October 2008

UTAH HEALTH SYSTEM REFORM

it's about all of us

Proposal Framework and Feedback from the Community Workgroup of the Health System Reform Task Force

Prepared by the
Utah Health Policy Project
on behalf of the Community Workgroup

Table of Contents

Special Thanks

The community workgroup formed by the Health System Reform Task Force has endeavored to bring the wisdom and perspective of Utah communities to bear on proposals for health system reform. This ambitious undertaking would not be possible without the following individuals:

- Audrey Anderson, intern with Utah Health Policy Project
- Alan Pruhs and the Association for Utah Community Health
- Bruce Reese, CEO of Bonneville International
- Dee Rowland and the staff of the Catholic Diocese
- Lew Swain, Senior Partner of The Boyer Company

Our regional facilitators:

- Lynn Hudgens, Mountainlands Community Health Center (Provo)
- Joe McKea, Uintah County (Vernal)
- Nancy Neff , Southwest Community Health Center (St. George)
- Lisa Nichols, Midtown Community Health Center (Ogden)
- Donna Singer, Utah Navajo Health Center (Montezuma Creek)

Executive Summary

During the 2008 General Session, the Utah Legislature began an important dialogue about the future of Utah's health care system. Out of this discussion the Health System Reform Task Force was formed and charged with developing a proposal for reform. The Task Force has since been seeking input from five stakeholder workgroups: Hospitals, Insurers, Practitioners, Businesses and the Community.

The Utah Health Policy Project and United Way of Salt Lake have been honored to serve as co-conveners of the community workgroup under the direction of Representative David Litvack, task force liaison. Through a unique partnership with the Association for Utah Community Health, the workgroup used teleconferencing technology to engage 13 different Utah communities and over 400 participants in discussions about the future of health care in Utah. This report is the result of a process that reached across the state for ideas and feedback on how to meet the objectives of HB 133 in reforming Utah's health care system. The end product is an accurate reflection of concerns and solutions from a statewide community.

Utah communities are ready for bold, far-reaching health system reforms. It is in the best interest of Utah's communities and individuals to make quality, cost-effective health care available to all. Reforms must therefore be bold and comprehensive, embracing the three pillars of reform: access, cost, and quality. To succeed, reforms must include at a minimum:

- a shift in the insurance market toward community rating…
- …coupled with a requirement on individuals to participate in coverage.
- In order to participate, however, coverage must be made affordable. All cost sharing obligations must reflect ability to pay, with the details to be determined through an affordability study.
- Decisions around what to include in a basic benefit package should be guided by evidence-based medicine through a commission that includes clinical expertise and consumer representation.

Yet, the community workgroup insists that none of these policy changes and paradigm shifts should be attempted in isolation. The group's preferences for reform are purposely presented as a framework with critical details missing. These details are so important that they should be figured out in concert with the other workgroups under the guidance of policymakers from the legislative and executive branches.

The reforms are, ultimately, about all of us. The community workgroup is looking forward to continuing the dialogue and policy development process begun by the courageous sponsors of HB133—however long it takes. Together, we can create a more responsive, financially sustainable health care system that leads to better health for all Utahns and a vibrant economy.

Proposal Overview

As one of five workgroups formed to give input to the health system reform task force, the Community Workgroup represents the largest, most diverse collection of stakeholders. As such, the group's assignment, to create a coherent proposal for reform, presented notable challenges. A subcommittee comprised of concerned citizens, providers, business owners and advocates was formed to translate public input into policy solutions. Following each workgroup meeting the subgroup further refined the proposal. The following broad goals and principles guide the community group's efforts to craft a proposal for health system reform:

1. It is in the best interest of Utah's communities to make health care available to all. Reforms must therefore be bold and comprehensive, embracing the three pillars of reform: access, cost, and quality:

    a. Every man, woman, and child in the state of Utah will have **access** to affordable health care and coverage.
    b. Utahns will receive the highest **quality** care based on best practices and evidence-based medicine. Disparities based on socio-economic and cultural differences will be reduced. Utahns will enjoy longer, healthier lives.
    c. The **cost** of that coverage will be sustainable over time, for all payers.

2. For health system reform to succeed, the workgroups must come together through a coordinating entity to study the impacts of their proposals on each other and on the community and to find mutually beneficial approaches to reform.

3. None of the policy changes and paradigm shifts that will be required can be attempted in isolation; to succeed, reforms must be implemented as a comprehensive package. However, certain incremental changes may be appropriate as a first step.

4. Cost containment and quality improvement strategies must be a top priority in the reforms. These will be *more* effective in improving overall health system performance *in combination* with policies that extend affordable health insurance coverage to every Utah resident.

5. The private health insurance market can serve as the platform for reform if we find better ways to manage risk. Insurers should compete over how well they keep us healthy; simply competing to avoid risk will not meet the objectives of the Task Force. Further, an appropriate balance must be found between the private market and public programs. Benefit design and cost sharing obligations must reflect ability to pay. For certain populations, it may be more cost-effective to have coverage in Medicaid and CHIP.

6. Responsibility for financing health care coverage must be shared between employers, government, and individuals (according to means). Individuals must take responsibility for obtaining coverage when it is affordable; government must provide a safety net for those individuals who are unable to obtain or afford coverage through an employer or on their own; employers must continue to share in the costs of providing health care. When all parties contribute to health care financing, costs will become more manageable over time.

