-to-reach families and to minimize churning. But not even these measures will suffice: reforms must also create a culture of "coverage and personal responsibility" to support prudent healthcare decision-making. Reforms must be designed to help consumers navigate their options and, from there, to make timely use of benefits.

A Detour through Children's Health and CHIPRA

About one year before passage of PPACA, there was actually no excuse not to cover most—if not all—of America's children. On February 4, 2009 the President signed CHIPRA (the Children's Health Insurance Program Re-Authorization Act) into law, giving states every possible incentive, along with funding, to cover uninsured children and help them become fully engaged, or "activated," health care consumers. CHIPRA marked the beginning of a paradigm shift in the United States, where barriers to affordable coverage would no longer be acceptable. In this respect we might view CHIPRA as the 'dress rehearsal' for the more systemic changes to be introduced, over so many years, by PPACA. In a state like Utah whose conservative leaders prefer to avoid an expanded role for government, this development has been met with ambivalence, to say the least. Utah has largely failed in efforts to simplify eligibility (on a scale of 1 to 10, we would probably score a "2"), and this is reflected in our meager budget for outreach. Furthermore, Utah is one of only three states that still have an asset test as part of its Medicaid application process. All of this is about to change—and not a moment too soon for Utah children. By 2014, the asset test will be history for

all Medicaid applicants. Additionally, CHIPRA sets aside outreach mini-grants to help families apply for and retain Medicaid and CHIP coverage for their children. The Association for Utah Community Health (AUCH) received the first such grant in Utah aimed at 'learning by doing' what it takes to enroll their young health center patients.

A pilot study by community health center-based family practitioner Dr. Carole Stipleman, demonstrated an increase in Medicaid/CHIP enrollment with a more focused, 1-on-1 application process. Awarded the CHIPRA grant in November, 2009 AUCH is beginning to see results only three months later. Nine enrollment specialists were hired and trained and as of January 2010, and placed in clinics throughout Utah. The premise of the grant was to enroll the uninsured children of families who had already established relationships with physicians in designated clinics. Participating clinics include the Bicknell Clinic, Wasatch Homeless Health Care (the 4th Street Clinic), Mountainlands in Provo and Payson, and the four Community Health Centers, Inc. in the Salt Lake City area. The enrollment specialists are also working as patient advocates and navigators, helping parents complete the application for Medicaid or CHIP and passing the completed application off to DWS staff to enter into the system. For the project's first full month of February 2010, they enrolled 149 children in the Salt Lake City area clinics. Results such as these demonstrate the value of providing funding for innovative, targeted, community-based outreach initiatives.

Maximizing Enrollment at the State Level

Utah was one of eight states to receive a grant from the Robert Wood Johnson Foundation aimed at maximizing enrollment of kids in Medicaid and CHIP. This effort is focused on streamlining the paperwork and overall process in order to remove barriers to enrollment and retention. The first year assessment stated that "Utah's advocacy community is small, and there are few community-based organizations (CBOs) that conduct outreach activities or provide application assistance to families."[vi] This highlights an important opportunity for UHPP and characterizes the need for the proposed CHAIN.

The Importance of Consumer Engagement

Even with affordable coverage options available, consumers still need help managing their choices, maintaining enrollment, making prudent use of benefits, and handling grievances or denials of claims. To this end, consumers will need practical information about costs, benefits, and provider networks within each insurance plan option. Some will need to learn the importance of having a primary care provider (PCP) or 'health home' (another key goal of reform) obtaining preventive screenings, and taking an active role in their care. The principal target population for health care reform is the uninsured and underinsured, though all consumers will ultimately benefit from the many structural changes and payment and delivery system reforms included in the reform package. Since uninsured and under-insured individuals have generally been disengaged from the health care system by virtue of their insurance status with as well as other social determinants of health (such as poverty, lack of stable employment, lack of access to spousal coverage, etc.), this population will require intensive assistance with outreach, health literacy education, and navigation.

Studies show remarkable variability in the degree to which even those *with* coverage know how to make appropriate use of their benefits. Thus we must also understand the varying levels of *patient activation*, a term coined by the Center for Health Care Strategies (CHCS) to describe "people's ability and willingness to take on the role of managing their health care."[vii] A recent study describes four levels of *consumer activation*:

- **Level 1**: The least-activated consumers are passive and may not feel confident enough to play an active role in their own health;
- **Level 2**: People may lack basic knowledge and confidence in their ability to manage their health;
- **Level 3**: People appear to be taking some action but may still lack confidence and skill to support all necessary behaviors;

- **Level 4**: The most activated level, people have adopted many of the behaviors to support their health but may not be able to maintain them in the face of life-stressors.

Over 20% of study population was found to occupy the lower 2 levels of patient activation. [viii] These individuals tend to lack a reliable source of care, which contributes to their passive approach to managing their health. They are also "more vulnerable to barriers to care and more easily dissuaded from taking action when faced with financial or health system barriers."[ix] This underscores the need to help such individuals navigate the new enrollment options and challenges they will soon face, in order to gradually advance them to higher levels of patient activation over time. Studies suggest this is a realizable goal: the more environmental supports that we can provide consumers to help them obtain regular care, the more proactive, involved, and "activated" they tend to become. [x]

In this report we use the broader concept of *consumer engagement* to include all phases of effective participation in the health care system – access, affordability, enrollment, understanding benefits and navigation. As independent agencies, health care navigators can be instrumental in facilitating every phase of the consumer engagement process:

- Outreach and eligibility assistance for public programs; in the private insurance market, how to navigate health plan options and premium subsidies;
- Educating consumers about their rights and responsibilities;
- How—and why—to choose a primary care provider; for those with chronic conditions how to get established in a health care home;
- Patient "activation" how and why to make pro-active use of benefits, including preventive screenings and to take full advantage of wellness supports;
- finally, for consumers at the highest level of engagement, systematic, community-based efforts aimed at , fine tuning health reform policies or the healthfulness of their local environments (for example, by advocating for safe, walkable communities).

Utah has a long way to go towards these goals, though we have notable strengths which will speed our journey down this path, for example a reasonably healthy and youthful population and a cultural emphasis on personal responsibility. What we don't have, and now we desperately need, is a strong, strategic, and well-connected infrastructure to support comprehensive and multifaceted consumer engagement.

