

**REPORT OF THE
EIGHTY-SECOND ARIZONA TOWN HALL
ON THE SUBJECT
“HEALTH CARE OPTIONS:
HEALTHY AGING — LATER LIFE DECISIONS”**

Health care issues—on numerous topics ranging from the quality of care, to accessibility, costs, funding and medical decision-making—have a significant impact on every segment of Arizona’s growing population, regardless of age, ethnicity, income or residency in urban or rural areas. While individual Arizona residents in different circumstances may disagree about the best way to address each of these issues, there is one significant health care issue that we all will have to face. Within twenty years, the so-called “baby boomer” generation born between 1946 and 1964 (approximately one-fifth of Arizona’s population) will have reached Social Security age, and by 2031 every baby boomer will be over 65, with the oldest being 85. As a result, Arizona’s elderly population is projected to triple by 2050. Some of the toughest questions involving health care in Arizona in the next twenty years relate to how we as individuals, as communities and as a state can deal with the health care challenges and opportunities that are presented by this approaching surge in Arizona’s elderly population.

A significant increase in Arizona’s elderly population will unquestionably strain the state’s already stretched budget for medical care, but it is likely to have other effects as well. For example, as the baby boomers enter old age they will not only increase the size of the elderly population, but they will cause a shift in its demographics, making it less uniform and more segmented. Generally speaking, as compared to the present elderly population, the baby boom group of elderly will have more variety between their individual levels of formal education and wealth, but will typically have fewer children and a lower proportion of married couple households. These and other trends in the demographics and way of life of Arizona’s elderly population will affect, and may complicate the state’s health care plans and policies for this group. However, despite the financial and planning burdens that will accompany this increase in Arizona’s elderly population, there also will be a great opportunity for the community to benefit from the influence of these more experienced citizens — a group that one author describes as “a vast, untapped social resource.”

Some of the toughest questions involving health care in Arizona in the next twenty years relate to how we as individuals, as communities and as a state can deal with the health care challenges presented by the approaching surge in Arizona’s elderly population.

The goal of this Arizona Town Hall was to openly discuss these issues and to exchange viewpoints and ideas in the belief that by working together we can better understand, address and plan for the health care needs of Arizona’s diverse and growing elderly population. The 133 participants of the 82nd Arizona Town Hall spent three days discussing the issues, learning from each other and seeking consensus on sound and effective strategies that could help our state prepare for and deal with this important public policy challenge. The conclusions and recommendations contained in this report represent the consensus reached by the Town Hall as a whole. While not all participants would agree with every one of these conclusions and recommendations, this report does reflect the significant topics on which consensus was reached during the 82nd Arizona Town Hall.

82ND TOWN HALL RECOMMENDATIONS

DEFINING THE KEY ISSUES AND CHALLENGES

Identifying Proper Roles and Responsibilities

The responsibilities for health must be shared and balanced between society and the individual. Each individual must take responsibility and an ownership interest in his or her own health, both by shouldering some of the financial burden for care and by taking appropriate preventive measures to lead a healthier lifestyle, recognizing the importance of the “concept of wellness.”

Arizonans age 65 and older should have a right to a basic level of quality health care. The quandary is determining how far this right extends—in other words, how we define “basic quality health care.” This will require us to make difficult decisions about what types of services should be made available to all Arizonans. The health care services to which Arizonans have a right are necessarily constrained by the financial resources available to pay for those services, and the growing demands on our health care system that affect the entire population. These factors must be given strong consideration.

Federal, state, county and tribal governments; individuals, families and friends; non-profit organizations (including charities); community organizations; and the private market all have key roles to play in the effective delivery and funding of health care for seniors. Presently, there is a hodgepodge of payers, providers and other organizations who determine how health care resources are allocated and provided, but these efforts need to become more coordinated under an integrated, system-wide approach and streamlined to the extent possible. Federal, state, county and tribal governments have distinct roles and responsibilities in providing and financing basic quality health care, including providing oversight, defining minimum levels of access, and establishing appropriate regulations and standards for the provision of health care.

The responsibilities for health must be shared and balanced between society and the individual.

Impact of Demographic Changes

There are a number of demographic changes already underway that will present significant challenges for the provision of health care for the elderly in Arizona. The greatest of these challenges is the tremendous growth in the sheer number of the elderly population that is presently occurring and that is anticipated to continue in the coming years, due in large part to the aging of the so-called “baby boomer” generation. Another important factor is that today’s elderly population is, on the whole, living longer and consuming more health care resources than prior generations, but may have more limited financial resources. The trend of in-migration of those 65 and older to Arizona also is continuing, and those individuals consume healthcare resources and are less likely to have their own caregiver and social support system. Added to this is the mixed impact of the seasonal influx of elderly residents. Within the state, some of the elderly population has relocated from urban to rural areas, which has caused problems for some rural areas with limited health care resources.