HB133 Reform Categories	Community Work Group Principles	Policy Solutions
Health Insurance Market Reforms	Competition based on efficiency, quality, equity & value	***Community rating*** limits the criteria insurers can use to determine premiums, thus preventing people with high risk profiles (people who have/had cancer, diabetes, asthma or other health care issues) from being priced out of or denied coverage. This is necessary to ensure that all Utahns – and not just the young and healthy – have access to health care and coverage. To be successful this must be combined with a requirement on all individuals to purchase insurance (details below). Young, healthy adults are more likely to be uninsured. By bringing them into the risk pool in a "community-rated" market, we will lower costs for everyone else and help to stabilize the individual market.
	Strengthen, expand, and stabilize the private market so that it can serve the interests of all consumers while functioning as the main platform for reforms.	***Reinsurance*** is a tool for sharing cost of highest risks (those who get really sick). This moderates risk in the private market by providing a financing mechanism to subsidize the highest cost enrollees. It ensures premiums stay stable for people and that adverse selection (all the unhealthy going to one plan and the healthy to another) does not have a detrimental effect on insurers in a community rated market.
		Risk Adjustment mechanism is a tool for adjusting costs between insurers usually on an annual basis to ensure that no one insurer is made to carry disproportionate risk/cost. This, too, helps to stabilize the private market. Risk adjustment thereby discourages cherry picking or "cream-skimming" of the low-risk patients.
Personal Responsibility and Wellness	Individual as 'buyer' of insurance; individual responsibility to carry insurance	***Individual Mandate:*** Every resident must have coverage either through an employer, public program, or through a policy purchased on the individual market. **IMPORTANT**: an individual mandate will only work if affordability is defined and expectations for what families and individuals can pay are appropriate (see below for details).
	Incentives for Healthy Lifestyles	***Wellness incentives should be part of every health care coverage plan in Utah***, including Medicaid and CHIP. Information about results from wellness initiatives should be accessible through the market facilitator (see below). All wellness initiatives should be structured to reward specific *changes* in behavior, not favorable health status prior to enrollment in a health plan, and maintaining good health status. Resources must be provided so that individuals can attain wellness goals. There must be a level playing field for people to pursue wellness goals. , Wellness incentives must take genetic, socio-economic, or other factors into account and be structured to assist people in reaching their goals. For example, persons with disabilities and others with functional limitations should be given incentives to participate in alternative activities, as outlined in the Americans with Disabilities Act. Develop an ***educational campaign about the purpose and importance of insurance for maintaining good health***, targeting youth, families on the path to self sufficiency, and immigrants and refugees.
	Incentives for appropriate use of health care	*Reforms should include a plan for every Utahn to have a* ***Medical Home.*** . A medical home provides a coherent system of care wherein a primary care provider works with

		patients, families, and other health care professionals to assist patients in accessing all needed medical services. It focuses on preventive care and the management of chronic illnesses, thus reducing the need for more costly forms of care such as high level specialty care and emergency room visits .
	Adequate primary care infrastructure	***Address the shortage of primary care access points*** by allocating funds to 1) Workforce Financial Assistance Program (loan repayment program for primary health care professionals agreeing to work in medically underserved areas and 2) in other areas of the primary care infrastructure; 3) promote the field of family practice through changes to the payment structure, including enhanced reimbursement for primary and preventive care; 4) expand the use of 'mid-level' providers (ex. physicians' assistants and nurse practitioners).
	If individuals are responsible to carry insurance, insurance must be affordable	***Define affordability*** through a Utah-specific research study. *Utah's affordability study should include the parameters developed in a recent review of 6 different affordability studies by Community Catalyst (Affordable Health Care for All: What Does Affordable Really Mean?):* o *Affordability should be defined as some percentage of income that a household can devote to health care while still having sufficient income to address other basic necessities.* o *Premium costs are only one part of the cost of health care. Out of-pocket-costs, co-pays and deductibles must also be considered in the equation. If a family cannot afford the co-pay or deductible, then their health insurance will not incentivize them to seek primary and preventive care.* o *To encourage higher take-up rates of insurance, the affordability scale should be conservative. This will lend much-needed political legitimacy to the otherwise controversial concept of personal responsibility for obtaining insurance coverage. The public, even the so-called "young immortals" will be able to voluntarily respond to incentives to purchase insurance if coverage is truly affordable.* o *Finally, it should be conducted in conjunction with an independent actuary.*
Transparency & Value (& Quality)	Quality Product & Cost Containment: -Minimum/basic benefit package with proper health & economic incentives; -Increased cost sharing as care becomes more optional -implement proven strategies to limit cost growth	***Create Independent Health Benefits Commission*** (as formal, Governor appointed Public-Private Commission that includes consumer representation, has strong public oversight and accountability mechanisms to define the basic benefit package as a first step, then to continuously align the Basic Benefit Package with evidence-based medicine and arbitrate coverage decisions. As part of this Commission a mechanism to actually monitor and enforce quality standards must be developed. ***Basic Benefit Package***: every Utahn must have access to at least a Basic Benefit Package, as defined by the Independent Commission. ***A balanced approach to aging-in-place*** **and long-term care** focused on strengthening families, improving quality of life, and reducing costs through a

		combination of end-of-life care planning, a variety of public-private partnerships supporting informal caregivers, direct care staff recruitment and retention initiatives, development of crisis stabilization and alternative placement options, and ensuring that individuals are served in the most appropriate and cost effective manner and environment possible. ***Cost Containment***: For the sake of streamlining administrative processes and improving disease management and primary care delivery, reforms should support the full adoption of electronic medical records. Tort reform, when it preserves patients' rights to damages and reparations when the provider is clearly in error, may also be an effective strategy.
	Open Access for Buyers; quality info easily obtained; Fair, open, transparent marketplace	***Market facilitator*** *(1-stop shop)* ***mechanism must be established***, ideally as a public-private sector partnership. It can be a private, nonprofit organization, but it must be concrete. The market facilitator orchestrates ***portability, premium collection from multiple employers, transparency, product comparison, compliance with requirement to carry insurance.*** It could also function as a pool through which individuals can purchase affordable coverage, keep stable, consistent coverage, particularly as their incomes fluctuate.
	Eliminate disparities in health based on racial/ethnic, geographic, and socio-economic differences.	Establish an ***inter-agency council to systematically address disparities***, including the broader socio-economic determinants of health.
Tax Advantages	Shared responsibility	***Specify each sector's responsibility for sharing in the cost of coverage***. Health system reforms will call for a significant upfront (and ongoing) investment. Only some of these costs can be recouped through robust quality improvement and cost containment initiatives.
Optimizing Public Programs	Insurance must be affordable	***Use public programs, where appropriate, to ensure coverage access for low-income Utahns***. Conduct an independent affordability study to determine the proper boundary between the private market and public programs. Programs must be constructed to ensure that the cycling on and off of programs is minimized or eliminated (the market facilitator can help some with this).
Modernizing Governance		***Model proposed changes:*** Assess the full impact of potential changes made to private, public and government programs before implementing changes that could leave individuals with inferior care and coverage.

