

ARIZONA
HEALTH
FUTURES

APRIL 2011

AFTER THE DUST SETTLES



Part I: Arizona's Emerging Healthcare Landscape

*Our Most
Vulnerable
Citizens*



After the Dust Settles: An Overview

Arizona's recent budget crises have been some of the most severe in the country, and the worst is yet to come. Arizona's general fund budget (the source for most state spending) has already been reduced by more than 20 percent, from \$10.6 billion in FY2008 to \$8.5 billion in FY2011. Cuts to health and human services have been especially profound.

The state's general fund troubles are far from over. Until now, federal economic stimulus dollars have prevented more dramatic cuts, but that support will end as of September 2011. For FY2012, the budget shortfall was \$1.8.¹ At the time this report went to print, additional significant healthcare cuts were being proposed.

The cuts that have occurred to date are beginning to take their toll on people – especially our state's most vulnerable children and adults, such as people with behavioral health conditions and children with special health needs. Oftentimes, these people depend on publicly administered care. In part, this is because health coverage for people with chronic health conditions is often inaccessible or inadequate, and healthcare costs associated with their care are often out of the range of affordability for even middle-income families. It is also because people with complex conditions require coordinated systems of care – systems that the state has historically played an active role in creating.

Budget cuts – especially when they are deep and enduring – can undermine the sustainability of systems of care, affecting not only those who rely on these publicly administered systems, but also a far wider swath of Arizonans. For example, a provider of specialty services for children requires a certain minimum number of clients to remain economically viable and retain their skills. If the state no longer funds services, the provider may need to close or leave the state to continue

in their specialty. A hospital that no longer receives public funding can quickly go out of business, affecting even those who do not rely on public support. A rural Arizona nurse receiving partial public support may lose her job, causing an entire community to lose access to health care.

Budget cuts can also have ripple effects. When a person needing health care experiences cuts in public services, they may delay or forgo care, sometimes leading to additional public costs in the long run, when care is received in an emergency room, a jail, a hospital, a state mental institution or a school. Other times, state budget cuts are accompanied by a loss in federal matching dollars, essentially magnifying the impact of cuts exponentially.

In many instances, the budget cuts that have occurred seem to contradict the values and priorities of Arizonans. Nonetheless, additional cuts seem inevitable – at least in the short run. Raising additional revenue appears to be “off the table” for policy makers (even if there are indications that it may reflect citizens' values). Economic recovery is projected to be very slow. Even if an increase in revenue were enacted to temporarily sustain basic services, Arizona would not see a return to past funding levels any time soon.

Budget cuts – especially when they are deep and enduring – can undermine the sustainability of systems of care...



The Road Ahead

Looking ahead, it is likely that state funding for health and human services will be more limited than it has been in the past, requiring new ways of thinking about systems and care delivery. While some of the budget cuts (both those that have occurred and those being proposed) will likely harm some Arizonans and negatively affect some healthcare providers, change also brings new opportunities to rethink existing systems and shift away from “business as usual.”

As policy makers and advocates consider future budget cuts and how systems might be restored as the economy recovers, it is important to understand the impact of cuts that have occurred to date. We can glean lessons from what has already occurred and identify trends that portend where our healthcare system is moving and how the landscape has changed.

It is also useful to envision the type of healthcare system that is ultimately needed and desired if we are going to make our healthcare system better moving forward. A renewed system should complement or build upon changes already occurring in health care, including those spurred by healthcare reform’s efforts to control costs and improve quality. A revised healthcare system should also address past shortcomings. As one government official interviewed for this series stated, programs currently being reduced are not without their flaws. Indeed, many aspects of our healthcare system have been criticized for decades. For example, people with physical and mental disabilities have long criticized the complexity of the current systems and the lack of service integration. Moving forward, we have an opportunity to rebuild systems that are better than before, ones that better reflect the values and needs of the people they were meant to serve.

As systems are reshaped, it is also useful to build on the current strengths of our healthcare delivery system. There are many aspects of that system that are recognized nationally for their ability to meet the needs of the people they serve and to operate cost-effectively. For example, Arizona has long been a leader in the delivery of community-based, long-term care services. Gleaning lessons from that system is useful when considering the type of system changes that are needed moving forward.

“The systems being decimated are not without their flaws.”

state administrator

“In the middle of difficulty lies opportunity.”

– Albert Einstein



First in a Series

This is the first of three reports that examine the state budgetary and program cuts that have occurred to date and their consequences for the people who no longer receive care and the systems that served them. It considers opportunities to alter systems of care in the future to better address the needs and values of those served.

In the reports, we describe how current systems operate, how budget cuts have affected the people they serve and the healthcare system on which we all rely. We discuss the system that is ultimately desired, considering what we know about optimal healthcare delivery systems and the values that Arizonans hold. Finally, we also consider how we can build upon the strengths in our state's healthcare system and address long-standing weaknesses.

The reports view the impact of budget cuts and the possibilities for systems change through a trio of perspectives. They are as follows:

- **PART I: OUR MOST VULNERABLE CITIZENS** – In this first report, presented here, we describe the systems that serve people with mental health illnesses and substance abuse disorders, developmental disabilities or other special healthcare needs, and long-term care needs, as well as children born prematurely. We summarize budget cuts that have occurred in recent years and consider the impact of cuts. Finally, we describe the type of healthcare delivery system people with special health needs desire and require and opportunities for building improved systems moving forward.
- **PART II: PREVENTION AND PUBLIC HEALTH** – The second report will examine changes in funding for public health and prevention programs, the shifting roles of the Arizona Department of Health Services and county health departments, the efficacy of our public health system and opportunities to strengthen it moving forward.
- **PART III: THE SAFETY NET** – The final report will examine the impact of actual and proposed changes in funding for health coverage (e.g. AHCCCS and KidsCare) and primary care services (e.g. primary care funding, funding for community health centers and public health nursing). The impact on access to care for the privately insured, the uninsured, and the publicly insured also will be explored. Such analyses will consider the effect of funding cuts on the overall strength of the safety net.

There are a few special notes before we begin. Describing systems of care is immensely challenging. Systems of care are often characterized by their complexity. They include a multitude of organizations, funding streams and laws. In this and subsequent reports, we sometimes limit the breadth of our review for the sake of clarity and simplicity. For example, this report does not consider the role that the Department of Education plays in delivering services to children with special health needs.

Language is also a challenge when describing people with special health needs. Throughout this report, we refer to people with physical and mental disabilities as Arizona's most vulnerable citizens. This language is used to suggest that there may be a moral obligation to care for people with extraordinary health needs. However, as we have written in previous reports, people with physical and mental disabilities can be as resilient and capable as any of us. None of us, in the end, should be defined by our limitations.



Arizona's Most Vulnerable

As human beings, we are all vulnerable to becoming impaired – medically, mentally or socially. All of us – at one point or another – will experience “a decrement in health and thereby experience some degree of disability.”² Vulnerability is therefore a universal human experience.

Ethicists, philosophers and religious leaders have long argued that a just and moral society bears some responsibility for the care of society's most vulnerable members. In *Protecting the Vulnerable*, author and political philosopher Robert Goodin states that the “vulnerability of other human beings is the source of our responsibility to them. Vulnerability can come as a natural and inevitable part of life.... We acknowledge special responsibility for the vulnerability of families and friends but we must also acknowledge our much broader moral responsibility to protect the vulnerable of society at large.”³

Recent budget cuts have had an impact on our state's social compact to care for our state's most vulnerable citizens. To understand the impact, it is important to first understand the history and structure of the systems and services that serve vulnerable adults and children. Such an understanding of the current system and its history is also important for identifying ways in which systems might be rebuilt or strengthened in the future.

*As you did it to
one of the least of
these my brothers,
you did it to me.*

Matthew 25:40

A History of Care

Care for our state's most vulnerable citizens has a long history. In Arizona's early years, health care was very much a private experience. In the nineteenth century and for more than a century to come, most Arizonans gave birth, endured illness and died at home. They belonged to a largely frontier society. Few ever had occasion to visit a hospital. But even in those early years, there was an acknowledgement that special arrangements had to be made to care for some of society's most vulnerable members. Indeed, some of Arizona's earliest health institutions were those that cared for the chronically ill and the “mentally insane.”⁴

Beginning in the 1950s and continuing in waves over the next three decades, a movement began to transition people with mental illnesses or other long-term health needs out of institutions and into the community. At first, the focus was simply on removing people from these institutions. Gradually, the focus shifted to improving and expanding the number of community supports available for people with disabilities. Increasingly, emphasis was placed on the rights of individuals and rights that secured full community integration – such as access to housing and jobs.⁵ Over time, recognition grew of the cost-effectiveness of serving people in the community rather than in institutions, further reinforcing the need for community-based care and supports.⁶

The growth of systems of care was also influenced by health improvement and innovation. As medical knowledge and technology expanded, more and more people lived with conditions that once killed them. Increasingly, care for people with compromised physical or mental conditions required a wider scope of complex and varied services than was once expected. In tandem, Medicaid – a major payer of services – covered a wider array of services.

Today, care for the medically or mentally vulnerable is typically characterized by an array of coordinated care and services provided by a mix of healthcare and other professionals who assist individuals in managing daily life. The goal is to do more than just help people survive. Care is generally provided to help people recover or realize their full potential so they might lead rich and fulfilling lives and successfully contribute to society.

Complex, Interconnected Systems

Today, complex and interconnected systems exist to care for our state's most vulnerable citizens. These systems – formal and informal – include state agencies, doctors, hospitals, schools, faith-based organizations, social service providers, non-profits, peer supporters and families. Some of the services are paid for with public dollars – most notably Medicaid. Some are paid for with other federal monies that our state receives. Still other services are paid for by insurance, the individual, his or her family or charitable donations.

In this report, we focus on several interconnected systems that serve Arizona's most vulnerable citizens. These include the following:

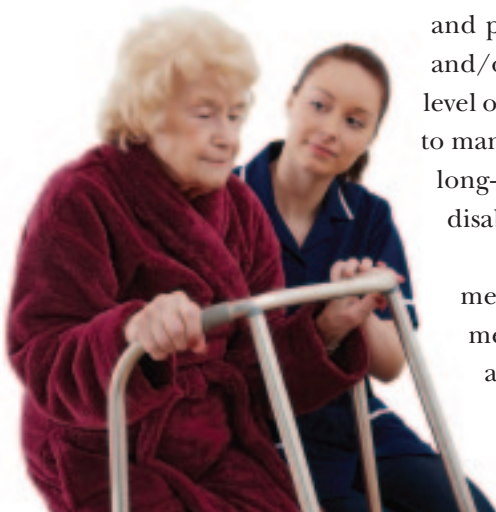
The Arizona Long Term Care System

The Arizona Long Term Care System (ALTCS) is part of our state's Medicaid agency, AHCCCS. ALTCS provides long-term care services to persons meeting federally prescribed income and resource standards who are at risk of being institutionalized. Many ALTCS members receive home- and community-based services in assisted living facilities or their own homes, allowing them to avoid more costly institutional care.

ALTCS services are available in Arizona to those with incomes of up to 300 percent of the Federal Benefit Rate.⁷ Eligibility is determined through an assessment that looks at medical condition as well as level of functioning.

ALTCS oversees service delivery to two distinct groups. The first is the elderly and physically disabled population, representing those who are age 65 or older and/or blind or disabled (at any age) and need ongoing services at an institutional level of care (such as a nursing home). ALTCS contracts with "program contractors" to manage and deliver all of their health needs – acute care, behavioral health and long-term care services. As of November 2010, over 27,000 elderly or physically disabled people were served by ALTCS.

The second group includes people with a developmental disability, such as mental retardation or cerebral palsy. ALTCS contracts with the Arizona Department of Economic Security's Division of Developmental Disabilities to provide acute care and long-term health services (more about DDD on page 8). As of November 2010, over 22,000 individuals with developmental disabilities were included in the ALTCS system.



Arizona History: The Pritzlaff Commission

When Arizona began its Medicaid program in 1982, it covered acute care services only. In 1984, a seven-member commission chaired by former Arizona State Senator John C. Pritzlaff produced a report identifying the need for a "system" of care that met the needs of the elderly and those with mental and physical impairments.

The envisioned system was to serve both people with low incomes and the middle class, recognizing that families with moderate income may also face challenges obtaining coordinated, integrated care due to geography, insurance limitations, the high cost of ongoing care, and the limited number of specialized providers. The report also recognized that "failure to provide needed options aimed at promoting individual independence will result in a high public cost as more dollars are funneled into institutional care."

In 1988, the Arizona Long Term Care System (ALTCS) was created.

Pritzlaff, John C. Jr., et al. "Long-term care in Arizona: The Pritzlaff Commission on long-term care, July 1984."

ALTCS services are paid for by the federal Medicaid program, requiring a state match of one dollar for every two federal dollars spent. ALTCS members are required to contribute toward the cost of their care based on their income and type of placement. Program contractors in the ALTCS system (including DDD) are paid monthly capitation rates for each person served. Because they receive one payment for all of their clients' needs, they are incentivized to manage and integrate care delivery. All ALTCS clients receive care coordination.

Behavioral Health Services

The Arizona Department of Health Services (through its Division of Behavioral Health Services) conducts day-to-day oversight of a system of care that serves adults and children with serious mental health and substance abuse treatment needs, including (but not limited to) adults with serious mental illnesses such as schizophrenia and bi-polar disorder, children with serious emotional disturbances, and children and adults needing substance abuse treatment. It is responsible for administering most publicly funded behavioral health services, with the exception of those services provided to non-DDD ALTCS members (see DDD and ALTCS sections for more information on behavioral healthcare delivery for those enrolled in ALTCS). In 2009, the Division of Behavioral Health Services served over 200,000 children and adults.

The Arizona Department of Health Services (ADHS) contracts with private regional administrative contractors called regional behavioral health authorities (RBHAs) that subcontract with private and non-profit health and social service providers for service delivery. These providers deliver highly specialized, individualized services, including individual or group therapy and counseling, hospitalization, family support training, medication, respite, therapeutic day programs, peer support and supported employment services. Clients receive services after completing an intake/assessment process. Case management is provided based on a client assessment.

The RBHAs are responsible for delivering needed behavioral health services to anyone enrolled in an AHCCCS acute care health plan.⁸ They receive a monthly capitated payment for each AHCCCS member living in their region. They are also charged with serving others (including the seriously mentally ill who do not qualify for Medicaid) using state-only and federal substance abuse grant monies, although care delivery for those receiving state-only assistance has always been limited due to funding. The RBHAs are also responsible for establishing a crisis system in each geographic region they serve, which is made available to anyone who needs services. People who receive behavioral health services through a RBHA-contracted provider generally obtain their other healthcare services through a separate health plan and an array of contracted health providers directly overseen by AHCCCS.