The state’s provision of health care also must take account of the needs of the growing racial and ethnic minorities within Arizona’s elderly population. Arizona’s racial and ethnic minorities currently are not faced with a large “baby boomer” generation. Their population’s average age is much younger. The state’s four major racial and ethnic elder populations range from 4% to 6.1% of their total populations. Elderly members of all ethnic groups have their own disproportional share of certain conditions. Some elderly members of minority groups have greater medical needs and often have less access to private health insurance than the elderly population as a whole. The minority elderly population sometimes suffers disproportionately from certain medical conditions and poses new and unique challenges to the health care industry through cultural and linguistic differences.

While the demands for elderly health care are growing, the state has fewer resources with which to address those demands. There is a serious disparity between the number of elderly and the number of health care providers in the state who are willing to care for elderly patients. The number of providers and ancillary services has not grown along with the size of the elderly population, and this will have a pronounced and inevitable impact on the availability of care. The state has a significant shortage of qualified health care professionals and health care facilities, particularly in rural communities. The financial resources available to address these problems also are becoming strained, due in part to Social Security’s and Medicare’s increased dependence on a smaller group of

While the demands for elderly health care are growing, the state has fewer resources with which to address those demands. The number of providers and ancillary services has not grown along with the size of the elderly population, and this will have a pronounced and inevitable impact on the availability of care.

workers paying to support a growing number of dependent recipients. The challenges posed by all of these issues cannot be overstated.

Health Care Concerns of the Baby Boom Generation

The aging baby boom generation faces a host of health care planning issues. The most significant of these issues is the need to plan for the cost of health care in their elderly years. Both individuals and society need to consider and plan for these costs. The baby boomer generation is, overall, not financially prepared to bear these costs. As a group, they are more “consumer driven,” and as a result they tend to have inadequate savings and significant amounts of debt. There also are lower-income segments of this age group that lack meaningful savings options, including many in Arizona’s racial and ethnic minority groups. To compound their lack of preparation, this group will have higher expectations and demands with respect to the quality of medical care they receive. While they are uncertain about

whether Medicare or Medicaid/AHCCCS will be available for them when they reach old age, many have not planned adequately for their own long-term medical care, and even may be in denial about those issues.

As the baby boomers age, their health care costs will increase as they begin to face chronic health conditions. The situation will be aggravated by the shortage of health care suppliers and caregivers. Technology will continue to change rapidly and lead to the development of more and better methods of treating health problems, but this also will increase significantly both the demand for medical services and their cost. Because of the population growth, there will be increased strain on services provided for people who are cognitively impaired and those with behavioral health issues and chemical dependence. The extent to which seniors elect to stay in the work force pursuing later-life professions will affect their ability to cope with health care costs.

One of the most important ways to address the needs of the aging baby boomer generation is to provide them education about planning for their future health care and the various options available to them, including assistance from family and community-based care options. Additional education about preventive care issues also is important. While baby boomers are more knowledgeable about preventive care issues than previous generations, they do not necessarily act on this knowledge. Education should seek to shift the emphasis from “quick fix” medical care to promoting strategies for healthy aging.

Refocusing Priorities

Arizona’s health care system should place greater emphasis on influencing people’s behavior to adopt and maintain healthy lifestyles. The state’s current medical system is skewed toward treating disease, illness and injury rather than promoting healthy living and management of chronic conditions. Indeed, it can be said that today we have a “sick care system,” not a “health care system.” That focus must change. Unhealthy behavior has a profound impact on the health care system, both in terms of the drain on finite health care resources and the impact on quality of life. We spend too little on the prevention of illness, even though there is a high benefit-to-cost ratio for such care.

The state’s current medical system is skewed toward treating disease, illness and injury rather than promoting healthy living and management of chronic conditions.

An education program addressing preventive care needs to begin at an early age and continue throughout a person’s life. We cannot focus only on the elderly. By placing a greater emphasis on the “wellness model” of health care, such a program would attempt to educate and inform people about both the benefits of healthy habits and the costs of unhealthy habits. This education could be advanced, in part, through the media or consumer marketing by presenting positive images of healthy lifestyles.