Initial Feedback from the Community (by topic area)

Dates of Discussion: June 16, 2008 and August 28, 2008

August 28th Sites: Bear River, Blanding, Salt Lake, St. George, Murray

Feedback from participants are shown in • bullets; Most of the feedback speaks for itself and is reflected in the proposal; some feedback elicited a specific response from the subcommittee (*italics*).

Access & primary care/Health Care Home

- Make sure everyone has access to care. People with disabilities are often refused private insurance that will address their needs and encouraged to apply for Medicaid. Medicaid has broader coverage than private insurance.
- Accessibility for people with disabilities: all clinics need to be accessible.

While we agree with this statement, our reform efforts will not address the physicality of existing health care sites within Utah. However, any funding that is received from the State for the purpose of expanding access to a "Health Care Home" will comply with ADA (American's with Disabilities Act) standards (e.g. funding to construct or remodel new access points).

- There must be access in different languages in a culturally appropriate manner so that all people, regardless of their language or culture, have equal access to health care (2)
- Ensure accessibility, including unemployed and retired.
- My fear is that reform only brings better care to state employees and state programs. This needs to be easy for the homeless 19 year old, the 25 year old recent graduate, the suburban father, the refugee that has been in Utah for 3 years, etc. (everyone).
- Must ensure timely access to care for those who work unconventional hours.

This issue should be addressed within the proposed Medical Home model. Various "Medical Home" definitions have previously addressed this issue. The American Academy of Family Physicians defined "Enhanced Access" as a core component of their "Patient-Centered Medical Home" definition. In their definition "enhanced access to care is available through systems such as open scheduling, expanded hours and new options for communication between patients, their personal physician, and practice staff."

- Transportation issues are a barrier to care (2).

This issue should be addressed through our attempt to expand access to "comprehensive" primary and preventive health care homes. Within the Community Health Center model of care, "comprehensive" refers to access to medical, dental, mental health, pharmacy and enabling services. Community Health Centers "enabling services" include case management, health education, translation or culturally appropriate care, and transportation needs.

- We don't have enough primary care providers to have a health care home plan.

This is a very good point that requires a systematic approach. Schools of Medicine must focus on expanding family practice as a viable and much needed option. In order to do so, the field of family practice (general/family practitioners, pediatricians, internists, etc.) must undergo changes in payment structure (enhanced payments) and move toward the primary care physician as the "first point of contact" or entry into the medical system. There are a host of additional changes that need to occur within the "system" that will take years to achieve. However, we have some "tools" at our disposal that will help us mitigate the current primary care provider shortage. Expanded use of "mid-level" providers such as Physician Assistants and Nurse Practitioners as primary care providers will help. In addition, we can attract more primary care providers to work in medically underserved areas by increasing funding for the Utah Health Care Workforce Financial Assistance

program or through innovative ideas such as "loan forgiveness" for primary care providers who agree to work in medically underserved areas.

- "Medical home" should be called "health care home" because it is not just medical.

Agreed! However, the reality is that not enough medical providers provide comprehensive services such as mental health, dental and enabling services. The "medical home" movement calls for the coordination of care across the complex health care system. While we would like all medical providers to become comprehensive in their approach, we cannot expect all practices to comply. We hope that all medical providers will comply with the Patient-Centered Medical Home definition in the future.

- Health care home could also be a team of providers.

Absolutely! Once again, we would refer to the "Patient-Centered Medical Home" definition in which "care is coordinated and/or integrated across all elements of the complex health care system (e.g. subspecialty care, hospitals, home health agencies, nursing homes, etc.) and the patient's community (e.g. family, public and private community-based services)"; and a "physician directed medical practice where the personal physician leads a team of providers at the practice level who collectively take responsibility for the ongoing care of patients". In a "comprehensive health care home" the team would also include dentists, and mental health therapists.

Affordability

- the legislature must study the question of affordability and what is truly affordable. What is reasonable to expect a person to pay for health coverage and access. Determine the percent of a person's income that should go towards health care (3).
- An independent affordability study is needed: for example, you can have a plan that includes comprehensive package, but high deductibles and co-pays may prevent you from using it.
- Modernize the way the health benefit works for families. I am a single mom and yet I pay the same monthly payment as a family of 3,4, and 6—why?
- Insurance prices aren't the only thing within that industry that needs attention. Look at deductibles, uncovered procedures, co pays, high deductibles, maximum co pays, denial coverage.

Absolutely! The community workgroup proposal specifically asks for a definition of affordability to be established through an independent study. Many states that have considered an individual mandate have conducted affordability studies to help policy makers set a standard and have a better understanding of what is truly affordable. This is positive for Utah because we can utilize the methods used by other states in designing our own study. The section regarding an affordability study will be strengthened by adding the following: Utah's affordability study should include the parameters developed in a recent review of 6 different affordability studies by Community Catalyst, Affordable Health Care for All: What Does Affordable Really Mean?

Affordability should be defined as some percentage of income that a household can devote to health care while still having sufficient income to address other necessities.

- *Premium costs are only one part of the cost of health care. Out of-pocket-costs, co-pays and deductibles must also be considered in the equation. If a family cannot afford the co-pay or deductible, then their health insurance will not incentivize them to seek primary and preventive care.*
- *To encourage higher take-up rates of insurance, the affordability scale should be conservative. This will lend much-needed political legitimacy to the otherwise controversial concept of personal responsibility for obtaining insurance coverage. The public, even the so-called "young immortals" will be able to voluntarily respond to incentives to purchase insurance if coverage is truly affordable.*
- *Finally, it should be conducted by or in conjunction with an independent actuary.*

Benefit Package

- Cover preventive services
- Mental health parity must be included in the benefit package (2).
- Mental health & substance abuse treatment must be integrated in primary care settings (2).

- Vision & dental must be included in all benefit packages.
- Must define what is meant by "comprehensive" "quality" health care at outset.
- Portable, affordable healthcare coverage for all citizens—basics. Gradually higher costs as care becomes elective. Allow people to buy into a wide pool of options. We do this for car/auto insurance where it's mandated. Should also for health.