Lessons from Past Efforts to Enhance Navigation in Utah

Our interest in a strong health care navigation infrastructure picks up where pioneers from Utah's disability community left off. In 1996 the Utah Governor's Council for People with Disabilities established the Managed Care Improvement Project (MCIP) with the purpose to learn about the brave new world of managed care in order to better manage its impacts on persons with physical and mental disabilities. While the experience of persons with disabilities was the principal focus of its efforts, the MCIP was also designed to model a collaborative problem solving process that could be replicated to serve other vulnerable populations, including low-income working parents, the elderly, ethnic and language minorities, and individuals with low literacy skills.

Published in 1998, the MCIP's major findings are relevant still…

- The Utah health care system is changing rapidly, becoming increasingly complex, and for many of our most vulnerable citizens, remains difficult to access;
- The complexity of the language used in health care, coupled with the additional barriers of race and disability decreases the effectiveness of our health care system
- The combined effects of increasing costs for services and decreasing options or affordable health plans leads to increased poverty;

- Managed care has the potential to improve the health of our citizens by increasing access to primary and preventive care and promoting the best standards of care…through applied knowledge. [xi]

Of the many ambitious recommendations generated by the MCIP, perhaps the most lasting and relevant for today was the proposal to create an Office of Consumer Health Assistance (OCHA) with a legislative mandate to "inform, educate, and advocate for consumers on their health care rights and responsibilities." Reflecting best practices nationwide, the MCIP recommended that OCHA be situated within an independent entity. But the Legislature decided instead to house the new agency within the Insurance Department, thereby fundamentally weakening its ability to independently advocate for consumers. Advocates faced a Hobson's choice: It was this or no OCHA at all. Of course, they chose the former, and the rest is history. This unfortunate decision, coupled with of the lack of funding for marketing and promotion of OCHA, explains the low utilization of OCHA through the years since 1999, when OCHA first opened.

	Total		**Justified**		**? of Fact**		**Unjustified**	
Year	**Count**	**% of Total**	**Count**	**% of Total**	**Count**	**% of Total**	**Count**	**% of Total**
1999	326	100.00%	70	21.50%	179	54.90%	77	23.60%
2000	244	100.00%	70	28.70%	123	50.40%	51	20.90%
2001	258	100.00%	127	49.20%	36	14.00%	95	36.80%
2002	174	100.00%	73	42.00%	27	15.50%	74	42.50%
2003	120	100.00%	54	45.00%	7	5.80%	59	49.20%
2004	135	100.00%	45	33.30%	20	14.80%	70	51.90%
2005	122	100.00%	39	32.00%	25	20.50%	58	47.50%
2006	107	100.00%	39	36.40%	10	9.30%	58	54.20%
2007	72	100.00%	18	25.00%	9	12.50%	45	62.50%
2008	106	100.00%	44	41.50%	7	6.60%	55	51.90%
Average	**166**	**100.00%**	**58**	**34.90%**	**44**	**26.50%**	**64**	**38.60%**

Utah Department of Insurance (2009). Utah Health Insurance Market Report. http://site.utah.gov/insurance/docs/Health/2009HlthInsMrktRprt.pdf

Utilization rates could be dramatically improved simply by informing consumers about OCHA and its mission, to help them with questions or complaints about insurance benefits. This office stands to benefit from the new health reform law, as federal money is set aside to set up or expand consumer health assistance programs. Another, more recent health reform effort in Utah has led to the creation of a web-based portal or "Exchange" where employers and consumers can shop for affordable, quality health insurance. Legislation was passed in 2007-08 to create and define parameters for the portal. The Utah Health Exchange went "live" in August of 2009, which means that Utah is second only to Massachusetts in creating this type of virtual store-front through which employers (and soon individuals) can directly compare health plans and find the best fit for their needs.

Utah's Exchange contains important building blocks for reform, yet there are steps that need to be taken in order to achieve its overall goals. In short, although Utah's Exchange was intended to provide a "filter," directing consumers to a select range of quality plans, it more closely resembles a flea market where just about any product can be bought and sold. Hence, employees using the Exchange in August of2009 were faced with a bewildering 66 plans to choose from, and 90% ended up simply choosing their employer's default selection—so much for using consumer choice to drive the market toward quality!

At the employer selection level, only 10% of employers (13 of 136) who signed up to use the Exchange in August of 2009 actually did so. The main reason for not using the Exchange was cost: Premiums turned out to

be between 6 and 60% higher on the Exchange, due to the fact that insurers can set different premiums for insurance in a defined benefit marketplace.[xii] Clearly, Utah's Exchange has a ways to go to become the fully functional one-stop shop that it was intended to be. With the right modifications, including premium subsidies and minimum benefit standards, Utah's Exchange can certainly become a useful and important tool. But this requires strategic mechanisms to pool risk and manage increased costs over time—exactly what will come into the picture with the full roll out of PPACA. The national health care reform law includes state-based exchanges, so Utah's Exchange could become even more critical to making health insurance accessible and affordable for Utah families.

To support this goal, it is clear that Exchanges must include resources for navigation and consumer health assistance. Utah's Exchange should apply for and use the Exchange planning grants set aside by PPACA to build out this capacity.

PART 2 LESSONS FROM BEST PRACTICES AROUND THE U.S.

Knowing what has worked, and not worked, for other state and local CHAPs, in addition to evaluating what already exists in Utah (part 3) allows us to set priorities for the proposed CHAIN. To this end, we conducted an inventory of nationally recognized consumer health assistance Programs (CHAPs). Our analysis identifies exactly what these programs are doing to serve the need for consumer health assistance and navigation in their communities and how they are designed Our analysis is followed in part 3 by an assessment of institutional capacity within Utah government and community-based agencies to meet such needs.

CONSUMER HEALTH ASSISTANCE PROGRAMS BEST PRACTICES AROUND THE U.S.