A more preventive model of health care also could be promoted through new financial incentives that would seek to realign the economic incentives and rewards for healthy behavior. This might include changing the payment

82ND TOWN HALL RECOMMENDATIONS

systems for health care providers to provide reimbursement for preventive services, rather than solely for treating existing conditions. The current reimbursement system that compensates health care providers primarily based upon encounter volume and procedures should be refocused to reward care that is evidence-based, inter-professional and intended to result in improved health outcomes. Also, financial incentives for healthy behavior may be provided directly to those individuals who avoid unhealthy habits in the form of reduced health insurance premiums or coverage options.

HEALTH CARE FACILITIES, PROVIDERS AND SERVICES

An Appropriate Continuum of Care

There are many important elements of an appropriate continuum of care for Arizona’s seniors, including, but not limited to:

- housing
- health & wellness education
- transportation
- telehealth (telemedicine)
- nutrition
- dental care (as one participant noted, “Our teeth are aging in place too!”)
- pharmaceutical care
- vision and hearing services
- family support
- social services
- mental & behavioral health services
- home care
- adult day health services
- assisted living
- institutional care
- continuing care
- acute care
- nursing home care
- hospice care

In addition to these elements, health care providers should seek to promote effective communication and sharing of information, and integrated and efficient case management, and to provide support and respite for caregivers. Seniors also should have opportunities and be encouraged to engage in physical, educational, cultural and community activities.

Some of the strengths of Arizona’s present continuum of care include the hospice care system, the local area agencies on aging, and the design and flexibility of Arizona’s long-term care system AHCCCS/ALTCS, but only for the individuals who qualify for that program. The individuals who actually provide health care in the system are, for the most part, “caring caregivers” who provide professional service despite the difficulties they face.

With the exception of those who qualify for AHCCCS/ALTCS, what we have today is a collection of uncoordinated public and private services, not a system of care organized to work together.

Arizona’s continuum of care has some significant weaknesses. Its two main problems are its under-funding and its fragmented structure. The result is an environment where the elderly are unable to gain access to needed services, and many, especially minorities, are unaware of the services that are available. Arizona lacks sufficient funding and health care staffing to keep up with the increasing demand in elder care services—especially in the area of assisted living and home and community-based services. The state also lacks a strategic, long-term

82ND TOWN HALL RECOMMENDATIONS

plan to develop and utilize resources. Arizona's elder care is provided by a fragmented system with a number of different government agencies and providers. With the exception of those who qualify for AHCCCS/ALTCS, what we have today is a collection of uncoordinated public and private services, not a system of care organized to work together. As a result, there is a lack of both effective communication regarding patient information and coordination between the various providers. There is a lack of coordination of care and administration for the Medicare/Medicaid (AHCCCS) dual eligible patient. Dual eligible Arizonans would benefit greatly from the state seeking the primary administrative role for their care. The shortcomings of the current system are even more pronounced in Arizona's rural areas.

To improve the current health care continuum for the elderly, we need to improve and streamline communication between the various agencies and entities (both public and private). We should seek to align multiple financial and data sources so there is an integrated information system supporting patient care. Local coalitions could be charged with cataloging and informing the public about the various types of available health care services. We also must pursue the modification of state and local regulations to encourage the design and construction of environments for healthy aging to enhance the continuum of care.

Collaboration Between Health Care Providers and Payers

Under the current system, there are a number of barriers that interfere with efficient collaboration and cooperation between separate health care providers and payers. The primary barrier is the lack of an effective widespread system for sharing patient information and the cost of establishing such a system. Current confusion about patient privacy laws and regulations such as the Health Insurance Portability and Accountability Act ("HIPAA") may constrain cooperation by adding an additional administrative burden in the information sharing process between medical providers and payers, so those statutes and regulations may need to be better understood in order to facilitate the sharing of information while adequately addressing patient confidentiality.

Arizona should seek to overcome these barriers and increase effective collaboration between health care providers and payers. The key to accomplishing this goal is facilitating and encouraging the secure, effective and reliable communication of patient data, which will likely require the formation of some type of centralized data repository. This can be accomplished using information sharing technology that already exists. The system might utilize technology from similar large database systems, such as electronic medical records systems, credit reporting systems, or other community-supported database systems, although it would be expensive to set up such a system. Collaboration also can be improved by promoting active interdisciplinary case management practices for patients who are being treated by multiple providers. Cross-disciplinary education and training for medical providers can help instill a culture of collaboration.

Adequate Health Care Facilities and Human Resources

Today, Arizona faces a crisis with insufficient financial and human resources necessary to provide health care for our population. We can expect this problem to reach catastrophic proportions in the future unless we plan now to address the root causes of this crisis.