Over the years, the behavioral health service delivery system has been greatly influenced by two lawsuits against the state, namely *Arnold v. Sarn* (1981) and *JK v. Griffith* (1991). The former lawsuit – a class action suit filed alleging that the state did not adequately fund a comprehensive mental health system – sought to enforce the community mental health system required by statute (A.R.S. §§ 36-550 through 36-550.08) on behalf of persons with serious mental illness in Maricopa County. The latter class action lawsuit was filed on behalf of Medicaid-eligible children who did not receive necessary mental health services. In the latter case, AHCCCS and ADHS were the defendants.

In 2001, the department entered into a settlement agreement in the *JK v. Griffith* suit, expanding the number of covered services and specialty providers available to children in the behavioral health system and committing to deliver care according to a core set of

Arizona's innovative Medicaid long-term care service delivery system (ALTCS) has been a national leader in supporting members in the community and encouraging home- and community-based services rather than costly nursing home or other institutionalized care.

CRS provides family-centered surgical, medical, dental, genetic, and rehabilitative treatment for children under age 21 with specific qualifying chronic and disabling conditions.

“principles.”⁹ In March 2010, a court-ordered stay was issued due to state budget issues, putting on “hold” all current court orders in the Arnold v. Sarn case until June 30, 2012.¹⁰

Children’s Rehabilitation Services

The Department of Health Services’ Children’s Rehabilitative Services (CRS) (like its predecessor, Crippled Children’s Services) was created in 1929 to provide health care to children with complex healthcare needs requiring an integrated approach that coordinates care delivered by a variety of care professionals. The program provides family-centered surgical, medical, dental, genetic, and rehabilitative treatment for children under age 21 with specific qualifying chronic and disabling conditions defined in state statute, including scoliosis, cerebral palsy, spina bifida, cystic fibrosis, sickle cell anemia, metabolic and endocrine disorders, heart defects, neurosensory disorders affecting vision and hearing, cleft lip/cleft palate and other cranial-facial disorders, and many other congenital anomalies and conditions.

In 2009, over 21,000 children and young adults received health care and related support services from the CRS program. CRS members receive care for their eligible conditions through regionally based, multi-specialty interdisciplinary clinics. Arizona Physicians Independent Practice Association (APIPA) contracts with each of the clinics on a fee-for-service basis. CRS members are also enrolled in AHCCCS, wherein each member has a primary care physician who manages their care and a health plan that pays for care not related to their CRS-eligible condition.

Medicaid and CHIP (called KidsCare in Arizona) pay for most of the services provided through this system (using federal dollars, which require a state match), although other public and private dollars (including private health insurance and payments by families) are leveraged. In the past, approximately 4,000 children received services from state-only funding, but such funding was eliminated in 2010.

Effective January 1, 2011, AHCCCS took over administrative oversight of CRS. APIPA, the acute care provider for many children served by CRS, continues to work with the four regionally based specialty clinics now serving children and families eligible for CRS services as an AHCCCS contractor – at least for the short term. It is currently unclear what service delivery for these children will look like once the current APIPA contract expires in 2011.

The Division of Developmental Disabilities

The Arizona Department of Economic Security’s Division of Developmental Disabilities (DDD) provides services to individuals with specified diagnostic conditions, namely cognitive disabilities, cerebral palsy, autism or epilepsy. As of June 30, 2009, the Division of Developmental Disabilities served over 30,000 adults and children.

The division acts like a fully capitated health plan, contracting with individual providers (including health plans, acute care providers, rehabilitation providers, and long-term care providers) for the delivery of a wide array of services such as home health nurse or aide services, attendant care, respite, transportation, habilitation services, durable medical equipment, day treatment and training programs. DDD accesses behavioral health services through the RBHA system for the delivery of needed behavioral health services for its members. Support coordinators who work for DDD are responsible for coordinating care delivery.

People who qualify for both DDD and Medicaid have their services paid for through the Arizona Long Term Care System (ALTCS) or the AHCCCS acute care system. The Division of Developmental Disabilities also provides 100 percent state-funded services for 7,893 (FY 2011 YTD) children and adults ineligible for Medicaid. The scope of available services for this group is the same as for the ALTCS-eligible group; however, there are sometimes waiting lists for state-only funded services.

The Arizona Early Intervention Program

The Arizona Early Intervention Program (AzEIP) is designed to provide early intervention services for children from birth to age three who have disabilities or developmental delays. The program is part of a continuum of intervention resources for children who need specialized services in order to be successful in school.

AzEIP is based on a federal grant program (IDEA) aimed at enhancing the development of infants and toddlers with disabilities to

- reduce educational costs by minimizing the need for special education through early intervention and
- minimize the likelihood of institutionalization, maximize independent living, and enhance the capacity of families to meet their child's needs.

Families seeking AzEIP services must complete an assessment to determine if they qualify for services. There are no income-eligibility restrictions for enrollment in the program. Services provided through this early intervention program include assistive technology, health services, nursing services, occupational therapy, speech-language pathology, vision services, service coordination, physical therapy, family training and home visits and social work services. A service coordinator coordinates service delivery. Federal law requires AzEIP services to be delivered in a child's "natural environment" (unlike Medicaid, where services are often provided in a medical setting). Federal law also requires that early intervention dollars be used after other available monies are used for services, including Medicaid and private insurance.¹¹

Children enrolled in AzEIP are transitioned to the local school agency by age 3. At that time, a child is once again assessed, and an individual plan for developmental and educational services is developed in conjunction with the schools.

AzEIP is administered as a partnership among the Department of Economic Security, Arizona State Schools for the Deaf and the Blind, the Arizona Department of Education, the Arizona Department of Health Services and AHCCCS. The agency where most services are received takes the "lead" in coordinating the care for the child. From October 1, 2009, to September 30, 2010, over 10,000 children were served.

AzEIP is a state- and federally-funded program for children, with the majority of funding from the federal AzEIP Grant (\$10 million). State funding (\$3.6 million) represents approximately 25 percent of the funding.

AzEIP is designed to provide early intervention services for children from birth to age three who have disabilities or developmental delays.



The High Risk Perinatal Care Program's combined funding streams allow for the creation of a high-quality system of care that is available to everyone who needs it.

High Risk Perinatal Care Program

Managed by the Arizona Department of Health Services, the High Risk Perinatal Care Program is a public-private partnership among ADHS, the Arizona Perinatal Trust, AHCCCS, hospitals and physicians. The program's goal is to assure that *all* pregnant women and newborns receive risk-appropriate care so that infant mortality is reduced and long-term impairment is avoided.

The system of care provided includes risk identification, medical consultation, specialized transport for high-risk pregnant women and critically ill newborns, specialized hospital and physician care and home-based follow-up. ADHS contracts with specialty transport providers, hospitals, physicians, local health departments and community-based organizations to provide services. In FY 2009, over 5,000 infants received high-risk perinatal services. Over 1,000 critically ill pregnant women and 1,000 newborns were transported to the appropriate level of care. Community health nurses, through local non-profit organizations and county health departments, made over 13,000 visits to medically fragile infants and their families after they were discharged from the hospital.

Services are funded through a combination of public and private sources: Medicaid (AHCCCS), state-only funding, the federal Maternal and Child Health Block Grant, private insurance and individual families. The combined funding streams allow for the creation of a high-quality system of care that is available to everyone who needs it. However, payment for that care varies based on Medicaid eligibility, income and insurance status.

System Characteristics, Strengths and Challenges

Two interrelated (and sometimes competing) approaches have informed and influenced the design of various programs for vulnerable populations over the years. The first is a focus on the individual and respect for his or her choices and rights. The second is a focus on the community and how vulnerable populations can best be supported by, integrated into, and helped to contribute to the community at large.¹²

Arizona's programs for serving vulnerable populations have had many successes in both areas. Some notable accomplishments addressing one or both concerns include the following:

- **LEADER IN LONG-TERM HOME-AND-COMMUNITY-BASED CARE** Arizona's innovative Medicaid long-term care service delivery system (ALTCS) has been a national leader in supporting members in the community and encouraging home- and community-based services rather than costly nursing home or other institutionalized care. Currently, over 70 percent of elderly or physically disabled members have their long-term care needs met in a non-institutional setting such as their own home, a family home or an assisted living facility.¹³

In 2010, 89 percent of people with developmental disabilities who were served by ALTCS received services in their own home or with their families – a figure that is striking when compared to the national median of 62.7 percent. The commitment to home- and family-based care honors the needs of families while simultaneously providing cost-effective care.¹⁴



- **LEADER IN COMMUNITY-BASED CARE FOR HIGH-RISK NEWBORNS** – Arizona’s High Risk Perinatal Program has resulted in a regional system of community-based, intensive services for high-risk infants and their mothers aimed at preventing mortality and the need for more expensive long-term services. This nationally acclaimed program has contributed to Arizona claiming an infant mortality rate that falls below the national average.¹⁵
- **SUCCESS INTEGRATING SERVICES TO MEET THE SELF-IDENTIFIED NEEDS OF CHILDREN AND FAMILIES** – The Division of Behavioral Health Services has developed a “systems of care” approach to planning and service delivery which engages families as well as the child welfare, developmental disability and juvenile justice systems. While families continue to receive services from independent agencies, planning and coordination are intended to ensure that each family has one integrated service plan meeting their goals.
- **CENTERS OF EXCELLENCE** – CRS has developed an integrated model of service delivery across multiple disciplines to provide the best, most effective care for children with special healthcare needs. The multi-disciplinary specialty “center of excellence” model has proven effective for families and children.¹⁶
- **CONSUMER, FAMILY AND COMMUNITY INVOLVEMENT** – Many of the systems that serve vulnerable children and adults have engaged consumers and families over the years in informing and defining system delivery. For example, the behavioral health system has defined core principles related to care for children which include family involvement. The system currently includes child-family teams in its service delivery approach. These teams provide a facilitated team-based support planning process. A team creates, implements, and monitors a custom-fit service plan driven by the needs of the youth and family. They include within the plan a mix of professional and community resources, based on the unique strengths and culture of the youth and the family.¹⁷

Over the years, ADHS has also supported the consumer’s voice and advocacy through its support of organizations such as the Arizona Behavioral Health Planning Council, MIKID, NAMI, the Family Involvement Center and Visions of Hope. Similarly, the Arizona Department of Services has engaged (and even paid) some parents in the past to inform system delivery and allow families to become better advocates on behalf of their children.¹⁸

System Criticisms

While there are many laudable aspects of the public programs serving vulnerable populations, there are also criticisms.

FRAGMENTED, REDUNDANT SERVICE DELIVERY – Numerous studies and work groups have identified Arizona’s fragmented service delivery as a barrier to vulnerable populations receiving appropriate services in recent years.¹⁹ For example, the Arizona Department of Health Services made the following conclusion in a child health needs assessment it released in 2009, after receiving input from families and providers statewide:

Concerns among providers and families alike indicated that the system of care is fragmented and is confusing to navigate, with lengthy and redundant eligibility processes and unpredictable benefits. Children are often split up among several agencies for different aspects of their care. Fragmentation also exists between primary and specialty care.²⁰

Arizona History: Need for Service Integration

The 1984 Pritzlaff Commission on Long-Term Care recommended that the legislature establish one entity responsible for “overview responsibilities for the developmentally disabled, chronically mentally ill and physically disabled.” It noted that if “this unit is not established, funding and services are likely to remain fragmented, with fewer opportunities to coordinate and consolidate common services and higher overall public expenditures.”

“If you are a behavioral health client, you will get pretty good care. If you are an AHCCCS client and you have diabetes, you will also get good treatment. But if you are a behavioral health client with diabetes, you’re...”

“...screwed.”

conversation between a system administrator and a physician, the latter completing the sentence of the first

Interviews also reaffirmed the long-standing concern about the lack of integration between acute care and behavioral health care in our state. Such concerns are bolstered by data suggesting that there needs to be greater emphasis on the physical health concerns of those who suffer from serious mental health conditions. Data submitted in 2000 by the Arizona Department of Health Services as part of a 16-state study showed that people in Arizona with serious mental illnesses are dying nearly 32 years earlier than their age-marked contemporaries.²¹

Still others expressed concern about redundancies and inefficiencies among programs. For example:

- One system observer noted that families enrolled in AzEIP who are also eligible for Medicaid receive AzEIP services that could sometimes be paid for by AHCCCS (allowing AzEIP dollars to be better leveraged). However, AHCCCS providers do not always deliver services in a child’s natural environment – making the leveraging of such dollars for early intervention services sometimes elusive.
- Several people interviewed noted that existing service provider networks can be inefficient. Different agencies at times contract for the same or similar services. In some instances, experts interviewed believed there may be too many contracted providers for care to be well integrated or for economies of scale to be realized.
- One expert interviewed noted that multiple programs include care coordination or case management, resulting in unnecessary burdens for families. Said the expert, “Sometimes families end up having to coordinate coordination of care among care coordinators.”

ARBITRARY BARRIERS TO SERVICES – In our interviews with families and individuals with disabilities, many complained about the illogical eligibility requirements driving service delivery. For most services, income eligibility limits access. However, access to care is also limited by individual program criteria based on diagnosis and/or functioning that, at times, leaves people ineligible for public services even though the needs of the child or adult are clear and unmet.

For example, in the Children’s Rehabilitation Services program, eligibility is limited by the specific diagnosis of the child. The CRS program provides multi-disciplinary specialty care for children with one or more of the 21 specific eligible diagnoses (such as spina bifida or cleft lip/palate). The list of qualifying diagnoses is based more on the unique circumstances that have affected the program’s evolution over time than on the children who might best benefit from such a coordinated system of long-term, specialized health care designed to address children with complex health conditions. As a result, many children with special healthcare needs who could benefit from CRS’s coordinated care approach do not meet the CRS program’s eligibility requirements, which limit services to those with specific conditions, including children with hemophilia, diabetes, or asthma and those requiring transplants.²² On the other hand, one expert on children with special health needs interviewed suggested that CRS’s wide set of existing eligibility criteria could be “cleaned out for efficiency.” In other words, he suggested that some diagnoses, while requiring treatment, did not necessitate enrollment in a CRS-type model.

Numerous efforts over the years have addressed concerns about integration, efficiency and access to care. These initiatives have included attempts to integrate case management, combine screening processes or integrate eligibility processes, coordinate procurement and service contracting, and integrate information systems. While there have been some enduring successes such as those described above, many other projects were short-lived or

have not been brought to scale due to the cost of integration, collaboration and coordination. Integrated purchasing efforts, for example, required extensive coordination among agencies, ultimately undermining their sustainability. Initiatives to coordinate care – even though care coordination is considered “a critical factor in a high performance health care system”²³ – sometimes require additional financial resources, which are difficult to support and maintain under current funding mechanisms.