Most of the concerns regarding the comprehensiveness of the benefit package are addressed in the current proposal, although the proposal avoids specifying definitions for "comprehensive" or "quality." The basic benefit plan will be developed by a private-public commission using evidence based medicine as a guideline for coverage. The good news is that evidence-based medicine should provide the rationale to include basic mental health and dental benefits in the basic benefit package. Anything not covered in the basic plan could possibly (see discussion on affordability, above) be available in other plans such that no one will be denied basic mental health, dental or vision coverage.

Cost Containment (CC)

- Cost containment needs to be more developed: consider, for example, tort reform as a cost containment strategy.
- Reforms must contain mechanisms to limit costs—i.e. establish certificate of need, larger risk pools.

The Community Group has learned that the Provider Group is working on recommendations for tort reform. When they have a proposal we will ask to review in the hope that consensus can be built around their recommendations. As the community group, we will keep an eye on patient rights as they pertain to tort reform, knowing that patients must have an avenue for seeking damages when the provider is clearly in error. Otherwise, it is safe to assume that the practice of "defensive medicine" generally adds to the overall cost to the patient.

- Need to go after inefficiencies to drive down most of cost: an estimated $1,700 is overpaid per individual; this is about cost reduction more than cost containment.

Because cost is the primary obstacle to health coverage in Utah, particularly in light of the new revenue projections, cost containment must be explicitly built into every level of reform. When all residents have coverage, risk is spread more broadly over a large population which, ultimately, should drive down premiums. Tort reform, if/when it does not compromise patient rights, holds the promise to end the practice of "defensive medicine" which has led providers to be guided by their fear of lawsuits rather than the needs of patients or the financial health of the overall healthcare system. Electronic medical records, streamlined administrative processes, and improved chronic disease management can all mitigate or limit cost growth. All of these strategies are/will be currently built into the workgroup's reform proposal.

Federal Front

- Should not work on this in isolation from national context & presidential election.

We agree 100%. Health reform is arguably the top domestic issue in this Presidential election year. This means that, no matter who takes the White House, states will likely have fresh opportunities, options, and possibly resources to address the problem. Due to the economic downturn and declining revenues, states that are further along than Utah in their reform process have found that they've hit a wall: They cannot move forward with their plans without significant Federal fiscal relief or new funding for expansions. The bi-partisan support gathering around Sen. Bennett's Healthy Americans Act, could help to jumpstart the Federal reform discussion in early 2009. This bill contains several provisions that could help facilitate otherwise difficult changes for Utah, particularly around risk management and ERISA laws. Yet, a national strategy has serious obstacles (namely 60 votes in the Senate), so we can't stop working at the state level.

Financing

- Ask for $ without apologies, we must spend significant $ upfront to reform health care.
- Why are we asking for an all payer approach? We should at least consider reforms involving only government and individuals as payers (ERISA laws will make it difficult to ask employers to share in the cost).

There's no question that health reform will call for significant upfront and ongoing investments. However, reform proposals must simultaneously find savings and innovative ways to improve efficiency and value – particularly during these lean budget years.

Financing must be built on shared responsibility, and given that the majority of Utahns currently receive health coverage through an employer, sound proposals must find ways to help workers and employers keep that coverage. Employer-sponsored coverage is the foundation of our health care system and employers play a key role in not only handling the administrative side of health benefits but also in pooling risk – when enrollees are organized into large groups, such as those formed through work, they are able to negotiate better coverage and are not subject to health underwriting. Policies that seek to remove employers from the provision of health care coverage must protect consumers by providing a mechanism for pooling risk, leveraging buying power, and simplifying administration (For example, by creating the proposed market facilitator).

Insurance market reforms & Risk Management

- Community rating: can't we make an actuarially sound analysis of whether & how this can work?
- Reformed health system must be based on community rating. This would eliminate cherry picking. We must change insurance practices so policies compete on quality.

Community rating, or modified community rating has been tried in other states and we are fortunate to be able to learn from their experience. One of the main lessons learned is that without other major policy changes (a requirement on individuals to participate, reinsurance and risk adjustment mechanisms) community rating will fail. With any proposal that is put forth, it will be important for Utah to model the proposal and work on making changes accordingly.

- There is good data in insurance industry to help design risk adjusters—but this data is currently in private hands.
- Both reinsurance and risk adjustments work well in Switzerland & Netherlands. We should draw lessons from there.

True! They (Switzerland & Netherlands) also have community rating, so their systems will be important to explore.

Under current conditions, many Utahns are unable to obtain insurance. This is because insurers are able to vary premiums, exclude certain types of coverage, or deny coverage based on an applicant's health status. To ensure that all Utahns have access to coverage, the rules of the individual and small group market must change. Community rating limits the criteria insurers can use to determine premiums, thus preventing people with high risk profiles from being priced out of or denied coverage. Because insurers must therefore take on more unknown risk under community rating, risk adjustment and reinsurance will help level the playing field, ensuring that no one insurer ends up with the most expensive enrollees. Research shows that both of these tools can reduce insurers' losses from high cost patients thus helping to lower premiums. An individual mandate can also help control premium cost under community rating by making sure that the healthy, as well as the sick, buy health insurance.

Other policy options that improve the individual and small group market include:

- *Tighter rate banding – reduces premium price variation between high risk and low risk enrollees*

- *Combine the individual and small group markets: This will reduce premiums in the individual market by spreading risk over a larger population.*
- *Guaranteed Issue -- requires insurers to accept all applicants, thus reducing the number of Utahns denied coverage.*

Long-Term Care and Disability Angles in Reforms

- People with disabilities have much to gain (and lose) in health system reforms.
- Move away from facility based care to community support—attach the funding to the individual purchasing and not to the place that provides the services.

Utah's 65 and older population is expected to increase by 127,000 over the next 12 years. There are also an estimated 55,000 students receiving special education services. It is reasonable to anticipate that a fair number of individuals from both of these populations will likely require long-term care in the near future. Given the spiraling cost of health care and the fact that the state already spends nearly 60% of its Medicaid budget on long-term care, it is only prudent to take advantage of the opportunity created by the health reform process to ensure that our limited resources are expended as wisely as possible.