In the future, there likely will be a shortage in physical facilities, including a shortage in hospital bed capacity. The availability of health care services in the home also should be expanded to help alleviate this problem. Of even bigger concern is Arizona's worsening human resource shortage with respect to the number of qualified doctors, nurses and other professional health care providers and caregivers available to provide services to the growing elderly population. The number of those medical providers is not presently keeping pace with the communities' needs. Arizona especially needs more physicians who have been trained in the area of elder health care. Also, Arizona is currently training only a fraction of the nurses it needs and it is not successfully retaining the nurses it now has.

The reasons for these shortages are different for each profession, and a comprehensive plan to address our future needs is essential. At a minimum, a concerted effort is necessary to fund our educational system to allow for a dramatic expansion of our capacity to educate more health care professionals. Also, the model of malpractice insurance and tort must be reformed if Arizona is to have any realistic hope of recruiting and retaining a sufficient number of health care professionals to care for our population. Specialized education that addresses health care

82ND TOWN HALL RECOMMENDATIONS

practices for the elderly also should be provided. Health care and educational institutions should be encouraged to provide continuing education about aging and end-of-life care for all of its health care professionals. Efforts also should be made to improve working conditions where necessary. In order to support professional health care providers, the educational preparation of informal caregivers (family and friends) also is critical.

Paying the Bill – Funding Adequate Health Care

The nation and the federal government should give to health care the same funding priority they ascribe to public safety, national defense and education. The implications of not covering needed medical services for Arizona’s oldest citizens are straightforward—many individuals and families will likely suffer without adequate medical care. In addition, inadequate coverage for the elderly imposes significant costs on the rest of society and on the state’s medical system as a whole. If left uncorrected, the medical condition of individuals who are denied services and medication will continue to deteriorate until they eventually require much more extensive (and expensive) medical treatment. Health care costs for the uninsured ultimately are passed on to society as a whole and borne by other portions of the population or health care system.

The nation and the federal government should give to health care the same funding priority they ascribe to public safety, national defense and education.

Arizona’s ability to deal with the future cost of health care for the elderly and indigent is in question. Although federal restrictions limit the state’s creativity in addressing this problem, we should continue to look for new alternatives for funding these needs. At the same time, Arizona should be mindful of proposed budget cuts and attempt to leverage any federal funds it receives for this purpose to maximize the benefit provided to its residents.

The cost of prescription drugs is one of the most pressing issues for Arizona’s health care system. The primary problem is the lack of resources, both on the individual and state level, to adequately cover rising prescription drug costs. The high cost of prescription drugs is due at least in part to drug companies expending excessive resources on marketing that often is unnecessary or of questionable benefit to the public. One possible result of this direct marketing to consumers is that some doctors may over-prescribe medications for their patients. Consumers are forced to absorb those marketing costs. Individuals who cannot afford to pay the high prices for the drugs they need are forced to seek them elsewhere or go without. Arizona’s recently adopted state program providing discounts on prescription drugs for its Medicare-eligible residents is a welcome start, but more needs to be done.

The high cost of prescription drugs is due at least in part to drug companies expending excessive resources on marketing that often is unnecessary or of questionable benefit to the public.

The cost of prescription drugs is primarily a national problem, and must be addressed in a meaningful fashion by the federal government. With limited exceptions, Medicare does not cover prescription drugs. The federal government needs to rethink this approach to reflect present medical realities, and provide some form of significant assistance in covering the rising cost of prescription drugs. One alternative would be to expand Medicare coverage, in full or in part, for necessary prescription drugs. In addition, both federal and state governments should try to find ways to reduce the costs of prescription drugs. A concerted effort by health care professionals to use generic drugs and to reduce the frequency of over-prescribing or redundant prescriptions should be encouraged.

Medicare’s failure to provide long-term care services creates a serious breach in the continuum of care. Medicare reform should include expansion to cover these services.

CHRONIC AND END-OF-LIFE CARE AND DECISION MAKING

Making and Fulfilling Chronic and End-of-Life Care Decisions

Although long-term care and end-of-life issues are complex and emotionally charged, these are very important issues for which every individual should discuss and plan. Such decisions ultimately must be made by the individual with the support of his or her family. However, Arizona must provide people with the information and resources that are necessary to make these decisions. Individuals should be encouraged to begin making long-term care and end-of-life decisions early in life. This is not just a concern of the elderly. In making these important decisions, individuals should consider the financial, emotional and quality-of-life implications of their choices, as well as their impact on family, friends and significant others, and their own personal beliefs.