Many of the same concerns that existed over twenty years ago about integration, redundancy, and services based on eligibility rather than need remain today. The challenge in altering or transforming the current systems of care for vulnerable children and adults is to address long-standing challenges and maintain and build upon system strengths.

“The more complicated the needs, the more the [overall] system falls apart.”

system administrator

Complex System of Care: An Example*

Jacob is a 2-1/2 year-old boy with an infectious smile. He loves Elmo, playing with toy cars and having his mom read to him. While Jacob is like other toddlers in many ways, he has also been diagnosed with cerebral palsy (CP). He has difficulty walking, swallowing, speaking and breathing. The child also has mild cognitive disability, as well as what appears to be some behavioral health issues. Jacob has also been diagnosed with asthma. His mother had to quit her job two years ago to care for him. Jacob, his mother, and his four-year-old sister are now enrolled in AHCCCS.

CRS

Jacob’s family visits a Children’s Rehabilitative Services CP clinic to see the orthopedist and neurologist, which is 90 miles from their home. He also receives occasional adjustments to his leg braces at a site near his home. X-rays needed by his doctors are typically taken at an off-site location and then sent to the clinic. The CRS care coordinator and family jointly develop a service plan, which is periodically assessed and monitored by the care coordinator.

AHCCCS

Jacob and his family visit his pediatrician (who is a contracted AHCCCS provider) at a private office to receive his well-child visits and have Jacob’s asthma treated. The primary care doctor never talks to the CRS clinic providers directly. Instead, medical summaries from both the CRS clinic and the primary care doctors are carried back and forth by the family. Sometimes, the AHCCCS health plan and the CRS administrator argue about who will pay for treatment. For example, when Jacob was hospitalized for breathing problems last January, was it due to his asthma or his CP?

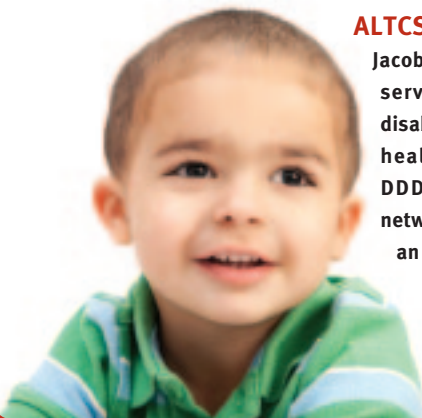
ALTCS/DDD

Jacob and his family receive services for his cognitive disability, CP and behavioral health issues through a DDD-contracted provider network. His family receives an array of services including respite, durable

medical equipment and habilitative service such as physical therapy. Services are provided at various offices. In some instances, they are provided in the home – even though the family would prefer to have all services provided in one location. The Division of Developmental Disabilities Health Care Services coordinates the acute care services for persons with developmental disabilities who are enrolled in the Arizona Long Term Care System (ALTCS). The DDD care coordinator also refers the family to a behavioral health provider (part of the RBHA provider network) for an assessment of the child’s behavioral health needs. Depending on that assessment, the child may receive services through that behavioral health provider – or be referred back to the child’s pediatrician – for treatment. The DDD support coordinator works with the family to develop and monitor a service plan and coordinate all of the child’s care, but such management is challenging given the fact that the child is involved with multiple systems.

AzEIP

Jacob receives speech therapy, family training and various nursing services through AzEIP. His AzEIP care coordinator currently works to coordinate service delivery among the various systems, developing and monitoring a service plan in conjunction with the family. She is also preparing Jacob to transition from early intervention services to special education preschool offered through their local school district as Jacob approaches the age of three. Jacob’s family will soon have to undergo a whole new range of assessments before he is able to qualify for special education preschool through the local education agency funded by the state’s education system.



* Case is fictional, but represents the complexities many children and families with complicated care requirements face.



Budget Cuts *and Their Impact*

Late 2007 marked the beginning of a vast economic downturn in the United States and Arizona. Over the next four years (FY 2008 to FY 2011), the governor called the Arizona Legislature into special session seven times to address cumulative budget shortfalls of \$12.5 billion.²⁴ Resulting budget cuts had a significant impact on our state's CHIP and Medicaid programs – health insurance programs that play a major role in providing needed services to vulnerable children and adults. In addition, state budget cuts dramatically reduced services for many children and adults who received state-only services.²⁵ Other programs serving vulnerable adults and children were also cut or eliminated entirely.

The budget cuts that have been implemented are limiting access to quality care for vulnerable adults and children, jeopardizing their health and health outcomes over the long term. The cuts have also weakened our state's system for providing health and human services for vulnerable children and adults with significant health needs – a system that serves not only those who are uninsured or who have publicly financed health coverage, but also those who have private health insurance. The resulting changes are reshaping our state's healthcare system for years to come.

Significant Cuts to Services

The three state agencies that oversee the administration of publicly funded health and human services for vulnerable children and adults have seen large reductions over the past three years:

- The Department of Economic Security saw a 25 percent reduction in the state (general fund) dollars it receives – from \$796 million in 2008 to \$594 million in 2011.²⁶
- The Arizona Department of Health Services' general fund budget for non-Medicaid services was reduced by more than 47 percent over the same time period – from \$270 million (FY 2008) to \$143 million in FY 2011.²⁷
- AHCCCS has made reductions of \$874 million from FY 2008 through FY 2011 (including Medicaid reductions to the Department of Economic Security and the Department of Health Services).²⁸

The impact on vulnerable children and adults and the programs and providers that serve them in our state has been substantial:

- Over 149,000 vulnerable adults and children have lost access to some or all services from Arizona's public healthcare system, and an additional 80,000 children are on the KidsCare waiting list.
- Virtually all state-only funded behavioral health services have been dramatically reduced or eliminated. Over 4,600 children have lost behavioral health services.²⁹ Nearly 6,300 adults lost access to substance abuse treatment services.³⁰ Almost 32,000 people who received state-funded behavioral health services saw their services reduced. This included loss of brand-name medication; inpatient, outpatient, and residential services; and housing, beginning on July 1, 2010. (Members were transitioned to other housing, including HUD housing.) Cuts affected over

*“I’m bi-polar.
It’s a really
complicated thing
to stay well.
One thing that’s
critical is routine
and structure.
But since these
budget cuts,
almost all of
that has been
taken away.”*

*behavioral health client,
Tempe*

14,000 people with serious mental illnesses, 11,700 people receiving general mental health treatment and 6,300 people receiving substance abuse services.³¹

- Over 4,000 children with disorders such as cystic fibrosis and spina bifida no longer receive therapeutic or other medical services from the Children’s Rehabilitation Services program, potentially resulting in long-term health impairment.³²
- An estimated 700 children and adults with developmental disabilities lost the home- and community-based services that allowed them to live independently or semi-independently.³³

Below, we take a closer look at the budget cuts and their related impact.

AHCCCS-Funded Services

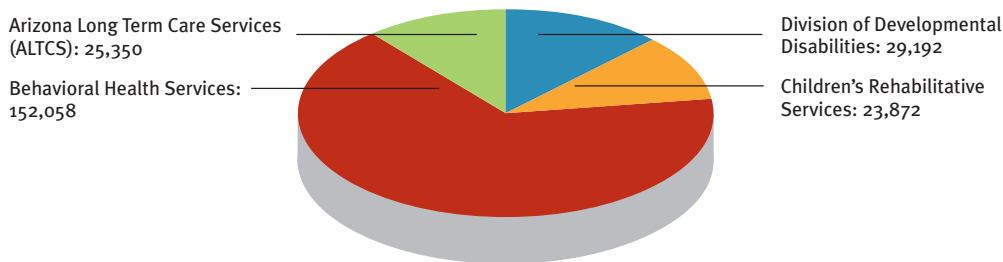
The AHCCCS and KidsCare programs – Arizona’s versions of the Medicaid and CHIP health insurance programs for low-income individuals – fund many of the health and support services provided to Arizona’s vulnerable children and adults, just as in other states. They also provide health coverage for approximately one in four Arizonans. Thus, reductions in eligibility or services related to these two health insurance programs have an impact on care for thousands of vulnerable adults and children.

Over the years, Medicaid has broadened from primarily providing medical care to the welfare population to being the main source of health insurance for millions of low-income Americans. It is the primary means of access to acute and long-term care for aged and non-aged people with disabilities.³⁴ In Arizona, significant numbers of vulnerable adults and children depend on Medicaid and CHIP to finance needed health and social support services through contracted health plans, private healthcare providers, and non-profit community-based agencies. Both Medicaid and CHIP cover a broad spectrum of services, ranging from basic medical care to behavioral health and long-term services and supports to enable individuals with disabilities to live independently.

Over 149,000 vulnerable adults and children have lost access to some or all services.

Medicaid and CHIP’s Role in Serving Vulnerable Adults and Children

Number of People Served in 2008



Source: ALTCSS-AHCCCS Population by Eligibility Category Comparison-June 2008, DDD numbers from JLBC FY2010 Baseline Report for July, 2009, Department of Health Services-Division of Behavioral Health Services: Enrollment/Penetration numbers, June 2008, and Children’s Rehabilitative Services, Monthly Enrollment Report FY2008.

In Arizona, services for vulnerable adults and children eligible for Medicaid and CHIP are provided by various state agencies through intergovernmental agreements with AHCCCS, Arizona’s designated recipient of Medicaid and CHIP dollars from the federal government. Thus, cuts to AHCCCS have ripple effects across state agencies and programs.

FY2010 Medicaid / AHCCCS Funding Flow

SELECTED MEDICAID-FUNDED PROGRAMS

FUND SOURCES

Federal Medicaid Funding
U.S. Department of Health and Human Services, Centers for Medicare and Medicaid Services
\$6,960,163,000

Match Funding
County Contributions, Tobacco Tax, Tobacco Settlement, and State General Fund
\$2,165,611,705



Acute Care Services
Basic medical care for low-income populations and emergency medical services. Basic Medicaid includes traditional Medicaid (\$2,986,252,500), Proposition 204 (\$2,376,882,700), and KidsCare (\$90,395,600).

Basic Medicaid Contracts with acute care health plans
\$5,453,530,800

Children's Rehabilitative Services
\$97,795,600**

Long-Term Care (ALTCS) for the elderly and people with physical disabilities

Program Contractors For the elderly and persons with physical disabilities
\$1,262,451,400

Long-Term Care (ALTCS) for people with developmental disabilities

Arizona Department of Economic Security (Division of Developmental Disabilities) Services for persons with developmental disabilities
\$797,120,205

Behavioral Health Services
Public behavioral health services for adults and children (mental health, substance abuse, and serious mental illness)

Arizona Department of Health Services (Division of Behavioral Health Services) Contracts with regional and tribal behavioral health authorities
\$1,255,127,200

Direct Services Claiming
Formerly Medicaid in the Public Schools

Direct Services Claiming
\$28,829,700

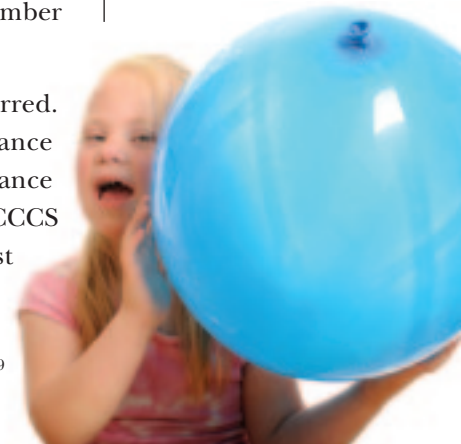
Payments to Hospitals
Includes Rural Hospital Reimbursement Program, Critical Access Hospital, and Disproportionate Share

Payments to Hospitals
\$850,000*

Source: FY 2011 JLBC Baseline Book. *This amount is a partial payment. Additional payments were made in FY2011. **The \$97 million CRS amount was removed from the ADHS total and included in the amount for basic Medicaid.

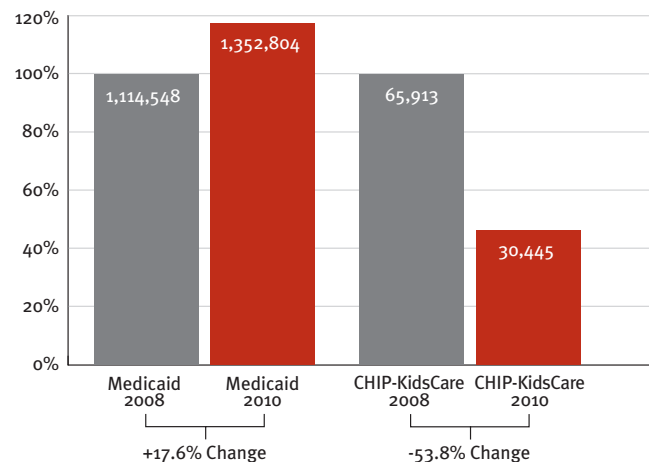
In the past several years, the overall number of people served by AHCCCS has increased in response to the economic downturn. As many Arizonans lost their jobs or their health coverage, they turned to AHCCCS for insurance. At the same time, AHCCCS received significant state budget cuts. The resulting “squeeze” caused AHCCCS to curtail health coverage for many adults and children. AHCCCS also eliminated some types of services paid for by Medicaid (coverage for many of those who receive services through AHCCCS is required by state or federal law as a condition of our participation in the federal Medicaid program, and the law also requires that many services be covered). These overall reductions in AHCCCS eligibility and services include the following:

- DRAMATIC REDUCTION IN KIDSCARE** – A policy change implemented on December 31, 2009, resulted in over 22,000 children losing KidsCare health insurance in just one year.³⁵ At that time, AHCCCS “froze” enrollment in KidsCare, allowing no additional families to enroll their children. However, that policy change also affected those already enrolled. Prior to the freeze in December 2009, children typically “churned” on and off of the program for a variety of reasons, including changes in family income (making them temporarily ineligible for coverage). As of December 17, 2010, there were 80,650 children³⁶ on the KidsCare waiting list.³⁷
- OTHER ELIGIBILITY REDUCTIONS** – Other coverage reductions have also occurred. More than 9,200 parents whose children were on KidsCare lost their insurance in late 2009. Two hundred and fifty people receiving federal disability insurance who were not yet eligible for Medicare benefits lost their temporary AHCCCS insurance coverage. Fifteen hundred low-income adults with disabilities lost general assistance support beginning in February 2009.³⁸ Ninety-three thousand people who qualified for both Medicaid and Medicare lost subsidies for prescription drugs (helping them fill what is referred to as the “donut hole”) in 2009.³⁹
- PROVIDER PAYMENT CUTS** – Healthcare providers have experienced a series of rate cuts for Medicaid-paid services recently. During FY 2009 and FY 2010, most providers (except hospitals and nursing facilities) experienced a rate cut of up to 5 percent. As of April 1, 2011, AHCCCS will be reducing provider rates for hospitals and outpatient providers, physicians, dental providers, emergency and non-emergency transportation providers, and long-term care home- and community-based providers of care for the elderly.
- ELIMINATION OF SOME SERVICES** – In response to their budget cuts, AHCCCS eliminated some types of services that clients can receive. Beginning September 30, 2009, adult denture coverage was eliminated. Effective October 1, 2010, most dental care, podiatry, insulin pumps, well exams and orthotics were no longer covered. In addition, some types of transplants were no longer covered, and limits were placed on the number of physical therapy visits allowed.