Utah prides itself on the strength of its families and communities. Nowhere is this more evident than in long-term care, where families consistently make extraordinary sacrifices to keep loved ones at home and friends and neighbors regularly step up to fill in the gaps. In 2005, for example, approximately 200,000 Utahns provided nearly $2 billion worth of informal care. Unfortunately, national surveys have found that caregiving can be detrimental to both health and economic productivity. In one survey, almost twice as many caregivers reported their health as being fair to poor compared to the general population. In another, 69% said they arrived late or left the workplace early. If respite care and other proactive supports were available through a timebank, a network of students, retiree missionaries, AmeriCorps/Vista volunteers, after school programs, or a public-private trust fund, family members, friends, and neighbors would have no problem continuing to do their part.

Even so, the formal infrastructure which supports informal caregivers needs to be dramatically enhanced and expanded. Providers are unable to attract and retain a sufficient number of direct care staff to support individuals and families at home or in their communities. Also, families in rural areas of the state are increasingly finding themselves in a bind because of a lack of short-term crisis stabilization or alternative placement options. These challenges demand innovative solutions such as paying family members, work-study or student loan forgiveness programs, and professionalizing the field through the establishment of a career track.

With facility-based care often 5 times or more the cost of community-based supports, it is crucial that long-term care is delivered in the most appropriate and cost-effective manner and environment possible. However, the system will only change once the federal funding streams begin to flow in a different direction. Therefore, Utah's congressional delegation must be urged to help shift the focus of federal Medicaid from facility-based care to community-based supports. To this end, the Department of Health and Human Services should follow the lead of states like Texas, Washington, and Vermont in combining the facility-based and community-based budgets so that the money can follow the person rather than the person following the money. They should also increase the availability of respite care, day supports, and other services by adopting the Personal Care and Home and Community-Based Services Medicaid state plan options included in the Deficit Reduction Act.

Besides being one of the major cost drivers for decades to come, long-term care represents one of the areas of health reform where changes in policy and practice can have a real and immediate positive impact in the lives of individuals and families and on the system as a whole.

Long Term Care and Aging in Place

- Any health reform plan should be integrated with aging in place plans. Also, there are not enough home care providers!

Yes, health reforms should support a balanced, systematic approach to aging in place. This will improve the quality of life for Utah's rapidly growing aging population and save the state millions of dollars. It thus satisfies the community workgroup's interest in financially sustainable health reforms. A balanced approach to aging in place includes:

- *Personal commitment to improved late age: prevention and wellness practices, including life-style choices such as weight management, physical and mental activity, and personal financial responsibility.*
- *Preparation of end-of-life choice documents.*
- *Work force development geared to truly supporting health care at home: this translates to training MDs and other providers to see and treat patients at home. Medical transport is far more expensive than house calls.*
- *Societal shift: Health reforms should support a healthier relationship to aging, morbidity, and mortality, including greater acceptance of an individual's choice to NOT pursue aggressive treatment to prolong life. Non-treatment is a valid (and far less expensive) option that should receive equal access to services via funding. However, such a shift will require trained medical practitioners, (again, the labor pool issue) as well as homemaker level aides who provide functional supports in the home. More than merely a cost-saving measure, this shifts the emphasis to enhancing human dignity at the end of life. It also brings the family and community back to the center of the aging process (away from institutions or government).*
- *Caregiver support will become more and more essential to this shift, in terms of training, respite care, and greater workplace flexibility for workers who are also family caregivers.*
- *Smarter management of poly-pharmacy as it relates to declining cognition and balance issues, as well as cost savings for Medicare and Medicaid. The cost of medication is so overwhelming: it makes sense to refine a person's regime to avoid costly problems.*

Medicaid

- The Medicaid Work Incentives (MWI) Program needs to take into account the fact that on some months small business owners may not make any $. On these months they should not have to pay premiums.

Reform proposals must be tailored in a way that will allow working people with disabilities to have stable and consistent coverage. In the name of "optimizing public programs," one of the categories of reform, the Medicaid Work Incentive program should be reconfigured to prevent individuals from cycling on and off of the insured roles.

- Be very careful about proposing any Medicaid waivers. Even though Medicaid is very dysfunctional, it is so critical to the most vulnerable groups in the community.
- Consider a Medicaid parents expansion.
- Implement medical homes in Medicaid to controls costs, encourages personal responsibility, improves quality. We can design a pilot project to demonstrate the vitality of medical homes.
- Consider a CHIP expansion to 250% FPL
- Families with children who have the SS1 definition of disability end up bankrupt because coverage is less than adequate. The Family Opportunity Act would help solve some of this problem by providing ways around coverage and letting parents buy into the program in a private and public partnership.

Personal or Individual Responsibility

- Make individuals responsible for their health, health insurance and health care (2)

- Health care access to all for basic, preventive care outside the hospital emergency rooms. Reforms should include the removal of unhealthy products from schools (i.e. soda pop). Incentives for healthy lifestyles (i.e. healthy weight maintenance).
- Before people can take on personal responsibility and take on individual mandates, the people must be educated; educate the public about options and good health choices, multiple languages; multiple media formats.I have concerns with individual responsibility: Administration for each family is complicated and overly burdensome for individuals. How would transient populations administer their own health care?

Process for Seeking Solutions

- Look at models in other states: look for track record on given approach
- Need to engage private sector leaders more, who have ears of legislators
- Community group is not just advocates: point out that we represent broad cross-section of stakeholders; what we have in common is that we represent those without vested interests
- Need to pin down top 3-4 changes needed, as per Rep. Dave Clark.
- Focus on what everyday folks will be most concerned about (ex: how to get transparency to work for real, busy people
- Also must represent those who DO have health care but don't know how to use it
- Learn from success of Health Policy Commission (HPC): its Technical Advisory Groups worked well.

Correct on all points above! To the first point, the subcommittee has considered models and lessons from other states before crafting the proposal, though we are sensitive to policymakers' preferences for local solutions. The second point is spot on: this is one of the many advantages of working with the United Way, which is adept at engaging private sector leaders. Also, UHPP and the U-SHARE coalition engage Chambers and other business groups. Point 3: of course, we are not just advocates, though many of us are proud to be advocates. The community workgroup includes providers, small business owners, concerned citizens, state government employees, academicians, safety net providers, and media. We certainly have work to do on points 4, 5, and 6. As the process moves along, we hope to get down to this level of detail. But by that point, the discussion should involve all of the workgroups. The HPC was successful in many respects, especially in the process that they used to develop specific solutions.