Individuals should be encouraged to begin making long-term care and end-of-life decisions early in life.

Whenever possible and when culturally acceptable, chronic care and end-of-life decisions should be made with input and support from trusted family, friends and advisors. This broad “team” of advisors can include spouses, children, other family members, friends and significant others, physicians, nurses, insurance and financial advisors, clergy or members of the faith-based community and community support groups. This should not be a one-time discussion; it should be a continuing dialogue through which the individual continues to convey his or her wishes.

Education must play a key role. In order to make an informed decision on long-term and end-of-life care, people need to be aware of their options, including the types of care available, the types of facilities in which they would receive that care, and the costs and quality of such facilities. For example, residents should be made aware of the options available to them through hospice care and other traditional and non-traditional care. The state should promote further education for Arizona residents about their end-of-life options and how to make an effective, enforceable decision. One important element of that education is to provide the public with comprehensive literature discussing long-term and end-of-life care options, including the forms necessary to execute enforceable advance directives for medical care. Such literature should take into account the views, beliefs and culture of the various different ethnic and cultural groups in Arizona with respect to this issue. An effort should be made to ensure that this literature is widely distributed among Arizona residents, possibly through employers, faith-based and community organizations, tribal communities and/or insurance companies. Although Arizona now provides a number of the necessary forms on the attorney general’s website, and other groups and programs around the state have developed videos that help explain these issues and options, more still needs to be done to educate and inform the public and to encourage outreach to rural areas. For instance, end-of-life coalitions have begun to assemble educational materials and community advisory groups to encourage individuals to make advance decisions. Provisions should be made for increased dialogue to follow up, as appropriate, on clarification of concepts and answering questions.

Of course, medical advance directives are rendered useless without knowledge of their existence and effective implementation of those directives by the individual’s family or advocate and medical service providers. An individual’s end-of-life decisions should be respected and carried out. To help accomplish this, physicians, nurses and other health care providers should be given continuing education in all the aspects of long-term and end-of-life care decisions, including the importance of communicating effectively with their patients on these issues and the importance of respecting and enforcing their patient’s decision. Copies of medical advance directives should be given to the individual’s health care providers. Individuals also have an obligation to keep advance directives forms in an accessible location and to review them periodically.

Arizona should create a single, centralized state repository. This repository should provide for storage of either the notice of the existence of medical advance directives, or, at the option of the resident, the full contents of the advance directive.

To further the effective use and enforcement of long-term and end-of-life care decisions, Town Hall recommends that Arizona create a single, centralized state repository either in the Department of Health Services or the Secretary of State’s office. This repository should provide

82ND TOWN HALL RECOMMENDATIONS

for storage of either the notice of the existence of medical advance directives, or, at the option of the resident, the full contents of the advance directive so that medical providers who need this information can be aware quickly of the existence or the contents of an advance directive. The repository must be made easily accessible to hospitals and to other medical services providers, and also to the individuals themselves, so that they remain able to change those advance directives at any time if they so choose. Consistent with the privacy interests of the individual, the repository may best be maintained in an electronic or computerized form to enable quick remote access, including access by emergency medical services. The repository should be a means for enhancing dissemination of information within an integrated system. To the extent possible, the repository should be based on other currently existing technology and systems, but other possible methods for transferring medical advance directive information, including wallet cards, additions to drivers' licenses through the Department of Motor Vehicles, bracelets and in-home posting also should be explored. However, it should be understood that this centralized repository is not a substitute for informed discussion about end-of-life issues, but rather an enhancement to that primary goal.

Long-Term and Chronic Care

The impact of chronic conditions on the health care system is enormous. Chronic conditions dramatically increase the costs of health care, and patients with multiple chronic conditions are the largest consumers of health care resources. These higher costs can lead to a lower quality of care for patients with chronic conditions. Chronic conditions involve multiple facets of care, including home and community-based services, different facilities, physicians, technicians, nurses and therapists, making effective treatment more complex. As the baby boomers age, the number of patients with chronic conditions will increase significantly, as will the costs of treating them.

As the baby boomers age, the number of patients with chronic conditions will increase significantly, as will the costs of treating them.

Although Arizona has a number of home and community-based services, assisted living, home health care and pain management options, these alternatives currently are not available to everyone. Those who are sufficiently affluent can pay for such care themselves, and lower income individuals can have such care covered by AHCCCS/ALTCS, but there is a large group of Arizona residents, including many in rural areas, who fall in between these categories and therefore are unable to utilize many of the options. The criteria used to determine the need for, and the allocation of home care and assisted living resources requires a balance among patient preference, cost-effectiveness and care availability. A combination of medical, social, financial and patient support system criteria determine whether a patient is best served by home care, assisted living or nursing home care.