Our proposal for a Consumer Health Assistance and Information Navigation program has been successfully brought to fruition in other states. Hence, we must note their accomplishments and learn from their challenges in order to move forward in Utah. Massachusetts, for example, provides a particularly useful and instructive comparison. They enhanced their consumer health assistance program (CHAP) in response to state legislative changes mandating health coverage, which dramatically increased the number of persons eligible for new affordable health insurance (or medical assistance) options. This is directly analogous to the challenge Utah will soon face as a result of the new federal health reform law. According to Families USA, CHAPs typically have two functions:

1. Educating consumers about their rights and responsibilities;
2. Identifying, investigating and helping to resolve consumers' complaints about health care benefits, claims, and services.[xiii]

In addition to these functions, the best practices have also adapted to the needs of local communities, for example taking on educational and navigation functions, facilitating or providing translation services, and even offering case management for specific populations. In the development of a CHAP, Families USA further recommends the following:

- First, define the scope of the program. The scope should be broad enough so that consumers need only contact *one* agency with questions about insurance, to obtain assistance with the application process, and to remedy problems or grievances. These are the core functions.
- Depending on resources, interest, and local needs, CHAPs may consider providing more extensive assistance or light case management through the continuum of care (outpatient, hospital, nursing home, etc.).
- Staff should have adequate expertise and training (which may take 6 months) with respect to:
    - accessing interpreting services for non-English speakers;
    - conducting outreach and education;

- providing accurate information on public *and* private coverage options.

Outreach activities must go further than simply publicizing the services offered (for example, b maintaining a website). Rather, staff must conduct coordinated community-based outreach efforts and should also monitor the effectiveness of these efforts by tracking how consumers heard about the program. Educational activities should be comprehensive, including such topics as

- Health coverage options;
- Consumer rights and responsibilities;
- The meaning and Importance of establishing a "medical home" and how to do so in cooperation with one's primary care provider;
- Basic steps for handling denials of claims, what to expect, and where to turn for assistance;
- The importance of preventive screenings, including how often and were to obtain them.

The results of such efforts must be carefully monitored to measure success, track new and pressing issues, address gaps in service, and communicate overall effectiveness to funding sources. In an effort to grasp the challenges of developing navigation systems and supports, UHPP decided to interview a select number of CHAPS around the country addressing similar needs and challenge as we can anticipate in Utah. Families USA helped us to identified 6 city or state-based CHAPs considered models of "best practices:"

- Massachusetts – Health Care for All (HCFA) and its Helpline;
- California – Health Consumer Alliance (HCA) and its Health Rights Hotline;
- Tennessee Health Assist (THA);
- Vermont – The Office of the Health Care Ombudsman (OHCO);
- New York City – The Managed Care Consumer Assistance Program (MCCAP);
- Baltimore HealthCare Access (BHCA).

Please see the following table for a detailed explanation of each program's services. Additionally, the *Details* Section of this report contains more specific information the populations served by each program, the geographic areas covered, services provided, organizational structures, funding sources, and relationships to other agencies and stakeholders in the health care system. It is important to note that each program was created in response to unique needs and policy circumstances identified at that time, and they each have continued to adapt to the shifting landscape of their respective health care systems.

	Outreach & Target Population	Eligibility Assistance	Retention & Renewal	Navigation Medical Homes Wellness	Problems / Rights / Claims	Link to Advocacy?	Data Collection	Reporting	
Baltimore Health Care Access	Phone # given on all managed care cards; referrals from state; website	Medicaid and CHIP (=M/C) , primarily	Renewal of M/C	Complete education & connection to providers; Education on use of 911 & ED.	Ombudsmen handles complaints, explains benefits, resolves problems	Medicaid funds it, so can't advocate. Forwards information to state.	State tracks calls. CHCA tracks their calls.	Cooperates with state in reporting	Annual Report
CA Health Consumer Alliance (=HCA)	General	Assists with eligibility.	Budget cuts have limited focus to eligibility and appeals.	Provides assistance with provision of services.	Provides representation at hearings (HCA, NHeLP).	Active in policy advocacy from HCA and Western Centers on Law and Poverty.	HCA has 1 database to collect data; local centers may collect other data.	Annual Report	
MA Health Care For All	Services provided in English, Spanish and Portuguese. Helpline phone #.	Uses online screening tool called Health Engine to complete applications; sends letters telling clients what to do, along with a HIPAA release form, allowing state to copy Helpline on any documents sent to client for follow up	Clients receive notice to renew within 45 days. HCFA tracks when clients must renew by providing information, helping fill out forms.	Helpline refers callers to providers to see what insurance they accept and choose accordingly. Advice is to sign up for the least expensive plan	Health Law Advocates is in-house legal team that helps clients under 300% of FPL thru appeals process.	Helpline is the direct link to the consumer voice in the State of Massachusetts. Every week the Helpline posts to the HCFA blog with a story from the Helpline		Annual Report	
NYC Managed Care Consumer Assistance Program	Helpline is noted on all promotional materials and website. Outreach at health Fairs.	Uninsured, public and private. COBRA. Doesn't help with choosing managed care, but educates consumer on what to consider in choosing.	Renewal process results in dropped enrollees and they call because they have been denied services.	Free training for consumers, service agencies. Provides education re: navigation, preventive care, use of ED, use of case management.	Database has 20 issues that the CHAP worker can choose.	Has story bank and clients are encouraged to advocate for their health care. MCCAP does not do advocacy.	Data collected on type of calls. Web based database generates reports	Strict deliverables owed to the city.	
TN Health Assist	Publications mailed in 13 languages. Pilot project in schools where barriers to care are identified. Any correspondence the state sends out (denials) must have TNHA phone #.	TennCare, CoverTN, CoverKids (SCHIP)	Campaigns for renewal focused on CoverKids. Contract with state for calling campaigns	EDUCATION: Navigation. Started with cases needing "extreme" case management, now into negotiations.	With access to the TennCare online eligibility system, TNHA can ID when people are dropped and why. HIPAA paperwork is at the ready to help clients. TN Justice provides legal help, when needed.	Able to track trends in use. TN justice provides legal help. TN Health Care Campaign is the policy oriented entity (UHPP's counterpart).		Reports trends and problems to state.	
VT Office of Health Care Ombudsman	All notices of decisions from the state say to call the ombudsman if need help. Website.	Serves all Vermont 50% state 25% commercial 25% uninsured		Training for CAPs, and social workers from hospitals.	Help with any issues. Some legal aid, some fair hearings. Only involved if previous care is denied and should be covered.	Act as consumer voice on healthcare policy.	Collects lots of data, able to track trends.	Reports data and trends to legislature.	

Discussion Draft for Partners: Please share feedback with judi@healthpolicyproject.org by July 30, 2010.