Total Number of Adults and Children Served by AHCCCS

Medicaid and CHIP, FY 2008 and FY 2010

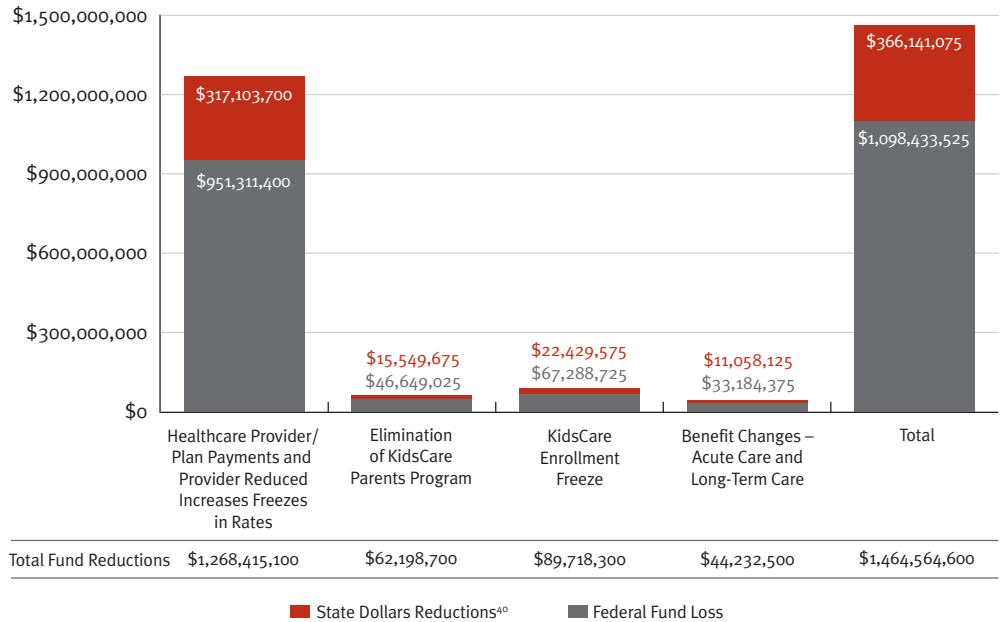


Source: Medicaid, AHCCCS Population as of July 1st, 1985-2010, KidsCare (CHIP) AHCCCS Population by Eligibility Category Comparison, July 2008.

State general fund cuts to AHCCCS also have resulted in the state losing significant federal dollars – \$1 billion – that also supported the provision of care and services for vulnerable children and adults. For every state dollar that is cut from Medicaid, our state receives at least two or three fewer dollars from the federal government.

Cumulative Federal Funds Lost as a Result of Select State Reductions to Medicaid/CHIP

FY 2008-FY 2011



Source: Arizona Health Care Cost Containment System, Cumulative Budget Reduction Savings Summary.

Other State Budget Cuts

In addition to cuts to AHCCCS and KidsCare, additional budget cuts affecting vulnerable adults and children were enacted. Such cuts included the elimination of services to over 44,000 people who received state-only funded services. These budget cuts were often more severe in terms of their impact on people served, since there are limits on the types of services that can be eliminated under Medicaid.

To understand how various budget cuts have had an impact on vulnerable adults and children and the systems that serve them, it is useful to take a closer look at specific programmatic cuts.

Impact on People and Systems

Arizona Long-Term Care Services (ALTCS)

To date, ALTCS has largely been spared significant budget cuts. ALTCS did experience decreases in state general fund appropriations from FY 2008 to FY 2010. However, total appropriations, including non-appropriated state and federal funds, continued to increase from FY 2008 to FY 2011. The FY 2011 general fund appropriation is slightly less than it was in FY 2009, but there was an almost eight percent enrollment growth during that same time period.

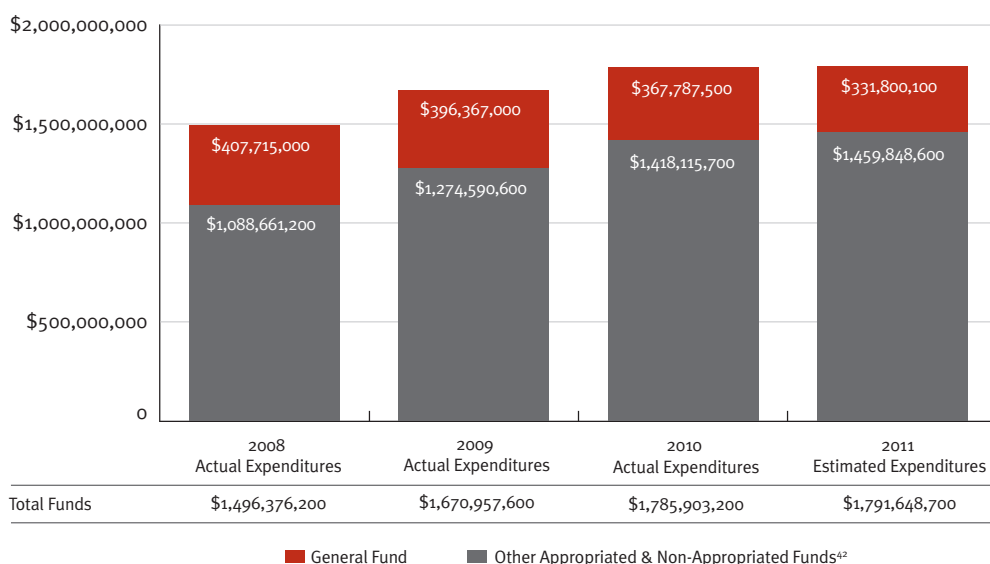
While ALTCS has been spared cuts, their members now have a more limited array of available benefits, and their members are subject to increased cost-sharing requirements. ALTCS provider rates have been reduced, and subsidies for prescription coverage for some members have been eliminated.

Behavioral Health Services

The Arizona Department of Health Services' Division of Behavioral Health Services has experienced significant funding changes over the past few years. From FY 2008 to FY 2010, the department's allocation of state dollars for behavioral health services decreased, although federal monies, including stimulus dollars and grants, helped increase overall program totals. According to ADHS, the FY 2011 budget for non-Medicaid services was \$127 million less than the budget two years earlier.⁴¹

Behavioral Health Services

Actual Expenditures for Fiscal Years 2008, 2009, and 2010 and Estimated Expenditures for 2011



Source: The Master List of State Government Programs: 2010-2013, published January 2011; Master List 2009-2011, published April 2010; Master List 2008-2010, published January 2009.

“The transition so far has been difficult but not disastrous.... But at some point, this is going to blow up on the state somehow.... Providers will survive; we will continue to deliver care... how, I am not sure.... We don’t whine about what we don’t have. We try to figure out how to make it work. We are looking at a new reality.”

*behavioral health provider,
northern Arizona*

To date, people enrolled in Medicaid or CHIP have seen few changes to their services or benefits. However, state-only clients experienced significant service reductions and, for some, loss of all services.

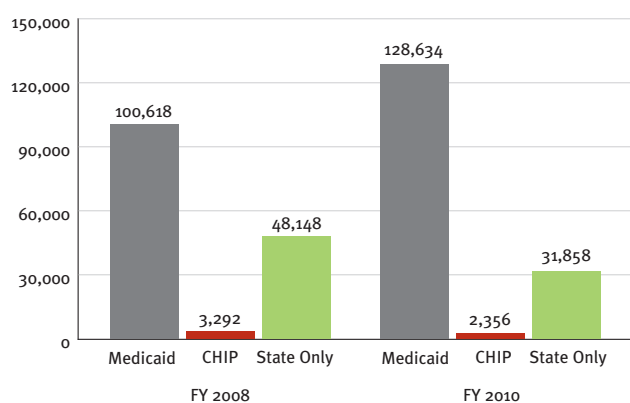
Budget reductions resulted in a decrease in the number of non-Medicaid clients served. Beginning in FY 2009, \$11 million in budget cuts led to service reductions for over 46,500 children and adults.⁴³ Approximately 30 percent (13,000) of those affected had a serious mental illness. Fifty-five hundred were children, 500 with serious emotional disturbances.

In FY 2010, budget cuts led the Arizona Department of Health Services to authorize the RBHAs to “safely transition” all state-only funded children and all non-seriously mentally ill adults to services available in the community. Over 11,700 adults and 4,600 children lost their state-only funded behavioral health treatment services.⁴⁵ Over 6,000 people lost state-funded substance abuse services.

In FY 2011, over \$30 million in additional state funding cuts resulted in significant service reductions for over 13,000 seriously mentally ill clients who do not qualify for Medicaid.⁴⁶ These clients no longer receive services such as inpatient, residential, housing, and outpatient services and brand-name medications. Over 2,600 individuals with serious mental illness also lost their housing subsidies. According to ADHS, the elimination of such services may result in an increased use of crisis services, emergency room visits, and uncompensated care at hospitals.⁴⁷ As of July 1, 2010, individuals not eligible for Medicaid receive a medication benefit

Number of People Receiving Behavioral Health Services by Funding Source⁴⁴

6.30.08 and 6.30.10



Source: DBHS Enrollment Penetration Report, June 2008, 2010, www.azdhs.gov/bhs/enroll_pen.htm.

that covers only generic medications, nursing support and lab tests.

Beyond the cuts to services for the non-Medicaid population, additional cuts have occurred impacting all members of the behavioral health system, including those who are eligible for Medicaid or CHIP. Cuts include the following:

- Residential services, inpatient services, counseling and case management services have been eliminated for all publicly funded behavioral health clients. Elimination of non-emergency transportation services for the Medicaid-eligible population was also planned but was not approved by the federal Centers for Medicare and Medicaid Services (CMS).
- Beginning in FY 2011, room and board for residential services may also be charged to Medicaid-eligible individuals.
- Like other Medicaid programs, provider rates were cut, and subsidies for prescription drug coverage were eliminated.

It is difficult to determine the full impact of these service reductions on people with behavioral health disorders. Information on what is happening to those losing services is sparse, although many of the clients and providers interviewed spoke of or predicted serious consequences:

- Several providers interviewed noted that they were fearful that nobody was tracking what was happening with those losing services, and they predicted that some would end up in emergency rooms or jails.

“Individuals will have to unravel... before beginning to receive care.”

behavioral health administrator

- One provider noted that his former clients are managing so far, although he is already beginning to lose touch with many of them.
- An advocate interviewed noted how she was concerned that some clients may decompensate and harm others or themselves. However, she was fearful of alarming the public, especially since the behavioral health community has worked for years to diminish the fear and stigma faced by those with mental illnesses.

Available data suggests that there has been an increase in demand for crisis services, although the uptick in demand is not necessarily limited to the state-only population:

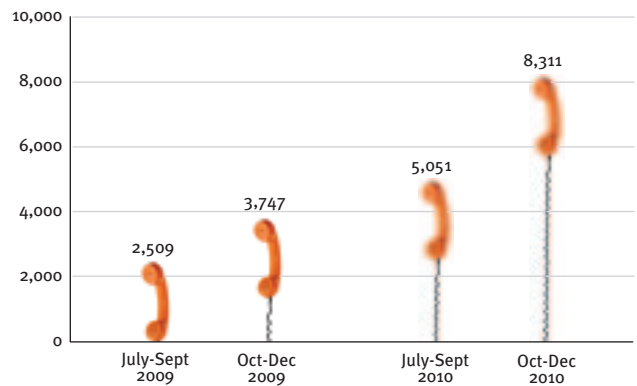
- The 24-hour behavioral health help line (warm line) operated by Visions of Hope in Maricopa County received 8,311 calls in October through December 2010, a 122 percent increase over the same period in 2009. As of January 15, 2011, 2,004 calls had been received in January. At this rate, over 12,000 calls are expected for the first quarter of 2011.
- Maricopa County’s crisis center (Urgent Psychiatric Care) has experienced a 43 percent increase in visits over the past two years. The number of visits includes all patients, regardless of payer source (AHCCCS, private insurance, or uninsured). There has been a steady increase in visits since December 2008.

National experts also have been weighing in on the potential of cuts imposing significant harm to people. In June 2010, several national organizations, including the American Psychiatric Association, wrote a letter to the governor expressing serious concerns about the discontinuation of brand-name psychotropic medications for non-Medicaid, seriously mentally ill clients. They wrote,

Mental health services research demonstrates that there is approximately a 70 percent chance of failure when an individual who is stable on one antipsychotic is forced to switch to another. With an average cost of \$1,881 for an emergency department visit in Arizona and an average psychiatric inpatient stay costing \$10,435, the price of inappropriate medication switches in non-covered care alone is too high. These costs will be shifted to Arizona hospitals and corrections facilities, tax payers, and society as a whole.

Visions of Hope Warm Line Calls

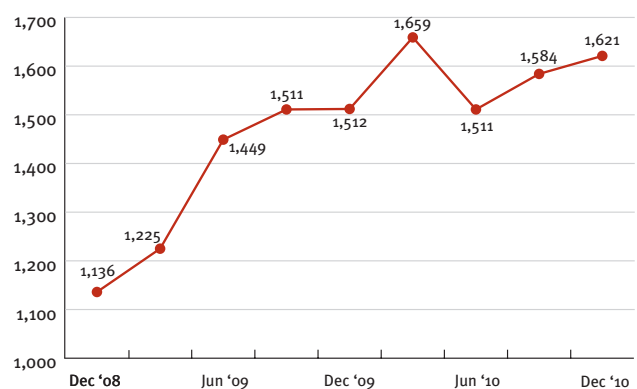
2009 through 2010



Source: Visions of Hope Executive Director, January 15, 2011.

Urgent Psychiatric Care Center Visits

Number of Visits in Selected Months, 2008-2010



Source: Kelli Williams, Connections Arizona, e-mail to L. Cannon Jan. 18, 2011.

“We end up doing a crisis plan with people but then are unable to provide them with much in terms of services. It is just weird and bizarre.”