To the extent possible, fulfilling the self-determination and expressed preferences of the patient should be the first priority in determining what type of long-term or chronic care is appropriate. Arizona's health care system needs to change its approach toward establishing "best practices" for the treatment of chronic conditions. The current model of the health care system focuses more on the treatment of acute care than chronic care. Applying the existing model to chronic care has resulted in a disconnect between curative care and chronic care. Another problem is that the provision of chronic care often is fragmented, with different providers and delivery systems, which increases costs and is confusing and time consuming for patients. In addition, we must address our society's reluctance to provide adequate pain management through medication. This reluctance often is caused by excessive fears of potential patient addiction and physicians' fears of government scrutiny of narcotic prescribing practices.

The system's focus needs to be changed to a more flexible and active case management approach to treating patients with chronic conditions. This should involve an interdisciplinary coordinated team approach to finding and carrying out the treatment that best suits the patient's wishes and needs, then tracking the patient's progress and continually reevaluating his or her needs. This approach should encourage and make available more options for home care and self-managed care. Financial incentives should be used to encourage the acute care system to place more emphasis on the effective treatment of chronic conditions. Communication and interaction with other groups across the nation that are currently addressing these same issues also should be encouraged.

Moral, Ethical and Financial Considerations

Individuals in the last phase of life typically require significantly more health care resources, while they also face uncertainty about their future quality of life. There is a broad range of moral, ethical and financial considerations that influence health care decisions in the last phase of a person's life. These include the patient's level of physical comfort and quality of life; the effectiveness of continued treatment; the anticipated expense of continued treatment; the financial and emotional impact on the patient's family, friends and loved ones; spiritual, religious and cultural considerations; and the availability of hospice, assisted living or home care.

The difficulty is in finding the proper balance between all these factors in each individual case. The analysis is complicated by our health care system that essentially views the factors on two different levels. The perspective of the individual and his or her loved ones tends to emphasize the moral, ethical and quality of life issues. Where the individual expresses no wishes to the contrary, medical providers' ethical obligations lead them to make every effort to continue treatment, even when some may consider it futile. At times, a patient's family also may encourage continued aggressive care to prolong the life of their family member. This decision may be complicated further by cultural and religious values that can influence important decisions about when and how to die. For example, members of certain cultures, including some Native American groups, avoid discussing death and dying as part of their tradition. Another significant complication is the difficulty of physicians making accurate prognosis, setting appropriate goals and discussing difficult decisions.

The most important factor in decisions on end-of-life care always must be the personal wishes of the patient and the fulfillment of the patient's own preferences. We need to ensure, however, that the patient is able to make an informed decision based on a review of all the available information, presented in a manner appropriate to the patient's culture, beliefs and language. Effective communication and education are key. This necessarily includes the need for physicians to be completely open and truthful with their patients about the likely outcome of continued treatment, the cost of such treatment, and the patient's quality of life if such treatment were pursued. Patients also should receive information about any other options available to them, such as hospice care, home care and palliative care, including the costs and likely outcome of treatment under each of those options.

The most important factor in decisions on end-of-life care always must be the personal wishes of the patient and the fulfillment of the patient's own preferences.

The question of the level of health care resources properly expended on patients during their final six months is a difficult one. Aggressive treatment of such patients undoubtedly imposes significant costs on the system. Patient decisions must be respected, but there is a lack of general agreement whether financial limits are appropriate. Also, it is not always clear when a condition is truly terminal, and a patient's future quality of life cannot be predicted with exactness. Therefore, the proper focus should be on what health care measures are appropriate under the circumstances and in light of the patient's informed wishes, not on the dollar amount expended.