The table shows a number of common patterns and themes across the best practices that will be instructive for Utah's CHAIN:

- The interface with Medicaid/CHIP eligibility systems and programs is very tight; some entities or partnerships are either funded through Medicaid or they have information sharing privileges;
- The capacity to serve non-English speakers is well developed;
- The legal assistance and or more informal support for grievances is a critical, and well integrated programmatic element;
- Finally, the connection to advocacy and policy work is well established. Consumers' experience with health coverage programs is fed directly into policy work or indirectly via the trends and analysis of the data collected by the CHAPS.

In addition to collecting the above details about CHAPs activities, we asked each director to provide recommendations that they would make the formation of a new program. To summarize the CHAP directors' recommendations, at a minimum CHAPs should:

- Work in close partnership with state agencies operating Medicaid and CHIP. This relationship should be close enough to…
    - permit access to clients' eligibility records, making it easier for the CHAP to assist with eligibility denials and renewals;
    - facilitate marketing and outreach, for example by providing the CHAP phone number on all insurance and managed care cards
- Continuously measure and report results. For example, state Medicaid agencies can create new *table-driven fields* (new categories of information on the application to show which CHAP (and which employee) helped with the enrollment and retention of individual clients. Issues with HIPAA confidentiality can be eliminated by Expanding the use of the proxy-function;
- Be prepared to adapt to the navigation needs in a given community, as these will change over time.
- Provide extensive training to staff and volunteers;
- Use or "subcontract" out Medicaid funds to support CHAP activities (although this necessarily excludes lobbying activities).

PART 3 CONSUMER ASSISTANCE & NAVIGATION FOR UTAH

Utah is home to many agencies that provide basic information about coverage and care, consumer health assistance and services for the poor, uninsured, underinsured, homeless and/or non-English speaking people. What's missing is a systematic integration of these efforts that is oriented to helping uninsured Utahns get and keep affordable insurance (or Medicaid/CHIP) coverage and use it wisely. In addition, Utah lacks resources designed to educate consumers about their rights within the health care and insurance systems and to help consumers handle grievances. This review will provide critical background information on how to close these gaps and how to design an *integrated* navigation network that capitalizes on local assets while minimizing redundancy.

The C.H.A.I.N. is built upon the core principle of a NO WRONG DOOR approach to outreach and navigation assistance. This means that whenever and wherever an individual consumer attempts to access the system, they will be welcomed and escorted through resources addressing issues of eligibility, enrollment, complaints and appeals, and health care decision making. This approach ensures that no matter how or why a consumer enters the "chain," he or she will quickly have access to the full range of relevant resources. The NO WRONG DOOR principle will be implemented by creating working partnerships across community, provider groups and health plans, and state government agencies. This will serve to connect, align, and augment the efforts of the different entities, so they are all 'singing from the same song sheet,' for the benefit of the consumer. But first, we need to understand what these entities are doing—or not doing—today.

GOVERNMENT SECTOR PROGRAMS

The Utah Department of Health oversees the **Medicaid** and **CHIP** programs, though eligibility is now handled by the Department of Workforce Services. These and the Primary Care Network (PCN), are public insurance programs designed for low-income people. Also included is Utah's Premium Partnership (UPP) for Health Insurance, which assists in paying the monthly premium for employer sponsored health insurance.

Resources devoted to outreach and consumer health assistance are very limited and increasingly so in this era of budget shortfalls. Once enrolled, however, beneficiaries receive a thorough orientation from an HPR (Health Plan Representative): here they learn about benefits, re-enrollment, education about and assistance in finding a health home with a primary care provider (PCP), information about rights and responsibilities and how to handle problems, including claim denials. CHIP has a very modest marketing budget, but Medicaid is more like a carefully guarded secret. This is consistent with the powerful cultural bias in Utah against government programs, though the bias has certainly been less pronounced around coverage for children. (here cite new NASHP report). For example, when children apply for CHIP, they are automatically screened for Medicaid eligibility as well.

Department of Workforce Services includes the **Eligibility Services Division** which is responsible for the application process for financial assistance, food stamps, childcare and/or Medicaid and CHIP. They took over these functions in June 2009, streamlining the application process from regional staff with different approaches and varying levels of oversight.

The Governor's Office of Economic Development houses the **Office of Consumer Health Services (OCHS)**—not to be confused with the **Office of Consumer Health Assistance (OCHA)**. While the focus of **OCHS** is to set up a web-based portal for the Health Insurance Exchange, **OCHA** (described in part 1), provides basic assistance to a small number of consumers, employers and insurance companies with regulatory advice, as well as, responding to consumers' inquiries and complaints.

PRIVATE SECTOR: COMMUNITY-BASED AGENCIES

2-1-1 Information and Referral, a program of Utah Food Bank Services, is a toll-free number for people to call when they need help finding affordable housing, health care, food, and tax preparation assistance. The principal objective of 211 is to refer callers to agencies best situated to handle the need at hand. A report from June 2009 showed a significant increase in the number of calls for most months in fiscal year 2009 compared to 2008.[xiv] Of the volume of identified needs, health care came in second after income support and assistance. Food/Meals came in third. Thanks to its statewide presence and convenient access point (simply dial…), 2-1-1 is able to facilitate outreach--though somewhat in reverse for these service organizations. Their semi-annually published booklet, *2-1-1 Human Services Directory* is a comprehensive and concise guide to resources by county.

Historically operated by 2-1-1/Utah Food Bank but now operated by the Department of Workforce Services, **UtahCares** is a related web site that helps those in need find state and community resources. A person in need could call 2-1-1 to find resources or use the UtahCares website. The website, available in both English and Spanish, leads a person through the options to identify the need and then it brings up appropriate resources. Of course, this is only helpful to those who have access to a computer and are able to read.

Association for Utah Community Health (AUCH), whose membership is comprised of Federally Qualified Health Centers (FQHCs) and other providers has as its mission to take care of the medically underserved in the state of Utah. AUCH was awarded the CHIPRA grant (*described above*) and, as of February, is beginning to see good results. Nine enrollment specialists were hired and trained and as of January 2010, and placed in clinics throughout the state. The premise of the grant was to enroll the uninsured children of families who had already established relationships with physicians in designated clinics. Participating clinics include Bicknell Clinic, Wasatch Homeless Health Care (the '4th Street Clinic'), Mountainlands in Provo County and Payson, and the four Community Health Centers, Inc. clinics around the Salt Lake City area. The enrollment specialists also serve as patient advocates and navigators, working one-on-one with parents to complete the application for Medicaid/CHIP, then pass the completed application off to DWS to enter into the system. For the project's first full month of February 2010, they enrolled 149 children in the Salt Lake City area clinics. This outreach model is based on a pilot study by CHC family practitioner Dr. Carol Stipleman, which demonstrated an increase in enrollment with a more focused, 1-on-1 application process.