Quality & Health Benefits Commission

- We need to further develop the electronic health records angle.
- Need a plan for actually monitoring quality that shows repercussions for not following quality standards.
- Chartered-Value Exchange is now building systems to improve transparency and drive consumers towards value and better alignment of incentives; goal is to incentivize consumers to use higher value providers.
- Best practice for providers—only ordering tests that research shows are valid/reliable; looking at treatments shown to be effective & paying for those "standardized care based on evidence."
- Medical home access for all individuals and families. Comprehensive, patient-centered primary and preventive medical care regardless of insurance and ability to pay. This saves money and enhances/enables personal responsibility (2).
- Health Benefits Commission needs to have good public oversight and accountability built around it and needs consumer representation.
- ½ of Western treatments given are not supported by evidence-based medicine. We must focus more on cost-effective care that delivers value.
- Consider the value of yoga, art therapy, massage, etc. in the reforms.
- Need to get buy-in of providers on any changes. They are responsible for much of the waste & provision of less than cost-effective care.

The first four points make specific recommendations on how to implement quality initiatives, including oversight and consumer representation. Our primary foray into quality is to assure that everyone has reliable access to a basic benefits package. This is the single most critical quality issue. While these additional recommendations and concerns for improving quality are valid, there are many ways to address quality, and we cannot address them all in our proposal. One point addresses wellness as it relates to non-medical practices, such as yoga and art therapy. While wellness clearly contributes to reduction of healthcare costs and enhances health care treatments, there is critical difference between healthcare and wellness: The wellness incentives in this proposal are directed toward quantifiable results of wellness initiatives and are thus more focused on eliminating non-healthy behavior present at the time of enrollment, for example, quitting smoking.

Small business

- Nonprofits must be included in discussions regarding solutions for small business.
- Enable small businesses to provide health insurance coverage at a reasonable cost.

Yes, most nonprofits are small businesses. As such, they should be engaged in the full reform discussion along with the rest of the small business community. In some states and localities, small businesses are allowed to buy in to other pools for coverage or at least for reinsurance (additional layer of insurance for catastrophic costs). However, when this approach was proposed for Utah it faced insurmountable obstacles. Given the role that nonprofits play in serving those in need, it might be politically more feasible to allow nonprofits to buy into larger risk pools. Such a policy would strengthen the nonprofit sector during a time of tremendous fiscal distress.

Transparency

- Transparency—consumers need access to quality assessments of providers, costs of procedures, etc. to make informed decisions.
- Transparency of cost, # of surgeries performed, average patient visit per diagnosis per facility.

Universal

- Every Utah should have quality health care as a right, affordable and portable (4)
- Everyone has to be in the system. Coverage for everyone needs to be guaranteed and community rating need to be as broad as possible.
- Must decide who is a Utahn. What about undocumented? What about snowbirds?

This is a great question and one that we will need to wrestle with as we move through the reform process. While the state currently has criteria to determine who is a resident (i.e. must have an established domicile in Utah and maintained continuous Utah residency for one year (12 calendar months)), there are people who may not fit into the current definition and need access to care. What we do know is that all people can access the emergency department which puts financial strains on the system if their visit could have been dealt with in a more appropriate place at a more appropriate time. We also know that we need and want healthy, productive people in our communities.

Authors of Responses

David Bolick, MD; Korey Capozza (Voices for Utah Children); Joyce Dolcourt (Arc of Utah); Kris Fawson (Utah Statewide Independent Living Council); Elizabeth Garbe, Judi Hilman, and Lincoln Nehring (Utah Health Policy Project); Bill Lee and Nick Marakis (concerned citizens); Peggy Matlin (Division of Aging Services, Department of Human Services); Laura Polacheck (AARP Utah); Alan Pruhs (Association for Utah Community Health); Andrew Riggle (Disability Law Center); Dee Rowland (Catholic Diocese); and Sheila Walsh-McDonald (Salt Lake Community Action Program).

Survey Responses to Specific Components of Reform from September 23, 2008 (n=145; *Expressed in Percentages)*

12 Regions: Blanding, Heber, Logan, Montezuma Creek, Monument Valley, Murray, Ogden, Provo, Salt Lake, St. George, Tooele, Vernal

I. Health Insurance Market Reforms	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	N/A	Deviation +/- 1.0 (%)
As a community we should share risk.	60%	18%	11%	5%	3%	3%	1
Community rating moves us in the right direction.	25%	36%	21%	5%	4%	10%	1.01
II. Personal Responsibility & Wellness							
Every individual should be responsible for having health insurance **if it is affordable.**	70%	14%	8%	1%	5%	1%	0.99
People who take care of their health and well being should be rewarded for maintaining and/or changing their behavior.	63%	16%	16%	1%	1%	1%	0.98
Every individual should have access to a medical home.	56%	25%	8%	5%	3%	3%	1
Affordability must be defined so that reform policies reflect ability to pay for health coverage **AND** care.	51%	25%	10%	0%	4%	7%	0.97
III. Transparency, Value & Quality							
An independent commission with consumer representation should be created to define a basic benefits package based on evidence based medicine.	38%	38%	10%	3%	4%	7%	1
A "market facilitator" is important to make portability, premium collection, transparency, and product comparison possible.	42%	30%	10%	1%	4%	12%	0.99
Individuals and small businesses should be able to pool risk through a market facilitator.	51%	30%	5%	0%	7%	7%	1
IV. Tax Advantages							
Employers, individuals and government must all contribute.	51%	22%	14%	3%	3%	8%	1.01
V. Optimizing Public Programs							
Public programs should help low income individuals and families.	59%	22%	5%	5%	1%	7%	0.99

Survey Responses to Specific Components of Reform from September 23, 2008 (n=145; *Expressed in Percentages)*

12 Regions: Blanding, Heber, Logan, Montezuma Creek, Monument Valley, Murray, Ogden, Provo, Salt Lake, St. George, Tooele, Vernal

An affordability study should be used to determine the proper boundary between public and private programs.	45%	30%	10%	1%	5%	8%	0.99
VI. Modernizing Governance							
An actuarial analysis of any large changes to the system should be done before they are implemented.	58%	21%	11%	0%	1%	10%	1.01
Defined Contribution (From First West proposal, not part of the Community Work Group Proposal.)							
Employers should be able to give people a set amount of money to purchase their own health insurance (defined contribution vs. the traditional defined benefit).	18%	12%	28%	12%	12%	18%	1
Total General Responses							
	6.87	3.39	1.67	0.42	0.57	1.02	