End-of-Life Decisions

The decision of how and when to die is an emotional one that raises religious, spiritual, moral and ethical implications. Because the decision of how and when to withdraw or withhold life-sustaining treatment is an inherently personal decision, it must remain in the hands of the terminally ill individual, so long as the individual remains competent. Ordinarily, the individual's decision whether to accept or deny medical treatment that will prolong his or her life should be fulfilled. It also is important that each individual have end-of-life options that are legally available and that will provide the opportunity to die in peace and with dignity. These options must include quality hospice care and palliative care in a comfortable setting for the patient, and that incorporate effective methods of pain management. It is essential that individuals, family members and advocates receive complete and honest information from their physicians and others about the cost and likely outcomes for each of their end-of-life options. The experience gained in ethics committees may serve as a growing foundation to assist Arizonans in making these vital decisions. These committees could be replicated and customized in additional facilities and community settings throughout the state. Special care should be taken to ensure that individuals expressing their end-of-life preferences are not suffering from depression or mental illness, and that they are not being unduly influenced by uninformed or ill-intentioned family members, caregivers or others. Subject to these safeguards, the

82ND TOWN HALL RECOMMENDATIONS

Town Hall felt that these decisions should be made only by the individual. Making the question of how and when to die a matter of public policy could lead to unintended consequences, and should be a matter of public debate.

This issue raises an additional important question: what consequences should there be for those who affirmatively assist others in carrying out a life-ending decision? So-called “physician assisted suicide” (and indeed the affirmative act of any person in carrying out the voluntary death of another) is not currently permitted in Arizona, but remains a very controversial issue. Despite expressing strongly-held opinions on both sides of the issue, the Town Hall was unable to reach any consensus on this aspect of end-of-life decisions. However, many participants did support the view that regardless of the legality of physician assisted suicide, no physician, nurse or other health care provider should ever be involuntarily compelled to assist in ending a patient’s life.

LOOKING TO THE FUTURE

Public Policies and Legislation

The governor and legislative leaders should appoint a citizens’ blue ribbon task force to develop a state health care strategic plan. This task force would engage in a comprehensive evaluation of the current health care system and make recommendations to the governor, legislature and our congressional delegation concerning legislation and regulations to deal with the issues raised by their findings and this Town Hall’s recommendations.

The governor and legislative leaders should appoint a citizens’ blue ribbon task force to develop a state health care strategic plan.

Because there are many policy issues that recur and require continuing dialogue, Town Hall recommends support for the creation of a statewide Health Policy Institute that would gather, analyze and disseminate health care data and create a forum for discussion, consensus building and informing policymakers.

In addition to any recommendations made elsewhere in this report, Town Hall recommends that the following specific policies or changes to legislation be adopted:

- ◆ The state should provide more support and incentives for the expansion of in-home care and for family and friend caregivers, especially in rural areas. This may include zoning changes to allow construction of needed improvements, and direct financial incentives designed to make home care more affordable.
- ◆ There should be an elimination of inefficiencies in all third-party payers such as the over-burdensome administrative costs that physicians and other health care providers incur for reimbursement.
- ◆ A centralized repository should be created within the Arizona Department of Health Services or the office of the Secretary of State for the notification of the existence of or the contents of medical advance directives executed by its residents that may be accessed by all health care facilities and providers.
- ◆ The state should consider expansion of Arizona’s Long Term Care System (ALTCS) to allow the participation of non-eligible Arizonans on a fee-for-service basis by transforming ALTCS from a government program to a quasi-governmental organization with a governance structure that would allow for more local input and control over design and implementation.
- ◆ The state should prepare and adopt a strategic plan to address the state’s shortage of physicians, nurses and other health care service providers. This should include a review of all facilities and staffing levels, as well as increased funding to state universities and community colleges for training health care teachers and providers. Attention should be given to the quality of services in all facilities.
- ◆ The federal government should adopt legislation addressing the high cost of prescription drugs.

82ND TOWN HALL RECOMMENDATIONS

- ◆ The state and federal governments should reform the model of malpractice insurance and tort as a means of reducing the burden of malpractice claims.
- ◆ Whenever possible, Medicare and Medicaid regulations should be streamlined, particularly with respect to dual-eligible individuals to resolve the lack of coordination between the two and the administrative and patient care problems they create. Specifically, the AHCCCS administration should take the lead and request a waiver from the Center for Medicare and Medicaid Services (CMS) to allow the AHCCCS administration to fulfill the primary administrative role for both the Medicare and Medicaid (AHCCCS) programs for AHCCCS-enrolled members.
- ◆ Health care payers should be encouraged to provide coverage for preventive health care treatments, and financial incentives should be used to encourage healthy lifestyles.
- ◆ Arizona should integrate health care and social services in a comprehensive case management system, with standardized training and certification for case managers.
- ◆ Medical savings plans that allow individuals to save money for medical expenses on a tax-exempt or tax-deferred basis should be expanded.