Health Access Project is a team of case managers serving low-income uninsured residents of Salt Lake County. Their clients are primarily uninsured individuals with household income at or below 150% poverty level. Fifty percent% of HAP clients are referred by local hospital emergency departments and from private providers. Local hospitals and the Salt Lake County Health Department fund the program. HAP has 10 staff comprised of 1 project director and 3 full-time case managers; the rest are AmeriCorps volunteers.

HAP refers clients to safety net clinics for primary care providers, and to specialists and for diagnostic testing. The costs are different depending on the provider: sliding scale, free, or a flat fee of $50. HAP has over 600 partnerships with physicians, providers, clinics and hospitals. Refugee groups are a part of their clientele, and each qualifies for 8 months of emergency Medicaid. During this period, eligible women and children are enrolled in Medicaid and CHIP.

Health Access Team is a similar team of case managers based out of the Midtown Community Health Center in Ogden that coordinates referrals for diagnostic tests, specialty services, and tertiary care. They work with referrals primarily from Weber County but also take referrals from the Farmington Clinic and Davis County and a few from Brigham City in Box Elder County. Data from Jan 1, 2009 to the present show that 80% of HAT clients are Hispanic and 65.2% are Spanish speaking. HAT clients complete a financial assessment on each referral and those who are 200% of poverty level or below are referred to diagnostic services or specialists who have already agreed to offer services for free or for a small fee. They also refer

patients to McKay-Dee Hospital and offer vouchers for those who are 150% of poverty level or below. The voucher allows them to have hospital services for an affordable $50 fee. For those with household income above 200% of poverty, the case managers refer them to the same resources but on a payment plan or at discounted rates. Patients above 150% of poverty who need services at McKay-Dee are referred to the hospital's financial services department.

Community Health Connect offers similar services for primarily uninsured residents of Provo and Utah County. The case managers coordinate referrals for diagnostic tests, specialists and also for dental care. Around 60% of CHC clients speak Spanish. Referrals generally come from local Federally Qualified Health Clinics, from free clinics, and from private primary care providers. They, like the Health Access Team, have partnered with services and specialists who are willing to provide services for free or a small fee. Community Health Connect coordinates referrals with various local hospitals. They closely case-manage the patients who are at 150% poverty level or below. If the client is above 150%, he or she is referred to discounted services and payment plans.

Utah Legal Services works at proactively identifying clients who are eligible for public services like Medicaid, food stamps, and WIC and getting them enrolled. ULS's own eligibility screening gathers much of the same information that is required when an individual applies for public programs. As a result, ULS is in a good position to target their outreach to families who will likely qualify for public programs. Currently their outreach efforts, however, are fairly rudimentary. The project is run by a single staff attorney who relies on a team of volunteers, mainly law students, to call families and encourage them to apply. Due to limited resources, ULS is not in a position to work directly as a liaison between clients and DWS or the Social Security Administration (SSA).

Programs Serving Persons with Disabilities and Seniors

Access Utah Network is an information and referral program serving individuals with disabilities and their caregivers since 1990. Its operators provide information and referrals on accessible housing, assistive technology, and financial and social supports (including health care) needed to live independently with a disability.

WorkAbility and the **Medicaid Work Incentives Program**: Since 2000, the Utah Department of Health in collaboration with other state agencies and organizations has worked to increase the employment and health care outcomes for people with disabilities in Utah. Most people with disabilities can be fully integrated in the workforce and community, but not without access to affordable, comprehensive health care coverage. WorkAbility is devoted to helping its target population take full advantage of opportunities for affordable insurance, Medicaid, and personal assistance (for details, see WorkAbility's health page). Their website also has information about healthy lifestyle choices for persons with disabilities.

The **Utah ADRC** (Aging and Disability Resource Connection) is an exciting new resource designed to connect seniors and persons with disability with the information and support they need to access community resources and services. As the ADRC gets fully underway, this will be the entity to watch. The overall design of the ADRC, in particular its emphasis on collaboration across the public and private sector agencies (the Department of Health, 2-1-1, Access Utah Network, the Area Agencies on Aging, and the Centers for Independent Living, and more) serving the target population, is roughly analogous to what we propose to build around the proposed CHAIN.

Consumer Engagement and Public Reporting Initiatives

The Utah Hospitals and Health Systems Association created **Utah CheckPoint**, a tool for public reporting of hospital quality measures in partnership with Health Insight. Back in 2004 the UHA partnered with the Utah Department of Health to create **Utah PricePoint**, a gateway to basic information about hospital services and charges. Around the time PricePoint was introduced, the UHA reflected a trend initiated by the American Hospital Association for hospitals to create and publish financial assistance policies and procedures modeled on best practices. Intermountain Healthcare was the first to do so, which is not surprising, given its nonprofit mission. Many Utah hospitals followed suit, with Utah PricePoint serving at first as the collection point and public directory for all of this information. Unfortunately, at the current time this transparency has all but disappeared. Although Intermountain Health Care maintains a decent financial assistance policy and publishes it on its hospitals' websites, the policies of other local hospitals are mixed at best, and detailed information can be difficult to obtain. In the 2010 legislative session the UHPP started to introduce legislation creating minimum standards for hospital financial assistance policies. The UHA asked us to pull the bill (and then the resolution) in exchange for a commitment to co-convene a task force with UHPP to revisit the need for a level playing field around these policies. UHPP is ready to convene this task force.