Final Discussion: Comment from Regions (October 7, 2008)

Location	Topic	Comments or Questions
St. George	Wellness	The call for a level playing field discourages personal responsibility. Need a stronger commitment on behalf of individuals. Obesity is not fully genetic-based. *Response: True with respect to a broad public health campaign, but certain populations simply cannot participate in wellness initiatives without a level playing field. Thus it's a balancing act.*
	Wellness Incentives	A monetary rewards system may not be the best avenue. People should be treated equally regardless.
	Primary care access	Another study shows that primary care physicians were not counseling their obese patients to lose weight—they should
Richfield	Various	Every man, woman, and child is a value to the community and thus deserves access to health care. Current policies discriminate against disabilities and low income. Must also recognize that there will be individuals who simply cannot pay. Also, mental health parity must be addressed. Furthermore, obesity is a genetic problem and not only a problem of self control. All communities need community (health) centers for free primary care rather than going to E.R.
	Affordability	Middle class individuals/working class have the most difficult time getting insurance. Can we address the percentage of income dedicated towards health care coverage?
	Mental Health	Frustrating that one must be broke in order to get coverage or go to emergency care. Also, need more mental health parity.
	Shared Responsibility for Financing	Need money to fund health care reform. Employers should be educated about the benefits for providing health care, money to be made to provide insurance. Are employers considered? Medicaid needs to cover services needed to become productive and employable. This ultimately affects the economy.
Provo	Capping profits of health insurers	Would this include administrative costs in insurance companies? *This admittedly controversial topic includes hospital administration etc. it has not been endorsed, but is simply an idea.*

	Wellness	Our community needs to be further educated about disease prevention and treatment. This education needs to be given early on. *Our proposal includes an educational campaign and education is also a part of the medical home concept.*
Vernal	Various	Will shift to community rating and wellness incentives bring a decrease in premiums? Agree with wellness incentive based on behavior. *Community rating really refers to managing and sharing risk as a community. The point is to combine risk and eliminate higher premiums based on health status.* Mental health parity is a great concept and the basic benefit package should include mental health, but affordability is also an issue. Perhaps there should be add ons (*wrap arounds*)? Providers need to improve chronic care management I like the idea of medical home, but need to address the movement of urgent care replacing emergency care. This, too, is expensive and inefficient.
	Medical Home	Concur with medical home concept as is very important. Should partner with groups (like American Cancer Society) that already conduct huge educational campaigns.
Tooele	Wellness	How do we integrate oral health into health system reform? In rural health, we have huge issues with underinsurance and the lack of dental insurance. Reforms should recognize that oral health is directly related to overall health. Individuals without dental coverage end up in E.R. needing very expensive procedures. *State Dental Director: this issue was discussed at the recent Oral Health Coalition meeting. This group met with Sen. Knudsen and wrote a letter to task force to make oral health part of the reforms.*
Ogden	The Process of Reform	Impressed that discussion is opened up to all, although it does come down to "dollar and cents" and the insurance companies do hold a lot of the purse strings. Have the insurance and brokers been brought in? Who sits on the task force? *There is an insurance workgroup. The task force is made up of legislators.*
	Medical Home	Retired pediatrician: we had only 15 minutes to diagnose and educate patients—not enough time. Primary physicians are the lowest paid even with PA's and NP's on board. The lofty goals of our proposal are not necessarily feasible, because insurance companies will not pay for the extra time to do these things. It's about compensation. Reforms should free up time to be able to help patients more fully.

		Nurse practitioner (NP): same concerns as above. I recognize the importance of education, but do we have mid level providers and nurses to help? These individuals are with patients 24/7 and have the information to augment primary care. The provider workgroup only includes physicians! This doesn't make any sense.
Logan	Defined Contribution	Glad to hear the discussion of the dangers of defined contributions. By shifting the burden to the individual we are passing the responsibility for payment onto those least able and over burdened. The result will be further cost shifting. A portal in theory could help, but glad to hear that the portal would have to be core component of reforms.
Salt Lake		Need more detail and must move the public. Health care is not seen as a right, yet we as a society have a fundamental obligation and is in our self interest to maintain a strong, healthy, and vibrant society. The fear of losing coverage interferes with transparency and electronic health records by preventing people from being open about their health issues. We absolutely need to force insurers to insure everyone and that coverage has to be affordable. Adhering to these principles will remove the fear and provide a better foundation for reform.
	Various	Father of child with special health care needs: Need to persuade legislators to follow through with total reform, as may be once in a lifetime opportunity. Money is squandered in inflated public salaries. The market facilitator needs oversight, accountability and transparency. Need to push the legislators as much as the public.
		Bioengineer PhD: Went to dermatologist and for 15 min charged $500 with only 33% covered by Medicare. Need to look at where these big costs are coming from. Part of it is that people have to higher two staffers to argue with the insurance companies. Doctors are refusing Medicare patients because of low reimbursement rate.
	The Process of Reform	Democratic Senator: There is a great desire to do something bold and right away through a bi-partisan efforts in cooperation with United Way. This could be something very positive, and I'm optimistic. But momentum does start from the grassroots level, so call your reps and senators.
		Legislators are moved by hearing even from only a few individuals on a given issue. Should explain to legislators that there will be negative implications from bad reform.
		Can we access what is put forth by the other workgroups? Are we