*behavioral health provider,
northern Arizona*

“Major providers are surviving because they have other fund sources. Smaller, less diversified providers have depleted their financial resources and now will close or merge with other providers.”

provider agency administrator

They also added the following in their letter to the governor:

Arizona already leads the nation in the percentage of mentally ill individuals who are jailed or imprisoned as a result of their untreated symptoms and behavior. An increase in this kind of incarceration is a foreseeable consequence of the program changes proposed by your Administration. The financial and human costs to the State of jailing the mentally ill far exceed the cost of treating these individuals. Therefore, any argument that the program changes will save the State money is short-sighted at best.

Cuts in services and provider rate reductions are also beginning to affect health and human services providers, potentially undermining the system of care for people with behavioral health needs. For example, as of June 1, 2010, four mental health service providers in Maricopa County cut 332 positions, including 147 social workers and case managers.⁴⁸ With the combination of reduced funding for state-only populations and provider rate reductions for AHCCCS programs, providers are struggling to stay in business, seeking alternative business models such as merging with other organizations and (for some) redefining and diversifying their current business.

The provider cuts also thwart the progress and effort that has been made over the past several years to address behavioral health workforce shortages.⁴⁹ They undermine efforts needed to expand the behavioral health workforce to respond to healthcare reform. Reform’s expansion of health coverage and behavioral health benefits means that demand for behavioral health services will increase in coming years, requiring an *expanded* behavioral health workforce to address those needs.⁵⁰ One provider we talked to said, “We need a bridge between now and 2014.”

One behavioral health provider we interviewed noted that the cuts create a “huge ethical dilemma” for many providers. He noted that they are being told by state administrators that they are to transition non-Medicaid-eligible populations into community support services. However, he noted that providers often feel ethically compelled to serve people after completing an assessment. He also said that they have an obligation as licensed professionals to provide care. He noted that in some instances, providers are delivering care and paying for it out of their financial reserves.

“I am not seeing any more people [with behavioral health problems] in the [ER]. But those that I am seeing seem to have greater acuity...The frustrating thing is that there is not much that I can offer them other than a referral to the [crisis unit].”

– emergency room physician



Budget Cuts and Their Impact: One Person's Story

Jane Whitfield is 67 and lives and works in the Tucson area. She has been bi-polar since she was 25.*

I had state behavioral health services. Really good care, with a combination of generic and brand-name drugs. Before, I had been through so much – suicidal ideation, mania, delusions – and I had a very hard time caring for my child. But then I got on the right drugs, including a brand-name drug, and I lived very well on the brand-name drug. I was balanced again. Really living a very good life. Held down a job, lived well, slept well. The whole deal....

Then the budget cuts came in July, and I had to go back to a generic drug. Next thing I know, I had a terrible allergic reaction. I'm itching everywhere, inside and out. I felt like it was affecting my throat. It was making it hard for me to breathe. I got restless leg syndrome, and it was a horrible distraction. No good sleep at all. I started feeling hopeless. That's not me. I can't live like that. I didn't want to step out of the house or into my car. I started into suicidal ideation again.

I tried going to [a behavioral health crisis provider] for help, but I'm not [eligible for Medicaid], so they couldn't help me.

And I have no choice but to stay on this drug. There are only two antipsychotics on the formulary now, one of which is inappropriate and just horrible for me.

I'm the kind of person who jumps out of bed ready to live life. I got to the point of wanting instead only to stay home under the covers. My boyfriend just kept talking to me and saying, "What are we gonna do?"

We finally decided we had no choice. We decided to buy drugs outside of the US. We started about four months ago. My nurse practitioner wrote the prescription, and we sent away for it. It's not very reliable.

Right now, I'm waiting for them in the mail. The last shipment got lost.

Going outside the system isn't what we wanted to do. We tried three drug assistance programs but didn't qualify because of income.

It's been a long road back. When you have a setback, it's much harder to get back to where you were. You have sleepless nights, lost dignity, lost quality of life. Your friends and co-workers see it. People work for a long time to get the right drugs and combination of drugs. It's taken me a long time to find the right drugs just to sleep at night and think clearly and focus during the day. These are newer drugs that work. Now, why would they give us a formulary with drugs from, what, 40 years ago? The community around you wants to see balanced lives, not lives that are unbalanced.

I no longer have a case manager – someone who knows my name, knows me, and advocates for me in the system. That's an important link to my having been so well. And I got great care from [their former behavioral health care provider]. I was able to talk and work with my great nurse practitioner. Now I have a medical assistant but no case manager. The case manager is really key, because you don't get lengthy time to talk with the doctor.

If something really serious happened – severe depression, more suicidal ideation – there's nowhere to go to get help. It's really worrisome. The cost of hospitalization is so scary. Even at \$200 co-pay, that'll break me financially.

When suicidal ideation comes, you can't just pull yourself up. You're not thinking logically. It was voices telling me that I needed to end this. Not me. I took so many pills, I was in a coma for a week, and they didn't think I was going to make it.

I don't know what the solution is for this mess. I know many social programs need help and got cut. But I also know this: A heart patient gets medication because without it he'll die. People need to understand that the medication we get is just as vital.

* Name has been changed.

“The apathy that I hear in meetings where people are discussing cuts is amazing. It does not seem like anybody is off limits from not being valued.”

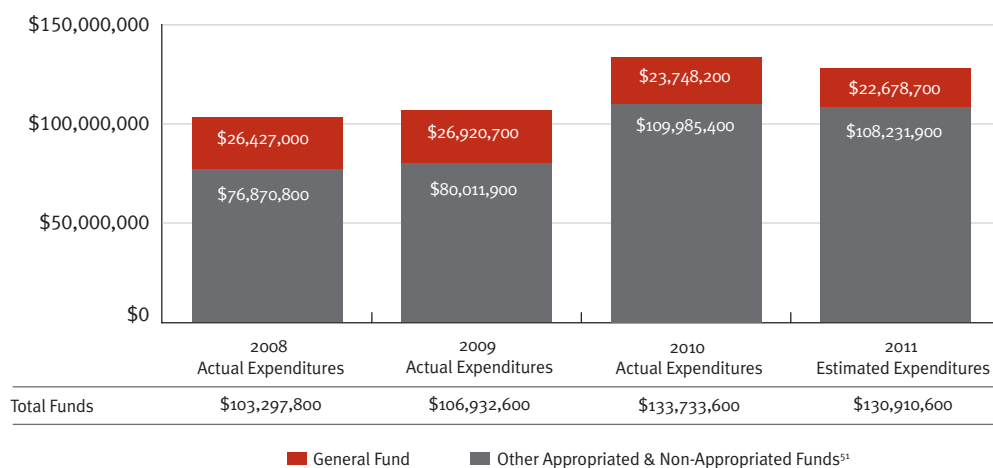
state administrator

Children With Special Health Care Needs

In 2009, Children’s Rehabilitative Services served more than 21,000 children, including 4,000 children who did not qualify for Medicaid or CHIP. Responding to an approximately \$3 million general fund reduction, CRS began making slow but sweeping changes in the services for state-only eligible children. Prior to March 2009, CRS covered the cost of medical services for families that did not qualify for Medicaid but fell below certain income limits. The service reductions for children in need of specialty health care have been implemented through a series of budget cuts and policy changes over the past two years.

Children’s Rehabilitation Services/ Children With Special Health Care Needs

Actual Expenditures for Fiscal Years 2008, 2009, and 2010 and Estimated Expenditures for 2011



Source: Master List of State Government Programs, <http://www.ospb.state.az.us/documents/2010/Master-List2010-2013>, published January 2011; Master List 2008-2010, published January 22, 2009.

Beginning in March 2009, CRS required state-only families to assume 100 percent of payment responsibility but allowed families access to the network of specialty providers and capped the amount billed to them for AHCCCS provider rates. Later that year on December 1, 2009, the CRS program discontinued services for all state-only funded children and disenrolled approximately 4,000 children between January and March of 2010.

The impact of these budget cuts is again difficult to gauge, but it is possible that the impact may be most significant over the long term. Administrators and advocates interviewed noted that if a child with a congenital newborn screening disorder does not receive treatment and therapy, they might experience chronic illness, irreversible developmental delay, or death. For those who survive, the potential impact on well-being and ability to work will cost the state a great deal more money for health care in the long run.

Many of those interviewed expressed concern and frustration about the inability to serve those in need. For example, one administrator we talked to questioned how the state could ethically continue to screen for metabolic disorders through its newborn screening program yet leave families whose children have disorders with no options for treatment or therapy.

Beginning January 1, 2011, AHCCCS took over the administrative oversight and the statutory responsibilities of the CRS program. This change may have significant consequences for many children with special health care needs. First, many of the people we talked to suggested that the move may mean services for non-Medicaid clients will not return, especially if the CRS services are eventually integrated into the Medicaid-funded, health plan-administered system of care. Also, many questioned how well the system of care developed for children with special needs will be maintained, since that system of care has blended services such as family support (paid for with Title V federal grant monies) with medical care (paid for with Medicaid and, formerly, state general fund dollars).

Other concerns were also expressed about this administrative change during our interviews. Some questioned whether families of children with special needs would be able to access the same expertise and quality of care that currently exists for their children in the future. They questioned the ability of an acute care system with multiple acute care health plans and providers to maintain or build the same level of expertise and specialty services that CRS has built over the years through its centers of excellence.

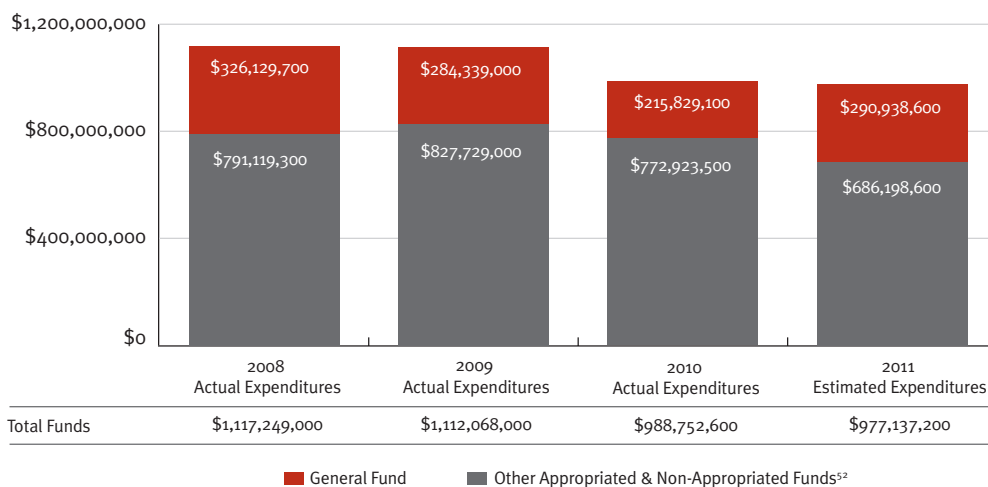
Adults and Children With Developmental Disabilities

The Arizona Department of Economic Security’s Division of Developmental Disabilities (DDD) incurred significant budget reductions from FY 2008 to FY 2011, including a \$42 million general fund decrease in FY 2009 and a \$68 million general fund decrease in FY 2010. Federal stimulus dollars helped backfill some of the general fund decreases; however, the cuts were still dramatic and resulted in lower total fund expenditures.



Division of Developmental Disabilities, Arizona Department of Economic Security

Actual Expenditures for Fiscal Years 2008, 2009, and 2010 and Estimated Expenditures for 2011



Source: Master List of State Government Programs, <http://www.azospb.gov/masterlists.asp>. Master List 2010-2013, published January 2010; Master List 2009-2011, published April 2010; Master List 2008-2010, published January 2009.

“I don’t trust AHCCCS to deliver care from a family-centered perspective.”

advocate for children with special needs

Cost sharing is only beginning to be implemented, but the impact may be significant.

Recent budget cuts of \$1.9 million in FY 2010 and \$3.7 million in FY 2011 included reductions in provider rates and services for adults and children with developmental disabilities receiving state-only funded services:

- Service provider rates were reduced 10 percent across the board, and enhanced rates for some contracts were eliminated effective March 1, 2009.⁵³
- The number of group homes was reduced to consolidate services to save \$1 million. Some state-only funded home- and community-based services (such as day programs and attendant care) were suspended on March 13, 2009, and later eliminated on May 31, 2010, affecting 400 adults and 300 children under three years of age receiving early intervention services.⁵⁴
- The Department of Economic Security increased the amount billed to a person's Supplemental Security Income for people receiving state-only services to reimburse the state for provided services effective July 1, 2010.⁵⁵

During FY 2009 and FY 2010, federal stimulus money provided \$15 million that essentially backfilled DDD state-only service cuts.

In addition to the cuts affecting state-only funded services, developmentally disabled adults and children covered by Medicaid also faced changes to their benefits that were also experienced by other groups receiving Medicaid-covered services, including increased cost-sharing, the elimination of prescription drug subsidies, and the elimination of some services such as bone-anchored hearing aids, cochlear implants and outpatient physical therapy.

Early Intervention

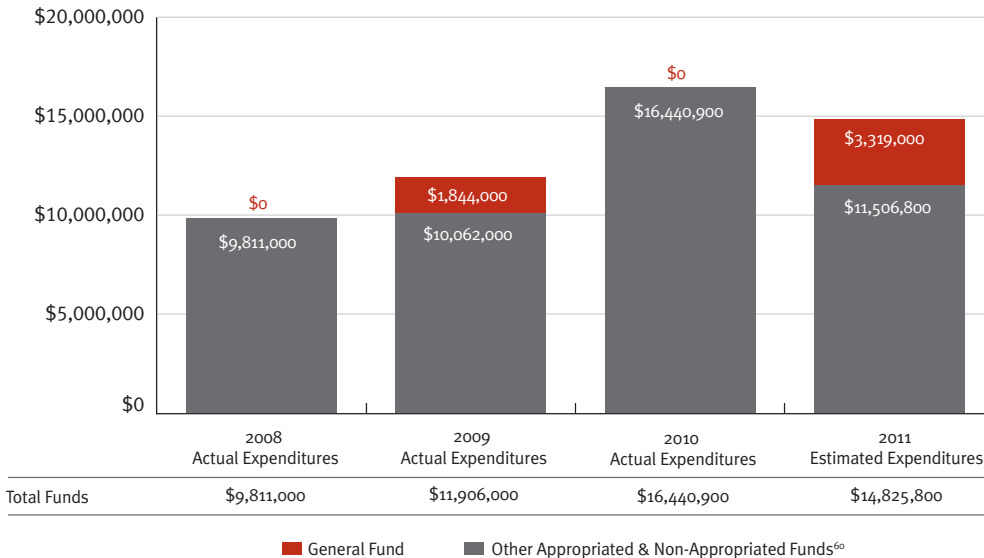
The Arizona Early Intervention Program (AzEIP) offers early intervention for children from birth to age 3 who have disabilities or are at risk for developmental delays. Services are provided through a community-based service delivery system. Over 10,000 children were served in 2010.⁵⁶

The AzEIP program receives most of its funding from federal sources. General fund appropriations to this program have varied from zero to \$1.8 million over the years. During FY 2010, state funding for early intervention services was eliminated effective November 1, 2010. Federal stimulus monies were essentially used to "backfill" state funding cuts in 2010. By 2011, the legislature restored the general fund appropriation. As one advocate pointed out, the lack of general fund appropriation in 2010 and the use of ARRA funding to backfill may have been violations of federal restrictions on how such monies could be used.⁵⁷

As a response to budget cuts, the Department of Economic Security is now implementing a family cost participation program for early intervention services (children who are ALTCS-eligible are excluded from cost participation).⁵⁸ Fees apply to services such as physical therapy, nursing services, speech-language pathology, family training and counseling, and assistive technology devices. Cost sharing is only beginning to be implemented, but the impact may be significant. Lacking information on families' incomes, AzEIP sent letters to families requesting that they return information on family income so that AzEIP could determine how much to charge families for services. According to one knowledgeable expert interviewed, approximately 30-40 percent of families failed to return the income information. As a result, these families will be required to pay the entire cost of services moving forward. These costs will hit families in rural areas especially hard, since provider rates in these areas are higher than in urban areas.