Advances in Medicine and Technology

Advances in technology present enormous opportunities for improving health care for Arizona's elderly. Improvements in technology already are being utilized, and will continue to be utilized to expand and improve available health care services. Technology can reduce facility and staffing demands and speed up the turnaround time for diagnosis and treatment. Advances in technology that already are improving the health care system include telemedicine, tele-radiology, home medical monitors and internet communications. These technologies are especially beneficial for medical care in rural or isolated communities. Internet technology also should be used as a tool for educating Arizona residents all across the state about the health care alternatives that are available to them, although differences in the use of computer technology among some ethnic and cultural groups, and between urban and rural residents should be taken into account. The Human Genome Project is an example of an advance in medical technology that holds tremendous promise for improving medical care in the future by allowing physicians to target and address hereditary medical problems at an extremely early stage. To fully benefit from these new technologies it is essential to restructure the current fragmented system.

Despite these benefits, changes in medical technology do, at least in the short term, cost more. These costs typically decline somewhat over time as the technology becomes more standardized. To keep costs down, medical service providers should do what they can to ensure that their existing technology is being utilized in the most efficient way possible. New developments in medical technology will raise the public's expectations and also will raise ethical, moral and distributive justice issues. These ethical and moral issues should be fully explored prior to, or contemporaneously with, the advent of these new technologies. For example, advances in genomics may allow the identification of a person's genetic predisposition to a serious disease, and that information may be misused for "genetic profiling." There also are questions about whether state and private insurance programs should cover the cost of the newest medical technology for patients who could not otherwise afford it. Despite these drawbacks, technology will continue to provide benefits for Arizona's health care system and should be pursued. With these technological advancements, we must educate the public about their effect on our health care.

New developments in medical technology will raise the public's expectations and also will raise ethical, moral and distributive justice issues.

Promoting Education, Dialogue and Community Change

Changing Arizona's health care system to adequately promote healthy aging and later life decision making will require education and increased dialogue within and between the health care community and the public. Individuals and families must be educated about the variety of health care options available to them, such as hospice, home care

82ND TOWN HALL RECOMMENDATIONS

and palliative care and also about the importance of adopting life strategies that will promote wellness and healthy aging in their later years. This education effort also should explain the health care problems and issues that Arizona currently is facing and will need to deal with in the near future. Any education and dialogue should be promoted in an age appropriate, culturally sensitive and linguistically appropriate manner.

The state should adopt a coordinated approach to education and dialogue that is designed to begin at an early age and continue throughout an individual's life. This should be pursued in a variety of ways though a number of different public and private channels, beginning with a coordinated effort by government agencies at all levels. Educational institutions, particularly those training health care service providers, should make changes to their curriculums to specifically address these issues. Public schools can address these issues as well, and should restore their requirements for physical education and health classes. Faith-based and community organizations also will play an important part, as will businesses that can distribute information to their employees. Area agencies on aging can provide a useful focal point for information exchange and dialogue. The Arizona Medical Association and other professional organizations also may help increase awareness and education among the medical community. We also should use education to discourage ageism, recognize and prevent elder abuse and promote respect for our elder population. Essential information about healthy aging and later life decisions should be distributed through public channels of information, including the media, the internet and public libraries. Public education about the benefits of hospice should be expanded and physicians should be urged to offer hospice referral as early as clinically appropriate.

In conjunction with this program of public education and dialogue, Arizona should take a lead in promoting itself as a state made up of elder-friendly communities. This is primarily a local issue, and economic development and planning groups should recognize and address elder-specific issues, and actively seek input from the elder population. Communities also need to acknowledge the benefits that can be provided by these more experienced members of society. Communities should address these issues in a range of areas, such as infrastructure, community life and recreational activities.

Arizona should take a lead in promoting itself as a state made up of elder-friendly communities.

Elder-friendly infrastructure changes could include installing adequate sidewalks, street lighting and parks, as well as affordable and appropriate housing, including housing that is handicapped-accessible. Affordable and convenient transportation for the elderly is also important.

It is equally important to foster a sense of community that affirmatively includes the elder population, and that promotes an active lifestyle for all its residents. Intergenerational community centers can promote beneficial interaction between younger and older citizens and provide volunteer opportunities for residents of all ages to share their skills and experience. Local school districts also might support a mentoring program with elder volunteers. In short, we should seek to promote community interdependence, not isolation.

Recreational and life-long learning opportunities also are an important aspect of elder-friendly communities. The goal must be to keep elders active and involved and to provide them with opportunities for continued intellectual and social development and growth, which may include continued involvement in the work force for those so inclined. Arizona's elder population can and should be a great resource for strengthening their communities. We should acknowledge and promote this resource by developing communities in which the elder population will be welcome and valued participants.

* * *