		working together with these other groups? Is there opportunity for public comment on Oct 13? *We are trying to work with the other workgroups now—has been difficult, part of the political obstacles we are facing. Sometimes there is public comment.*
		Rep. Clarke said that without a doubt there will be no community rating. Are we continuing with community rating? Are we going to negotiate? Make a statement? *We can't forget: The task force formed these 5 workgroups. Now they've got 3-4 of them in consensus around big changes needed like community rating…it is up to us, in this election year, to keep the legislators focused on this emerging statewide consensus for bold reforms.*
Murray	The proposal in general	Great plan with a lot of great ambitions and I commend you on that! Afraid to go out onto the market as an individual and will need health care in the future to cover foreseeable issues.
	Various	Mental health consumer: How long will mental health parity take to implement, what will it cost, what would the benefits be? Some things are out of consumers hands, ex. schizophrenics tend to have addictive personalities and therefore smoke and should not be penalized. I must have physical therapy through Medicaid to be able to work. Concerned about impact of new financial responsibilities on business- we cannot afford to guarantee coverage. We need to assess what business can afford to pay. Huge population that may fall through the cracks between coverage and Medicaid. Pay for performance should be for good performance and not for denying patients.
		Proposal correctly highlights need to address health disparities by forming an interagency council. The Hispanic Health Care Task Force would love to participate.
	Market Reforms	Make rules to make insurance companies more transparent, Need simple instructions on how to reduce negative underwriting score. Reasonable standards and clear language on forms and letters. Will put more questions and suggestions on the website.
Blanding	Medicaid 'optional' services	I'd like to see a requirement that insurance provide assistive technology in the bathroom. Coverage and services provided by Medicaid and Medicare should be more continuous and consistent. One year we have dental or vision care, the next eyar we don't! This is very confusing, especially for the elderly, who have to go through various coverage changes every year.

Glossary

As requested by workgroup members, below are some definitions of terms that have been or may be used in health reform proposals. Most definitions are from Community Catalyst's *A Consumer Guide to State Health Reform* and Families USA's *Glossary of Health Care Terms*.

Adverse selection

The trend of people only purchasing insurance when they are sick and have significant expenses. Or, the separation of healthier individuals into some plans and sicker individuals into other plans.

Case Characteristics

Case characteristics include things such as age, gender, industry, geography, family size and group size. States can choose what case characteristics insurers are allowed to use when underwriting an individual or group for an insurance policy.

Community Rating

Pure community rating does not allow underwriting on health status (medical underwriting) or case characteristics. This means insurers are required to rate everyone the same within a community, i.e. all community members pay the same premiums.

> **Adjusted or modified community rating** does not allow underwriting on health status (medical underwriting) but case characteristics can be used (within limits) to underwrite enrollees. For example, states may choose to underwrite according to age, so that as you grow older your premiums increase but they are lower when you are younger.

Fully Underwritten

Fully underwritten does not set limits on the amount an insurer can vary premium. The insurers are allowed to rate up an insurance policy without limits based on the insured's case characteristics and health status.

Guaranteed issue

A requirement that insurers sell insurance policies to anyone who seeks one, regardless of health, income, age or other factors.

Health Information Technology

Computerized records and other tools to streamline healthcare using advanced technology.

Medical Home

A medical home provides a coherent system of care wherein a primary care provider works with patients, families, and other health care professionals to assist patients in identifying and accessing all needed medical services. It focuses on preventive care and the management of chronic illnesses, thus reducing the need for costlier care such as emergency room visits and hospitalizations. The American Academy of Pediatrics defines a medical home as "a partnership between families and physicians to provide primary care which is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective."

Medical Underwriting

Medical underwriting is the practice that allows insurance carriers in the market to decide whom to sell coverage to, what benefits to offer, and what premiums to charge based on a number of criteria, including health status, prior medical claims, age, gender, and other factors. Medical underwriting is common in the individual insurance market, but is prohibited in some states. Many states have some restrictions on medical underwriting, or provide other options, such as high risk pools, to individuals turned down for insurance.

Preexisting Condition Exclusion

A policy of excluding certain people from obtaining insurance or treatment due to a preexisting medical condition/health status. This happens through the process of medical underwriting.

Rate bands

Rate bands allow medical underwriting and set limits on the amount an insurer can vary premiums. In general, insurers set an average premium rate, known as an index rate. The rate band then sets a floor and a ceiling for the index rate, limiting the amount an insurer can vary premiums for the healthy and sick within the band. People can be denied health insurance in a rate banded system.

Reinsurance

Reinsurance is insurance for insurance companies. A primary insurance company transfers risks of high cost claims to another private carrier or to a government-sponsored program. The insurer or government-sponsored program then assumes this risk and pays for some or all of these high cost claims. There are two types of reinsurance programs: in one, the government pays for some or all of the claims through general revenues; in the other, state law establishes an association of insurance companies and requires these companies to pool their resources to pay high cost claims.

Risk Pooling

Under this process, risk for all individuals—including the healthy and the sick—is combined into one risk pool or group, and the group's total expected claims are evaluated. This is used to try to calculate the required funding (raised through premiums and/or other subsidies) to support the payment of all expected claims for all members of the risk pool.

Conclusion and Next Steps

The community workgroup is pleased to note a remarkable consensus across the different workgroups and communities on the content and scope of reforms. While the current economic downturn limits available revenue for some of the 'downpayments' needed to initiate comprehensive reforms, efforts begun by HB133 should continue to move forward. If anything, the bleak economic outlook underscores the need for bold, far-reaching reforms that result in affordable access to care and coverage, better cost management, and improved quality of care for all.

Dialogue Continues on the Web Forum

To make sure that the proposed reforms make sense for the 'end-user,' the Utah community, open communication is vital. To this end, the workgroup created an online web forum. Community members, including representatives from other workgroups, are encouraged to offer commentary and suggestions as the reform process moves forward.

The web forum allowed people with limited mobility, those living in rural regions, and working Utahns with an interest in health care to be a part of this important conversation about the future of health care in Utah. The webforum is divided into three sections:

- **The Pages** are an information source. For example, we posted an overview of the reform process, the Community Workgroup's *Principles for Reform*, and the workgroup's proposal.
- **The Discussion Board** allows Community Workgroup members to ask questions, give feedback and make suggestions. This is the place for the community to continue discussions and dialogue begun at the regional satellite meetings. Examples of threads in the discussion pages are insurance market reforms & risk management, and long-term care/ aging in place.
- Finally, **the Files** section allowed us to post key documents, such as results of the comprehensive feedback form, which is also included in this report, or relevant research articles.

To join the web forum, send email to elizabeth@healthpolicyproject.org

The interest around the state for meaningful health system reform is deep and very personal. All Utahns feel the impacts of the health care crisis facing our state and nation. For the community workgroup, the process is not over until every man, woman, and child in the state has **access** to **quality**, **cost-effective**, affordable health care and coverage.