Arizona Early Intervention Services⁵⁹

Actual Expenditures for Fiscal Years 2008 and 2009, Agency Estimates for 2010 and 2011, and the 2011 JLBC Approved Appropriation



Source: Master List of State Government Programs, <http://www.ospb.state.az.us/documents/2010/MasterList2010-2013>, published January 2011; Master List 2008-2010, published January 22, 2009.

While AzEIP has been spared from cuts in the past because most of its funding comes from the federal government, it may not be as lucky moving ahead. This program has been considered for elimination previously.⁶¹ The loss of early intervention services could increase long-term costs, as children may need more costly intervention later in life.⁶² Under federal law, states cannot implement service restrictions or reductions without losing all federal support. Until recently, ARRA funds were used to support the growth of the program, insulating it from the impact of general fund reductions.

“As a parent, you pay for services for your child as a taxpayer, as someone who purchases health insurance, and as someone who has to pay a fee through AzEIP. Why are parents bearing the brunt of these budget-cutting measures?”

– early intervention advocate

High Risk Perinatal Services

Over four decades, the Arizona Department of Health Services built a nationally renowned program designed to meet the needs of high-risk pregnant women with limited access to health care and critically ill newborns at risk of developmental delays. By meeting the needs of pregnant women and at-risk infants, the program (along with medical technology) resulted in infant mortality rates that are lower than the national average.⁶³

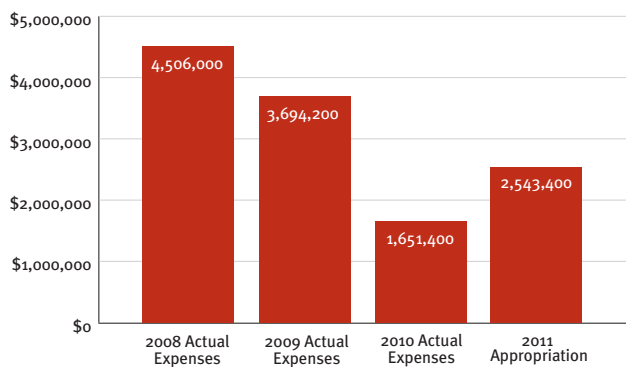
From FY 2008 to FY 2011, the High Risk Perinatal Program saw almost \$3 million in total general fund reductions. Responding to over \$800,000 in general fund cuts in FY 2009

alone, the High Risk Perinatal Program changed eligibility requirements to serve only the most ill infants, restricted transportation services for families living over 50 miles from the hospital, and eliminated services aimed at addressing the developmental needs of babies and young children.⁶⁴ To reduce the impact of recent budget cuts, the program secured \$500,000 in block grant monies for FY 2010 and FY 2011.

In FY 2009, the program served 5,358 critically ill newborns and their families in Arizona. Budget cuts have already changed the perinatal system. Fewer at-risk infants are receiving follow up, resulting in more infants likely having undetected developmental delays. Previously, infants could be enrolled if they had spent three days in a neonatal intensive care unit (NICU), but infants now have to spend at least five days in a NICU to qualify for services. In addition, the reduction in the number of community health nurses resulted in 8,800 fewer follow-up visits.

High Risk Perinatal Expenditures and Appropriations

General Funds, 2008-2011



Source: FY2010 JLBC Baseline Book, January 2009; FY2011 Baseline Book, January 2010; FY2012 Baseline Book, January 2011; and FY 2011 JLBC Appropriations Report, May 2010.

The Cliff Ahead

While significant state cuts to agencies and programs serving vulnerable adults and children have already occurred, the impact of many of those cuts to date has been minimized due to temporary increases in federal funding.

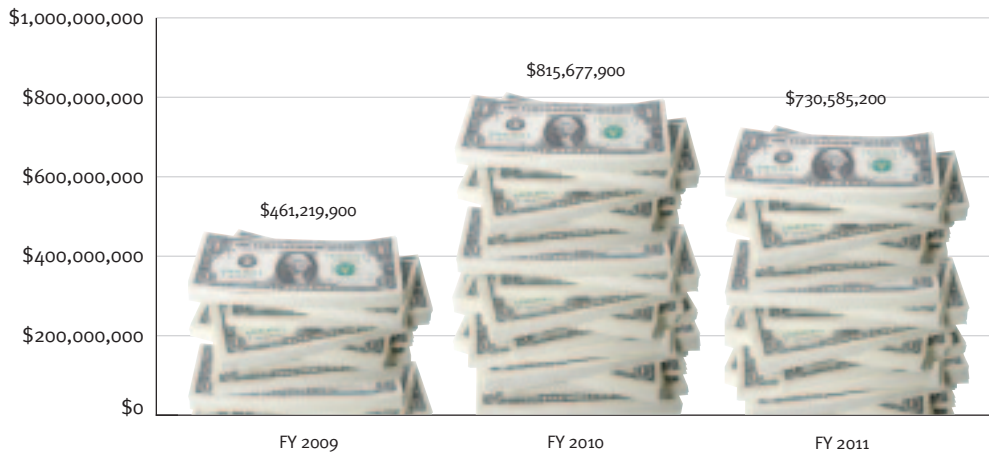
In February 2009, the president and Congress responded to the economic downturn by assisting states with federal stimulus dollars through the American Recovery and Reinvestment Act of 2009 (ARRA). Significant federal assistance was provided in the form of enhanced federal Medicaid matching rates.⁶⁵ Arizona received over \$2 billion in such healthcare assistance, with most of it flowing through AHCCCS. Federal assistance provided economic relief to Arizona by reducing the need for general fund dollars.

While ARRA funding curtailed the need for more dramatic budget reductions for a couple of years, federal economic stimulus funding will soon be ending (enhanced Medicaid funding will end in June 2011 and other ARRA funding must be expended by September 2011).

Our state is facing the difficult task of determining how it can provide health care and other services to its most vulnerable citizens while coping with diminished state revenue and an enduring gap between revenue and expenses. Economic recovery does not appear to be imminent. Indeed, economists project that Arizona's economic recovery will be slow and lag the nation's recovery, due in part to state and local budget challenges.⁶⁶

State Savings Attributed to Temporary Increase in Federal Financial Support for Medicaid

Expected General Fund Savings Associated with the Enhanced Federal Funding for Medicaid



Source: JLBC Overview of the American Recovery and Reinvestment Act for 2009 & 2010, from the FY 2011 Appropriations Report, May 2010. FY2011 represents the approximate amount that was received in August 2010.

Our state faces the difficult task of determining how it can provide health care and other services to its most vulnerable citizens while coping with diminished state revenue and an enduring gap between revenue and expenses.

At the time this report was written, the FY2012 budget was headed for the governor's desk. The budget contained an additional \$ 510 million in cuts to Medicaid, and provided the governor with wide discretion on how those cuts might be implemented. The governor, in turn, recently outlined a number of planned Medicaid cuts, including cuts affecting those who received coverage under Proposition 204, the voter-approved initiative that expanded Medicaid coverage to 100 percent of the federal poverty level in 2000. The governor's plan includes implementing an eligibility freeze for 220,000 childless adults and 60,000 parents earning between 75-100 percent of the federal poverty level. She has also proposed eliminating Medicaid coverage for the thousands of higher income individuals who face catastrophic health issues driving them into poverty. Some of the governor's proposed policy changes will require federal approval. Others will not.

The governor's plans to reduce Proposition 204 coverage will, however, almost certainly result in a lawsuit, since the legislature cannot roll back Proposition 204 without voter approval.

If Proposition 204 coverage is reduced, it will affect the vulnerable adults and children described in this report. For example, up to 73,000 people with a behavioral health condition may be affected under the governor's current proposal. Over 55,000 people with a nervous system disorder such as cerebral palsy, Alzheimer's disease or eye and ear problems may be affected.⁶⁷ While some may qualify for health coverage under other eligibility categories, others may end up with minimal access to health care.



A Reflection of Our Values?

The recent and impending cuts to health and human services seem to conflict with Arizonans' values and priorities.

Overall, Arizonans support state funding for health services. For example, they have consistently shown support for health care at the ballot box. Voters passed a ballot initiative in 2000 that expanded the state's Medicaid program to provide coverage for the working poor. Then, in May 2010, nearly two-thirds of voters passed Proposition 100, increasing the sales tax to avert cuts to education, health and public safety.

Numerous polls conducted over the past several years indicate that Arizonans identify health care as one of their top priorities, following support for K-12 education.⁶⁸ A poll conducted of 400 registered, high frequency Arizona voters conducted by Dr. Bruce Merrill at ASU in March 2010 confirmed that support for publicly funded health programs and services remains high:

- Two-thirds of the voters were opposed to funding cuts for AHCCCS.
- When asked about where state funding could be cut, less than one percent volunteered that they would cut AHCCCS.
- Fifty-five percent said that state spending on programs and services should be increased or kept where it was at that time.
- Eighty-one percent of voters supported maintaining or increasing funding for behavioral health services.

In October 2010, the Pew Center on the States and the Public Policy Institute of California conducted a survey of five states (Arizona, California, Florida, Illinois, and New York) to view each state's budget problems. These were among the findings:

- Over 80 percent of respondents indicated they were either very concerned (40 percent) or somewhat concerned (43 percent) about the effects of state spending reductions on government services.
- The two budget areas that respondents stated they most want to protect from state spending cuts were K-12 public education (57 percent) and Medicaid health insurance for low-income households (23 percent).
- A majority of respondents indicated they would be willing to pay higher taxes for K-12 public education (71 percent) and for health and human services (56 percent).

The March 2010 Arizona poll also suggests that there is support for increased taxes to avert cuts to health care or other key priorities:

- Fifty-six percent said they were currently under-taxed or taxed at the right level.
- Sixty-two percent supported raising the tax on sodas by one percent per ounce to fund health care for poor people.
- Sixty-three percent of voters said they would be willing to broaden the sales tax base, as long as a tax increase excluded food and medical expenses, to protect key priorities such as AHCCCS.
- Seventy-one percent of voters support raising taxes on high-income voters by one percent to make sure that lower socio-economic adults and children will receive adequate health care.
- Sixty-five percent support raising the tax on high incomes two percent.
- Sixty-eight percent of voters supported doubling the tax on alcohol to provide a dedicated funding source for AHCCCS.

Despite this support, revenue increases received little discussion during the 2011 legislative session. In fact, many candidates who won in recent legislative elections ran on platforms of downsizing government and cutting government spending. Accordingly, most of the proposals considered to reduce the deficit involved cutting or eliminating programs that Arizonans support. It's no wonder that the 2008 Gallup poll of Arizonans conducted for the Center for the Future of Arizona found that only 10 percent of Arizonans strongly agree that their leaders represent their interests.⁶⁹

But it is also important to recognize that voters often seem unwilling or unable to grasp the tough choices that lawmakers have to make – or how difficult it is going to be to balance the budget. For example, the March 2010 poll asked voters to identify areas where they thought cuts should occur if they had to be made. Most (70 percent) did not offer any opinion. Of those with opinions, ideas offered would not make many meaningful dents in state spending.

Our state appears to be headed towards unprecedented cuts to vital programs and services – including programs that serve our most vulnerable children and adults. Nobody we talked to wanted to predict where it all might end, but everyone agreed that we are in for quite a squall.

In the end, policy makers will have to solve the ongoing imbalance between revenues and expenditures. They also will need to ensure that budget decisions are in line with voters' values and that penny-wise budget cuts do not result in pound-foolish consequences.

Budgets, after all, are reflections of our values. Budgets represent choices made by policy makers on how to best manage the community's present and future resources. Ultimately, these budget choices have profound consequences for us all. They affect whether businesses come to our state or add jobs. They impact whether we receive federal dollars or attract private investment. They determine whether healthcare providers are able to stay in business. Finally, they determine whether Arizona's most vulnerable children and adults get needed services – or not.

“[T]he state has relied on short-term financial tools, long-term debt and overly optimistic revenue forecasts that mask the state’s ongoing financial condition in the short run.... It’s critical to the future of every family and business in Arizona that our structural deficit is eliminated and that we align our ongoing spending and ongoing revenue over the long term to avoid continued annual budget-deficit scrambles.”

Tom Franz, Greater Phoenix Leadership

After the Dust Settles

While the immediate future appears bleak, the shifting state and national landscapes offer new opportunities to rethink how health care for vulnerable adults and children is organized, paid for, and delivered in Arizona. As systems are altered or reshaped, changes should ultimately reflect the values of the people they were designed to serve, preserve and build upon strengths in the current system, and resolve long-standing system limitations.

Rethinking and Reshaping Systems

While dramatic budget cuts and system changes pose immediate threats and challenges to people and systems, they also provide opportunities to modify how care is organized and structured.

As noted in previous sections of this report, systems of care for vulnerable children and adults in this state are changing as a result of large budget cuts. Programs such as Children’s Rehabilitative Services have been moved to AHCCCS. Services for those who do not qualify for Medicaid have been severely cut or eliminated. Families – even those who are insured and those able to pay for care themselves – may in some instances be unable to access care or receive the same quality care that they received in the past. Providers are struggling, and in some instances, consolidating or rethinking their business models.