Health Insight, Utah Partnership for Value-Driven Healthcare and HealthScape *(coming soon)*
Health Insight is the federally-designated quality improvement organization (QIO) dedicated to improving the healthcare systems of Nevada and Utah. One project is the Utah Partnership for Value-Driven Healthcare, which exists to "maximize the availability and accuracy of value information to facilitate better healthcare decision making. Utah HealthScape is the Partnership's answer to consumer engagement. Once it is fully operational around August of 2010, it will give health care consumers an opportunity to share their experience with the health care system."[xv]

Where do we go from here: Recommendations for the Utah CHAIN

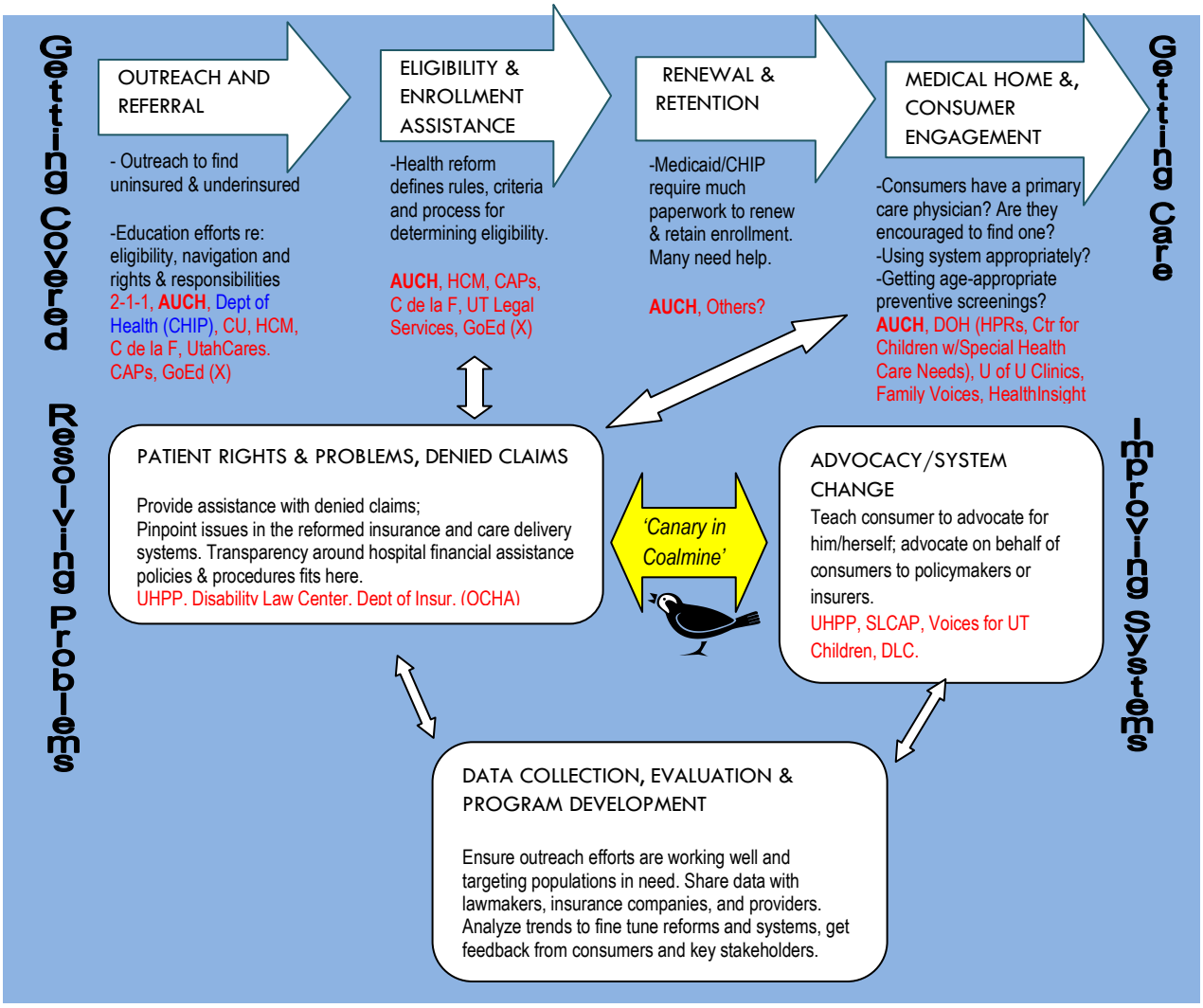
From our brief tour through the current public and private sector efforts related to consumer engagement we can draw four conclusions:

- These efforts are impressive to say the least, providing a diverse array of resources that can assist and engage consumers at multiple levels, addressing multiple needs.
- By the same token, it is clear that these resources are fairly disjointed and poorly coordinated. A novice consumer would likely have no idea how to navigate through his or her options in order to find the right resource for his or her situation.
- Most are designed to work with individuals who are *either* enrolled or *not* enrolled in public programs; They are not designed to help families *transition to enrollment,* which is where Utah currently (and increasingly) faces the most pressing concerns
- Few of these resources endeavor to educate consumers about their rights (or responsibilities) and very few groups are set up to help consumers with complaints or denials of claims.
- Overall, different resources are designed to solve specific problems, and none of them takes a coordinated, programmatic, policy-oriented approach to identifying and rectifying systemic gaps in our healthcare system and making long-term policy improvements.

Our recommendations and program design principles are based on three factors:

1. Consumer assistance and Navigator language in The Patient Protection and Affordable Care Act
2. Research about well-established state, local, and nonprofit CHAPS
3. Feedback from local partner agencies on what they feel is needed to better connect their clients with services and coverage options.

The foundation is the CHAIN network: A public-private sector partnership, the CHAIN will include Department of Health (access initiatives and public programs), Department of Workforce Services (DWS), and Department of Insurance (the Office of Consumer Health Assistance), and Governor's Office of Economic Development (Utah's Exchange) to maximize integration between community-based organization (CBO) activities and state agencies in navigation and further development of policy to further maximize enrollment and consumer engagement. A logic model helps to visualize the collaboration we have in mind across the full continuum of consumers' engagement with the health care delivery system:



1. Utilize a **'NO WRONG DOOR'** Approach to outreach and application assistance. Any agency serving the target population of low-income uninsured and under-enrolled individuals should have the knowledge and tools needed to guide clients through the application/enrollment/renewal (AER) process. This capacity is unusually under-developed amongst the organizations serving the uninsured, and this is why building this capacity is at the top of the to-do list for PPACA implementation. While facilitating understanding of the new federal health reforms, we plan to introduce likely partner organizations to the concept of a 'no-wrong door' approach to AER. The good news is that the interest to engage in these activities and to do so in a collaborative and coordinated fashion is quite strong, as we discovered in our assessment of Utah capacity. Participating agencies will draw on the following resources to extend their capacity to serve:

a. A common tool box on a website hosted by UHPP;
b. Learning while enrolling. Regular statewide satellite training sessions with Q & A for network members. Also webinars and conference calls. Research on best practices suggests we should consider certifying trained AER specialists. .
c. CLAS (Culturally and Linguistically Appropriate Services) Training to fully extend the above activities into minority communities and immigrant families.