As policy makers make and implement budget decisions and advocates respond to systems changes, both should define and articulate their visions for a healthcare system that serves vulnerable adults and children, since decisions made today ultimately affect how systems are reshaped in the long run.

To better serve consumers and reflect forces already at work, a reshaped system should

- be value-driven, focusing not only on cost containment but also quality and outcomes
- reflect the needs and values of the people it was meant to serve
- build on existing system strengths
- address long-standing system issues
- reflect Arizona’s (and the nation’s) shifting healthcare landscape.

“Significant improvement in value will require fundamental restructuring of healthcare delivery, not incremental improvements.”

Michael Porter, Institute for Strategy and Competitiveness, Harvard Business School



Value-Driven Health Care

As previously summarized, many of the state's solutions for managing its budget problems and controlling its healthcare costs have centered on limiting eligibility, reducing available services, reducing provider payments, and increasing cost sharing for covered individuals.

What is missing so far is a frank discussion of how we can provide better value in our publicly funded health care system. Little attention has been paid by policy makers to how we might produce better outcomes for people at the least possible cost.

$$\text{Value} = \text{Quality}/\text{Cost}$$

Many experts believe that improving value or quality in health care is the only way we will ever successfully control costs. Some of the central tenets of a value-based system include⁷⁰

- integrating and coordinating care delivery around medical conditions
- measuring how well value has been achieved, focusing on outcomes rather than process
 - reducing redundancies in administration and service delivery
- integrating and consolidating care across providers and regions, allowing for a sufficient client base to maximize cost effectiveness and acquired expertise
- rewarding cost containment *and* quality care for episodes of care
 - using technology to help coordinate care
- encouraging consumers to be active decision makers and participants in their own care delivery

Many of the principles or core values that experts have defined as being necessary for the planning and delivery of services for vulnerable populations mirror these same tenets. Regardless of which population is served – high-risk infants, people with disabilities or the elderly – these attributes should guide system redesign.

The overarching theme experts emphasize in creating systems of care for the vulnerable is that *care must be coordinated and connect with all aspects of the person's life*: their physical and mental health needs, the ability to function on a daily basis, their basic needs such as housing and transportation, and their connection to community and family.

According to Community Catalyst, coordinated care models that work well for consumers tend to

- place the individual and family at the center of care planning and delivery
- coordinate care across a continuum of medical and non-medical services, from primary and acute to long-term and home- or community-based care
- implement appropriate clinical and organizational supports needed to effectively coordinate care
- establish appropriate payment incentives for integrating and coordinating care and benefits from Medicare, Medicaid, and other payers
- incorporate the consumer voice in plan design and governance⁷¹

“The worst way to contain costs in health care is to worry about costs in health care. The only way to contain costs in health care is to worry about quality.”

Michael Porter, Institute for Strategy and Competitiveness, Harvard Business School

Values-Based Health Care

Any systems change should also reflect the values and needs of the vulnerable adults and families the system is meant to serve. Fortunately, consumers often define their needs and values in terms similar to those described in a value-driven healthcare system.

During a focus group that convened in August 2010, we talked to consumers and providers who work with vulnerable populations. They mentioned some of these same tenets when describing the type of healthcare system they ultimately would like to see. They described the importance of systems that are

- comprehensive, including direct medical care and other supports to help individuals reach their full potential
- consumer- and family-driven
- community-based
- integrated
- coordinated
- focused on individual needs
- accessible
- sustainable
- respectful
- efficient (eliminating unnecessary layers of administration)
- available based on need, not income, severity or diagnosis
- delivered in the least restrictive, most natural environment (if desired by the consumer)

Many of our interviews with advocates, family members, and providers serving children with special needs also echoed these same themes. For example, several people interviewed

Consumers and Values

SLHI convened a focus group comprised of people with disabilities and representatives of organizations that serve people with disabilities. They offered the following list of core values and characteristics of a system that would effectively serve people with disabilities:

- Disability is a natural part of the human experience, and people with disabilities are valued citizens in Arizona communities
- People with disabilities and their families need freedom to live in and be a part of their communities
- People with disabilities and their families need access to health care to live and be a part of communities
- A system of care needs to offer an array of services fully responsive to individual needs
- People with disabilities and their families are presumed to be capable of determining their needs and how best to meet them
- A service system needs to promote accountability to these shared values, be cost effective and ensure long-term sustainability



emphasized the need to get beyond silos that exist among various programs serving vulnerable children.

Many also reiterated how important it was for the system to be tailored to the needs of individuals and their unique conditions. For example, they noted that a diagnosis should not determine what services someone receives, emphasizing that the system should be driven based on medical and functional needs. Our interviews also revealed that both providers and consumers thought existing delivery systems were inflexible, offering more services than were necessary to some, offering unwanted services to others, and limiting services for others in need who did not meet a narrow definition for care. For example,

- One mother interviewed wondered why her child has to receive services in the home, when she would really prefer her child to be seen by a health professional in the office.
- A behavioral health provider interviewed questioned whether the community-based recovery supports offered to clients are needed for everyone. While he thought this approach was useful, he questioned whether money could be saved by tailoring such services to only those who most need it.
- Some questioned why people are required to receive service coordination or case management in the developmental disabilities or the behavioral health systems of care, even though people who are higher-functioning may not need such care.

Building on System Strengths

Many of the features of an ideal system described above exist in programs or systems currently operating in this state, as described earlier in this report. Thus, as advocates and policy makers look to reshape the healthcare delivery system for vulnerable adults and children, they should consider how current system strengths might be expanded or replicated.

The Arizona Long Term Care System (ALTCs) is a model for integrating the multiple care needs of vulnerable adults and children. It integrates care delivery by contracting with program contractors (health plans) responsible for administering and delivering all of the care that a client requires – behavioral healthcare, acute care, and home- and community-based services.

Children’s Rehabilitative Services is in many ways a model for provider integration. It has formed “centers of excellence” over the years, allowing families to address the many health care needs of their children in single locations with teams of knowledgeable experts. This center-based approach also allows for a sufficient number of clients to be served so that healthcare experts can gain and sustain their expertise in serving children with specialized needs – expertise that might otherwise dissipate if an individual healthcare provider were to treat only a few such clients each year. The integrated service delivery model was fostered through the years by a contracting approach that limited the number of providers and required those providing services to offer highly specialized, integrated care.

The Division of Developmental Disabilities currently operates a health plan that could be a model for consumer-driven health care in the future. Since 2003, it has operated a human services cooperative that contracts with the Division of Developmental Disabilities. A member-directed board of individuals with disabilities who use human services screens, selects and contracts with health and human services professionals who best fit their members’ needs. By definition, the co-ops are incorporated, owned, and directed by individuals and families who use human services to provide support that benefits the co-op’s membership.⁷²



“The approach needs to be on systems of care and more integration of mental and public health. There needs to be a more holistic approach. Systems should empower family/ consumer involvement in planning, service delivery and monitoring and should reward and support collaboration. Public education should support empowerment of vulnerable populations.”

family support agency administrator

“The greatest mistake would be to merge with acute care. For some people with minor behavioral health issues, this would be ok; however, for many, we would lose the value of this system of care. People with SMI need a stronger, more focused system on the supportive, inclusive, family-involved, community-based system of care.”

behavioral health provider

Long-Standing System Issues

As noted earlier in this report, the systems that serve vulnerable adults and children have been criticized for years for fragmented care, unnecessary service barriers, and system redundancies and inefficiencies.

While many efforts have occurred to address these issues, they have often been short-lived or limited in scope. In part, this is because reform efforts have often focused on leaving the basic structure of existing systems in place and merely adding an additional “piece” to “fix” underlying problems. For example, the lack of integration between behavioral health and acute care has been addressed with procedures requiring information sharing between systems or pilot projects that attempt to co-locate care. The overall organization of care and the financial incentives driving how care is delivered have largely gone unaltered.

For example, a behavioral health provider in one area of the state is experimenting with integrating the delivery of behavioral health care and acute care at the provider level. Although such a model of integrated care delivery is still in its infancy, early reports suggest some positive outcomes, although the full evaluation has not yet been completed. Unfortunately, this integrated care delivery experiment is currently struggling to remain viable, let alone expand. Because acute care providers are paid no more for providing care to behavioral health clients than for providing care to other clients, providers are barely staying afloat as they manage their behavioral health clientele’s significant acute care needs.

Ideas such as whether or not AHCCCS should be responsible for overseeing the behavioral health system (rather than the Arizona Department of Health Services) and whether AHCCCS’s contracted health plans or other entities (rather than RBHAs) should be responsible for administrative oversight of services have been discussed for years. Many advocates and health experts believe such change could possibly lead to improved integration between acute care and behavioral healthcare delivery. Such large-system changes, however, are very difficult to make, since people are often fearful of any large shift from the status quo. With dramatic cuts now disrupting business as usual, it may be easier for people to rethink assumptions on how care should be delivered and organized and experiment with new ideas.

Recognizing State and National Trends

State and national trends also require policy makers and advocates to rethink how care might be delivered in the future. As healthcare delivery changes, new incentives emerge, and health services funding shifts, the healthcare landscape will change. System redesign ultimately needs to reflect those changes.

- **MEDICAID’S GROWING ROLE** – One significant, long-term trend appears to be that Medicaid is taking on an increasingly prominent role in the delivery of care for vulnerable adults and children. This is occurring for three reasons. First, AHCCCS enrollment has expanded over the years, due to both the passage of a voter-approved initiative and the decline (seen both in the state as well as nationally) in employer-based coverage. Second, services funded only by the state to vulnerable children and adults are being downsized or eliminated. As a result, healthcare programs for vulnerable populations are beginning to be consolidated within the AHCCCS/Medicaid program since that is now the major source of funding currently available. For example, Children’s Rehabilitative Services has already been moved to AHCCCS. If this trend continues, additional programs operated by other agencies

such as behavioral health services (currently overseen by the Arizona Department of Health Services) and services for the developmentally disabled (currently overseen by the Arizona Department of Economic Security) may also be absorbed into AHCCCS.

Third, Medicaid will play a greater role in serving vulnerable adults and children under healthcare reform. Beginning in 2014, Medicaid eligibility will be expanded to 133 percent of the federal poverty level, resulting in many who formerly received state-only funded services receiving Medicaid-covered services. Medicaid's expansion may also mean that more people are likely to receive Medicaid-funded services for longer periods of time or even their entire lifetimes, thereby providing AHCCCS with a strong incentive to provide preventive care to achieve positive long-term health outcomes.

- **NEW OPPORTUNITIES TO COORDINATE CARE** – Healthcare reform provides new opportunities for states to implement medical home projects (called “health homes” in the legislation) centered on providing care for those with chronic illnesses (including those with chronic mental illnesses). A state can choose to modify its Medicaid state plan and receive a 90 percent match for eight quarters (two years). After that time, the state would receive its regular match rate for such services. Since this is part of Medicaid law, there is no separate appropriation or time limit on states moving forward on such an initiative. States also have the opportunity to apply for planning grants. AHCCCS recently received such a planning grant (\$500,000), which they plan to use to determine the feasibility of developing integrated health homes for persons with Serious Mental Illness.



Healthcare Reform and Its Impact

Healthcare reform, passed by Congress in March 2010, will likely have a profound effect on vulnerable adults and children. While the law remains contentious, and some aspects of the law may be repealed or go unfunded, it is likely that many major provisions will endure even if modified.

Healthcare reform will increase health insurance coverage dramatically beginning in 2014. Medicaid eligibility will expand from 100 to 133 percent of the federal poverty level. States will receive significant federal matches to pay for services delivered to their populations. In addition, insurance exchanges will be available to individuals and small groups, including some who will be subsidized to purchase private insurance.

The new law makes insurance more accessible for people with chronic conditions, who often have challenges purchasing or maintaining their private insurance. The law removes lifetime insurance limits, provides for parity between physical and mental health services, eliminates bans on coverage for people with pre-existing conditions, creates a national high-risk pool, prohibits insurers from considering health status when setting rates, and makes transparent the way insurance companies charge for coverage, making it easier for people to choose between plans.

Reform also provides opportunities for states to experiment with how care is delivered and paid for to improve quality and control costs. The law encourages creation of medical/health homes where care is delivered by a team and coordinated across settings, integration of medical and behavioral health, and outcome-based care. Recognizing that increased insurance coverage will likely lead to increased demand for services, the new law also creates new opportunities for states to expand their health care workforces and provides new monies to expand community health centers.

“These times may improve the system of care because it is about the community. Hopefully, the formal services and the community will partner more and share a common theme.”

*advocate and mother
of a child with disabilities*

- **PAYMENT REFORM** – Another significant trend likely to have an impact on systems that serve vulnerable adults and children is payment reform. Healthcare reform includes many new opportunities for providers and states to experiment with how care is paid for, so that they may incentivize quality and reduce costs. Hospitals and insurers are already beginning to explore such changes. Perhaps most importantly, AHCCCS – the state’s largest insurer, whose actions greatly influence all health care delivery in the state – has recently requested a waiver from the federal government, allowing it to experiment with alternative payment methods. Again, the focus will likely be on integrating care, incentivizing quality and controlling costs. As part of its waiver, AHCCCS hopes to create a “system whereby providers who are engaged in this effort can share in the savings of bending the cost curve.” They are interested in creating medical homes and accountable care organizations to achieve a more integrated healthcare delivery system.⁷³
- **CHANGES TO COVERED SERVICES** – Even if Arizona raises more revenue to shore up its Medicaid program in the future, it is likely that there still will be mounting national and state pressure to control Medicaid costs. Currently, the state is required to provide “mandatory” services required under federal law. In some instances, state law also mandates that some services be covered, such as chiropractic care. States have flexibility to change their own laws, as well as determine the amount, duration, and scope of the services they provide under Medicaid (though the services must be sufficient to achieve the purposes of the Medicaid program). For example, even though states must cover hospital and physician services, they can limit the number of paid hospital days or physician visits. AHCCCS has begun limiting or eliminating some optional covered services. It is also beginning to limit the scope and duration of services, announcing recently that it would limit inpatient hospital stays. In the future, rather than just limit or curtail services, they will likely tie the array of covered services and their scope and duration to outcomes. For example, services that are shown to improve cost and quality will likely remain, while other services may be eliminated.
- **CHANGING PROVIDER NETWORK** – Healthcare reform will also result in greater demand for care among vulnerable adults and children, as access to private health insurance improves. At the same time, if the trend continues, Medicaid provider rates (which have recently been cut) will likely remain stagnant. Thus, some providers we talked to said they are expanding their businesses to serve private as well as public payers. They may also merge with other providers as a result of recent budget cuts and to prepare for future growth potential.
- **CONSUMER AND COMMUNITY INVOLVEMENT** – In an odd way, recent budget cuts have provided consumers and communities with a greater voice in defining systems of care. For example, behavioral health consumers and providers have played active roles in defining how budget cuts are implemented for state-only consumers and how limited private resources might be leveraged. That’s not to say that consumer involvement is all-new. Consumers have been playing a role in defining systems of care for years. For example, CRS developed regional teams of family members over the years that helped define and advocate for systems changes. Recent budget cuts, however, have required state agencies, consumers, families and health care to work together more collaboratively and creatively than ever before. As a result, the community’s role in defining systems is unlikely to fade any time soon.