2. **PARTNER WITH STATE AGENCIES** like the Department of Health (access initiatives and public programs), Department of Workforce Services (DWS, which handles eligibility), and Department of Insurance (the Office of Consumer Health Assistance), and Governor's Office of Economic Development (home of Utah's Exchange) to maximize integration between community-based activities and state agencies in navigation and further development of policy to maximize enrollment and consumer engagement.

3. **MEASURE RESULTS** at every step along the consumer engagement continuum (from outreach to patient activation, and to participation in wellness programs). Develop metrics of success and tracking tools like the Top Dog interactive web database. Work with E-REP programmers at DWS to create fields that will allow us to track results in enrollment/retention at the CBO level. Data collection is essential for long-term success. Success will be measured at every step along the consumer engagement continuum (from outreach to taking charge of your health or patient activation). We will develop metrics of success and tracking tools like the Top Dog interactive web database. The CHAIN will interface with E-REP programmers at DWS to create fields that will allow us to track results in enrollment/retention at the CBO level. Data collection is essential for tracking and measuring success.

4. **HEALTH HELPLINE**: a dedicated toll free # is needed to facilitate CHAP and navigation activities and to test tools and pinpoint problems along the eligibility/claim approval/and consumer engagement continuum. Callers can get help overcoming their own barriers while also helping others, as canaries in the coalmine. The proposed health helpline should operate in conjunction or in collaboration with similar helplines like the statewide 2-1-1, Disability Law Center, OCHA, and Access Utah Network for persons with disabilities. In this respect Health Care for All MA's HelpLine is the model. The Helpline will also test tools and outreach techniques, interacting with consumers across the CE continuum while giving them a voice (the 'canary in the coalmine') to pinpoint problems and contribute toward systemic improvements.

5. **THE FULL CONTINUUM of CONSUMER ENGAGEMENT**. Partner agencies will have the tools and motivation to keep consumers engaged at every step, including the following arenas
   a. initial outreach and enrollment
   b. education about consumers' rights (for example around claim denials) and responsibilities
   c. 'health homes' (medical homes) and control of personal health records to
   d. participation in preventive screenings; health literacy
   e. wellness programs
   f. helping others: leadership development and policy engagement. Some consumers might become engaged in the project itself by serving on its advisory committee or on related advisory entities like the state's Medical Care Advisory Committee (MCAC), which weighs in on Medicaid policy.

6. **CLAS** (Culturally and Linguistically Appropriate Services) training to extend the above activities into minority communities and immigrant families.

PROPOSED NEXT STEPS

Almost all of the local partners and key informants interviewed for this report have graciously agreed to serve on the CHAIN Leadership Team. When the L-Team meets it will determine the final goals and strategies moving forward. We propose the following goals and strategies for their consideration:

Goal 1 Complete the assessment of current systems and resources related to consumer health assistance and navigation; determine and solidify interest in participating in the network. To this end, a broad range of possible partners and Utah service providers have been invited to complete a SurveyMonkey.

Goal 2: Establish the organizational, operational, and communications structures needed to fully establish the CHAIN network. Objectives include employing staff and recruiting volunteers, formalizing network affiliations, refining the intervention models and evaluation criteria and methods.

Goal 3: Test and implement the intervention models.

Goal 4 on Sustainability: A working group of the CHAIN Leadership Team will be formed to diversify funding. They will work in concert with the Development Committee of the Utah Health Policy Project.

PART 4 CONCLUSION

The idea for the CHAIN network crystallized in 2008, more than one year prior to passage of federal health reform. Through years of advocacy and story banking at the Utah Health Policy Project (and its predecessor, Utah Issues), we found ourselves constantly confronted with the gaps and blindspots in our current service delivery systems in terms of their capacity to help consumers access and use their coverage.

Too often, consumers in need are simply referred to charity care clinics and similar places for basic primary care. This begins to explain why an estimated one-third of Utah's uninsured are eligible for public programs but not enrolled. The stigma surrounding government programs in Utah may be partly to blame—but the real problem is a lack of understanding about how to apply for and keep benefits.

Far too often, consumers (like Sandra and Super Clark) are denied treatments for invalid (i.e. non-medical) reasons. Sometimes the consequences are deadly—as in Super Clark's case. Seasoned consumer health assistance programs around the nation know how to hold insurers (and Medicaid) accountable by educating consumers about their rights and helping them through the appeal process.

Now with federal health reforms underway, the need for the CHAIN (or something like it) is undeniable and growing more urgent with each passing day. By 2014 the rules of the insurance marketplace will change for the better—all the more reason to build capacity to connect consumers with coverage and educate the community how to use their coverage well—to take charge of their health.

APPENDIX A DETAILED ASSESSMENTS

Consumer Health Assistance Programs (CHAPs) Best Practices

Populations Served

The programs in Baltimore (BHCA) and New York City (NYC MCCAP) provide services for their respective municipalities, while the California (CA HCA) has services available in various counties. The other three are statewide programs. CA HCA and NYC MCCAP are decentralized, serving large populations, and in the case of CA HCA, spread out across a large geographic area. Each of the programs offers services in different languages, according to the diversity of each program's state, city or county population. For example, NYC MCCAP has a multilingual staff and written materials in 12 languages, Tennessee Health Assist (THA) in 13 languages, and Massachusetts Health Care for All (HCFA) in English, Spanish and Portuguese.

Scope of Services

These entities support consumers along the consumer engagement continuum from eligibility for public and/or private health insurance; assistance with claim denials, to re-enrollment, retention, and other issues. Four of the programs (MA HCFA, NYC MCCAP, CA HCA and Vermont OCHO) assist consumers enrolled in private *and* public insurance, while two of the programs focus on eligibility for public programs only (Medicaid and CHIP). BHCA, MA HCFA, NYC MCCAP, and THA assist with renewals, working with the Medicaid and CHIP programs to identify issues and track trends. Following numerous complaints that the renewal process for Medicaid and CHIP resulted in a lot of dropped enrollees, NYC MCCAP has been taking steps to improving the eligibility system. It is interesting to note that MA is the first state with an online Health Insurance Exchange that includes eligibility for public as well as private health insurance. While MA has mandated that all residents will have health care coverage, Vermont legislation identified basic "principles" in their ongoing quest for state health care reform, one of them being "to ensure universal access to and coverage for essential health care services for all Vermonters."[xvi]

Funding

The CHAPs have had a mix of limited funding from various resources. NYC MCCAP is completely funded by the NYC City Council through its Department of Health and Mental Hygiene. Though it is completely funded through public sources, its parent organization is the nonprofit Community Service Society of New York. NYC MCCAP distributes city funding to over 20 community-based organizations (legal group, HIV/AIDS, mental health, etc.). CA HCA is a decentralized independent nonprofit that coordinates services to nine community-based organizations who receive funding not from CA HCA, but from a hodgepodge of government and non-government sources.