Redesigning the System

AHCCCS has recently signaled an interest in engaging consumers in changing systems of care and potentially altering how care is delivered to different groups (including those currently served through behavioral health services and children’s rehabilitative services).⁷⁴ Thus, it appears that the redesign of systems serving vulnerable adults and children may be beginning.

As AHCCCS engages consumers in potential redesign, it is bound to face resistance (as well as support) from consumers, families, providers, and policy makers at various points in the process. Change of any kind is hard. Many people also benefit in some way from the status quo, including health providers or insurers who might have to dramatically change how they do business or whose business itself may no longer be deemed “value-added.”

Nonetheless, we think that the potential for reform should be embraced. It could lead to major improvements in systems of care.

Key questions that policy makers and advocates may want to consider when reshaping a system are

- How can pay incentivize quality?
- How do we make sure people with significant health needs are not underserved?
- How do we make sure that cost-effective, quality services are delivered?
- How do we make sure that providers who care for those with greater needs are adequately compensated?
- How will oversight of the system be performed?
- How can we reduce layers of administration and promote integration efficiency?
- How can assessment and entry into the system of care be made as efficient and accessible as possible?
- How can we deliver services that many groups of vulnerable adults and children need – such as medically necessary transportation and pharmacy – most efficiently and cost-effectively?
- How do we make sure care is coordinated for those who need it?
- How do we create a system that best leverages all funding sources – Medicaid, federal grant monies, private insurance and self-pay?
- How do we ensure that everyone can access high-quality systems of care – not just those who are eligible for Medicaid?
- How do we ensure that client health information is efficiently shared among health providers?
- How do we optimize consumer and family voice and peer support in the system?
- How do we balance the need for a high-quality, cost-effective provider network with the desire of individuals to receive care in their community addressing specialized needs?
- How do we measure, monitor and reward outcomes?

“Everybody gives lip service to wanting things integrated, but everyone wants their own pot of money.”

former public administrator

A Transformed System

The recent move of Children’s Rehabilitative Services to AHCCCS portends one scenario of what a transformed system of care might look like for vulnerable adults and children in the future.

Such a system could feature AHCCCS taking a more direct role in administering systems of care for vulnerable adults and children. This could include AHCCCS more directly overseeing specialized health plans or providers of services for children and adults with developmental disabilities, children with special healthcare needs, and people with behavioral health conditions.

Currently, AHCCCS oversees the administration of acute care services (Medicaid) through privately contracted health plans for general health (AHCCCS) and long-term care (the Arizona Long-Term Care System [ALTCS]) services for the elderly and people with physical disabilities. Specialized services for people qualifying for AHCCCS or ALTCS are administered by other state agencies, namely the Department of Economic Security (providing long-term care for people with developmental disabilities) or the Department of Health Services (providing behavioral health services and – until recently – children’s rehabilitative services).

In the future, AHCCCS could conduct day-to-day oversight of all of these systems of care for vulnerable adults and children, allowing the system of care for all Medicaid-eligible clients to be directly overseen by one agency. It could build upon its ALTCS model, in which a variety of contracted health plans provide a wide array of coordinated, integrated, cost-efficient home- and community-based and institutional services.

In a transformed system, a consumer or his or her family would complete one application or assessment to apply for services, eliminating the need for the consumer to navigate multiple eligibility and assessment systems. If the individual was eligible for Medicaid or CHIP, he or she would be enrolled in an acute care health plan or a specialized health plan based on his or her needs and preferences. An enrollment broker within AHCCCS familiar with special health needs might help people navigate the selection process to best meet their needs. Specialized health plans could be designed to serve unique populations requiring a level of specialization not generally available. If people did not qualify for Medicaid, they could be referred to the health insurance exchange, where they may qualify for other coverage and subsidies.

In a transformed system, diagnosis alone would not dictate whether someone received care. For example, someone with a behavioral health disorder who was high-functioning but had chronic health needs could be served through an acute care health plan. The person’s medical home might be a primary care physician or even a specialist, but the full range of required care would be provided or coordinated from that medical home. A physically healthy adult or child with a behavioral health disorder requiring attention might designate a behavioral health provider as his or her medical home. Care coordination would be provided by the provider best suited to understand and manage an individual’s needs.

People with more chronic, long-term needs could receive care through ALTCS-like health plans, where a wider and possibly more intense array of care would be provided and integrated with home- and community-based services. These health plans could include the current ALTCS health plans or other specialty health plans designed to meet the specific, similar needs of groups of individuals (such as people with serious mental illness or developmental disabilities). Specialty plans offered might include consumer-run cooperatives, in which consumers direct and oversee the composition of the provider network.

Specialty plans could be overseen by AHCCCS/ALTCS, building off of its expertise in overseeing community-based systems of care for people with complex needs. Medicaid/AHCCCS would ensure that the number of people served through a specialty plan was large enough to minimize administrative costs, yet small enough to address specialized consumer needs, achieving both efficiency and quality. Specialty plans would not have to be limited by geography, allowing more consumers

with similar health needs to participate. The need for community-based services might be addressed through local provider contracts or telemedicine.

Provider networks might also look quite different in a transformed system. To ensure that care is well integrated and clinical expertise is fostered, ALTCS and the AHCCCS health plans could be required to ensure that some services are delivered through designated “centers of excellence,” where care is integrated and clinical expertise is fostered. This approach might make care less geographically accessible, but such limitations could be mitigated by allowing some services (such as medication monitoring) to be performed locally through other subcontractors.

Contracts for functions such as transportation might also be consolidated across various populations of vulnerable adults and children, bolstering administrative efficiencies, accessibility and the financial viability of some providers.

In a transformed system, more providers and specialty health plans could serve both publicly-funded individuals and those with private health insurance. By expanding the payer base, providers would diversify their income and become more financially viable. They would also allow people with private health coverage access to cost-effective, integrated care from centers of excellence. Opportunities would exist for higher-income individuals to access the system with some limited public support – either through some type of “buy-in” or through changes in the state’s Medicaid waiver. Other public funding such as Title V monies might also be blended into the service delivery system (through an interagency agreement), paying for services that are not covered by Medicaid or CHIP, funding functions such as care coordination, or training health plan providers on family-centered care practices.

Finally, a transformed system would change how health plans are paid. Plans would be compensated based on the diagnosis and health needs of the individual consumer. Plans would be responsible for managing all of the individual’s health needs, and plans and providers would be paid more if patient-centered outcomes were achieved. Providers serving clients with more costly healthcare needs would be paid more or have their financial risk adjusted, diminishing their incentive to care for only those with less costly needs or underserve their clients. Rigorous outcome monitoring would ensure that cost-effective outcomes were achieved.

What could a transformed system of care look like for vulnerable adults and children in the future?



Other Considerations

As system changes occur, other related issues and implications may also need to be addressed.

- **A SYSTEM BASED ON NEED** – In a transformed system, people would receive care based on their medical, functional, and self-identified needs. Programs such as Children’s Rehabilitative Services may no longer exist. If this approach is taken, Arizona law and rules creating diagnosis-specific programs and services may need to be revised, interagency agreements may need to be developed to allow transfer of funding, AHCCCS contracting may need to be revised, and Medicaid waivers may need to be sought.

In a transformed system, people would be able to access the system of care regardless of income or resources. People who did not meet income eligibility guidelines for state-funded services would be able to access the same high-quality service delivery system and pay for care themselves or through private health insurance. Opportunities may also be created for people to “buy” into Medicaid, or Medicaid might be expanded to certain populations with special needs through changes in our state’s Medicaid waiver (see Opportunity to Expand Home- and Community-Based Services, next page). The expanded client base may create better economies of scale for contracted providers, better securing their financial viability.

- **BROADER ARRAY OF FUNDING** – As we have indicated in this report, state-only funding for many services and populations appears to be disappearing. To rebuild systems of care in the future, additional state dollars may be needed to sustain systems that rely on blended funding to provide needed services, such as the High-Risk Perinatal Program. However, it is also true that it is possible to better leverage exist-

ing resources. For example, AHCCCS and AzEIP services could be better coordinated to ensure that AzEIP dollars go farther. Private insurance could also be required to cover some services (such as early intervention) that it currently does not cover to ensure that the public sector does not bear all of the costs of supporting a high-quality system of care for vulnerable children and adults, as currently occurs in 12 other states.⁷⁵ Middle-income families could be subject to reasonable cost sharing, where some (but not all) of the costs of care are borne by families.

- **BLENDING OR BRAIDING OF FUNDING** – Vulnerable adults and children sometimes require services that go beyond what Medicaid will reimburse. To ensure that vulnerable adults and children have access to a full array of needed integrated services, there may be a need for blending of funding streams in a revised system, such as blending Medicaid funding with federal Title V block grant monies or substance abuse grants currently administered by ADHS.⁷⁶ This would likely require interagency agreements and closer collaboration between AHCCCS and agencies such as ADHS.

Medicaid Buy-In Programs

Medicaid buy-in programs allow an individual or family whose adjusted gross income is up to 300 percent of the federal poverty level to pay a *premium* to access Medicaid. Normally, such a family would not be eligible because its income is too high. Through buy-in programs, they can use it as their only insurance or as a supplement to private insurance. The federal Family Opportunity Act enabled states to provide this program for children who meet SSI disability criteria. Such programs not only alleviate family financial hardship, but also provide an incentive for families to keep their private coverage, because they can still get the more comprehensive benefits of Medicaid. Texas implemented such a program for children and youth with special health needs in 2009.

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Opportunity to Expand Home- and Community-Based Services

Healthcare reform provides new opportunities for states to offer services and supports to particular groups with significant health needs statewide who earn up to 300 percent of the Federal Benefit Rate *before* they need institutional care, opening up a new avenue for states providing home- and community-based services to people with mental health and substance abuse disorders, and leverage federal funding.

Improving access to home- and community-based services, August 6, 2010 letter to state Medicaid directors from Cindy Mann, Director, Center for Medicaid, CHIP and Survey & Certification, CMS.

- **ADMINISTRATIVE CAPACITY** – If current agency responsibilities are shifted, there may be a need to supplement some of the dollars lost by agencies whose programs are moved to other agencies if they are to be able to successfully administer their remaining programs. Alternatively, they may need to further reduce their responsibilities or functions in response to their decreased administrative capacity.
- **CHANGING AGENCY ROLES** – If oversight of the behavioral health system is transferred to AHCCCS, the Arizona Department of Health Services will have an opportunity to shift its role in the areas of mental health and children with special needs, focusing more on prevention or systems development instead of oversight and direct care services. That role is part of what is expected of a responsive public health system that educates people about their health, promotes and encourages healthy behaviors, links people to needed personal health services, monitors the population's health status, mobilizes the community to respond through personal action, licenses and monitors health care facilities, and fosters the development of a competent health care workforce. The ADHS public health role could clearly be focused on population-based health initiatives affecting all Arizonans. Similarly, if DES were no longer providing services to the developmentally disabled, they could focus more on their core role of promoting the safety, well-being, and self-sufficiency of children, adults and families.

If AHCCCS takes on a greater role in overseeing the administration of services for vulnerable adults and children, it will need to become more engaged with consumers and advocates to meet the expectations of communities that are accustomed to consumer involvement. Numerous people we talked to noted that AHCCCS does not have much history of actively engaging consumers and families in designing care delivery, involving consumers in the development of treatment plans, or supporting consumer advocacy. Many also noted that such a shift would require a significant cultural change for AHCCCS, whose very name focuses more on cost containment than on care delivery, consumer engagement or quality.



- **AZEIP** – As noted in this report, Arizona’s early intervention program plays an important role in serving young children with developmental delays. As system changes occur, policy makers and advocates should consider AzEIP’s role in a transformed system. Unlike the other programs considered in this report, AzEIP is primarily funded by a federal grant, and eligibility is not affected by income. However, some of the services provided through AzEIP mirror services available in other systems, including DDD and Medicaid.⁷⁷ Thus any revised system should envision how AzEIP might “fit” and interact with the other system components. A wide array of models exists among states for operating early intervention programs, including having early intervention services as part of the state department of education.⁷⁸ In a transformed system, early intervention services would be well coordinated with the other health services young children received and redundancies would not occur. Also, the transition from early intervention services (for children under three) to other services for children with special education needs (for school-aged children) would occur seamlessly.
- **ARNOLD V. SARN** – Any changes to the service delivery system for people with serious mental illnesses will affect the state’s compliance with the requirements determined by the *Arnold v. Sarn* lawsuit. Over the years, this long-standing decision has done much to improve service delivery for adults with serious mental illnesses. However, it has also imposed system requirements and process monitoring that may conflict with some of the goals of a transformed system and the realities of a system whose funding has been cut dramatically for those who do not qualify for Medicaid. Policy makers and advocates will have to consider the role of *Arnold v. Sarn* when moving forward, as well as whether changes in state law describing the state’s service delivery obligations are needed.
- **CRISIS BEHAVIORAL HEALTH SERVICES** – In a transformed system, there will still be a need for a behavioral health crisis system that is available to everyone. However, the oversight and administration of such services might look different than it does today. Currently, crisis services are overseen and administered by RBHAs. One possibility would be for the Arizona Department of Health Services – the state’s public health leader – to take the lead in this area, contracting with area providers and forming partnerships with law enforcement and community-based organizations to develop a robust crisis services network. This network could include community-based prevention services, helping to reduce the high number of suicides and providing substance abuse prevention services. The crisis providers, in turn, could become contractors of any entity responsible for administering Medicaid-funded behavioral services, allowing crisis services to be covered for Medicaid enrollees. A new source of state funding might be needed to create a truly robust crisis system, but the infancy of such a system might begin in the midst of any restructuring of the behavioral health system.

Final Thoughts

Arizona's healthcare system is undergoing substantial changes. Funding cuts are undermining the services and systems that serve vulnerable children and adults. In the short run, further cuts seem inevitable in the absence of other solutions to balance our state's budget.

It is important, however, to recognize that short-term setbacks can become long-term gains. Arizona has the opportunity to rethink how care for vulnerable adults and children is delivered and improve systems of care in the long term. Change is already occurring. The question is whether the changes yet to occur will move us towards better quality care and more efficient and effective systems that serve vulnerable children and families.



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