BHCA is a nonprofit funded largely through grants. They receive a care coordination grant from Medicaid and eligibility funding from the Maryland Department of Health and Mental Hygiene. The Vermont Office of the Health Care Ombudsman (OHCO) is an independent nonprofit with half of its funding coming from the state Medicaid program and the other half from the State Department of Banking, Insurance, Securities and Health Care Administration. MA HCFA's Helpline purposely does not receive any funding from the state's Medicaid or CHIP programs; instead it relies, however tenuously on the state's block grant program for outreach and enrollment. THA is unique in that it receives funding from private foundations and also

generates revenue from providing translation services, along with its usual funding from the TennCare (Medicaid) Bureau, state grants and contracts.

Collaboration with Other Agencies

All of the CHAPS describe an ongoing and concerted effort to cooperate and collaborate with stakeholders and other health care entities within their service areas. As noted above, an active working relationship with the state Medicaid and CHIP programs is critical to the success of the CHAP. NYC MCCAP, MA HCFA, and BHCA were created in response to the state Medicaid transitioning to managed care—precisely how Utah's MCIP started!; their primary focus is thus on Medicaid and CHIP beneficiaries. In MA, state officials allow providers and community-based organizations to complete the application form on behalf of the consumer and have just one application for three programs (Medicaid, CommCare, and Uncompensated Care Program). For all six of the interviewed CHAPS, the majority of phone calls or inquiries are from Medicaid or CHIP consumers. A significant component of this connection that facilitates quick resolution for denial problems (in claims or access) is access to the Medicaid and CHIP enrollment records.

The NYC MCCAP and CA HCA have formal working relationships with the community-based organizations, through their contracting and referral networking. In NYC, the organizations include legal groups, specialist agencies, such as HIV/AIDS, mental health and immigrant-focused organizations while in CA they are county-based, local healthcare centers.

Other working relationships involve collaboration and communication with the state's 2-1-1 program, insurance companies, primary care providers, and legal aid programs. BHCA even collaborated with the fire department to educate frequent callers about the appropriate use of 9-1-1. NYC MCCAP and Vermont OHCO offer training to social service agencies on helping consumers navigate the health care system.

Data Collection and Reporting

All of our best practices' contacts can attest to the importance of data collection and evaluation to the long-term success of the program. These data and evaluation results help them identify trends and issues, communicate with stakeholders, and report to the agencies funding the CHAPS. Some of the CHAPS reported using identified trends and issues to educate policymakers and to document the need for specific policy changes or improvements in administrative practices and procedures.

According to the 2008 MA HCFA Annual Report [LINK], its Helpline handled 34,781 calls seeking assistance in gaining health care coverage and navigating its complexities. CA HCA stated in its 2008 annual report [LINK] that it assisted 27,950 through its 9 local offices with medical, oral health, coverage, medical debt, city indigent care and culturally linguistic competent healthcare services. THA [LINK] reported that it served 52,720 in 2008 with interpreting, case management, information and referral, and case monitoring for kids in state custody. BHCA Annual Report [LINK] for 2008 states that it helped about 40,000 with eligibility, 15,000 with renewal, and had 5,500 home visits with the CARE case management program (for high risk cases, pregnant women, children, homeless and those in drug treatment programs). Vermont and NY MCCAP did not have accessible annual reports. These numbers represent a dramatic contrast with Utah OCHA's volume of calls: at most 326 a year, a glaring reminder of the need to situate these services within independent entities.

APPENDIX B PROPOSED TIME FRAME FOR GOALS & OBJECTIVES

Quarter	Activities	Work Product or Deliverable(s)
Fall	Announce formation of CHAIN.	News release, web announcement
	Complete assessment of current systems & resources	
	Build out & formalize CHAIN; finalize evaluation criteria and methodology. *CHAIN partners meet every other month in year 1, thereafter on a quarterly basis.*	Minutes, list of members, web presence
	Develop toolbox and training materials, website; arrange for Spanish and other translation.	Materials, website (also in translation)
	Recruit and train CHAIN & Helpline staff.	Job descriptions
	Establish referral & data collection mechanisms for Helpline.	'TopDog' Interactive Web Database
Winter	Establish and begin marketing of Helpline.	Promotional brochures and other materials
	Work with Departments of Health and Workforce Services to create table-driven fields in E-REP and expanded proxy functions in Medicaid/CHIP application process.	E-REP fields and mailings to proxies.
	1st statewide satellite training session with webcast on enrollment assistance and purpose of CHAIN and certification process.	Webcast posted online; training certificates (#).
Spring	Report on first full quarter of CHAIN.	Report
	2nd satellite training session on consumer rights and responsibilities and purpose of Helpline.	Rights & Responsibilities Curriculum; factsheet
	Collect and disseminate health literacy materials on age-appropriate preventive screenings, etc.	Health literacy materials
Summer	3rd satellite training on topics to be determined (for example: importance of becoming established with primary care provider; use of personal health records, wellness programs, CLAS training, etc.).	Webcast; factsheets.
	4th training on additional topic from list above.	Webcast, factsheets
	Provide 1st advocacy training for Helpline callers and consumers activated through CHAIN partners.	List of attendees; Storybank entries
	Report on Year 1 results, lessons learned, and recommendations for year 2.	Report, news release

ENDNOTES

[i] For details see Georgetown University's Center for Children and Families (2009). The CHIPRA Act. http://ccf.georgetown.edu/index/cms-filesystem-action?file=ccf%20publications/federal%20schip%20policy/chip%20summary%2003-09.pdf. Utah has taken advantage of some of these opportunities and mainly in the private or nonprofit sector.

[ii] Center for Health Care Rights (2003). *From Concept to Operations: A Guide to Developing Assistance Programs for Health Care Consumers.*

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