



TITLE V

MATERNAL CHILD HEALTH

FIVE YEAR NEEDS ASSESSMENT

2005



TABLE OF CONTENTS

INTRODUCTION	1
NEEDS ASSESSMENT METHODOLOGY	2
Public Input	2
Data Sources	3
OVERVIEW OF THE STATE.....	9
Population Growth	9
Race/Ethnicity	9
Language Spoken.....	11
Economy	11
Homelessness	12
Education.....	13
Juvenile Delinquency	14
HEALTH CARE SYSTEMS	15
Health Insurance.....	15
Managed Care	15
Arizona Health Care Cost Containment System	16
General and Special Hospitals.....	17
Professional Health Care Providers	17
Perinatal System.....	19
Oral Health.....	20
Behavioral Health.....	21
Arizona Immunization Program.....	22
Medical Home Project.....	23
Community Health Centers.....	24
School-Based Health Centers.....	24
Other Projects to Increase Access to Care	25
Telemedicine.....	25
Cultural Competence	26
WOMEN OF CHILDBEARING YEARS.....	29
Access to Care.....	29
Mortality and Morbidity	29
Injury and Poisoning	31
Mental Health.....	33
Preventive Health Care	34
Physical Activity, Nutrition, Weight, and Risk Behaviors	36
Sexually Transmitted Disease (STD)	40
Family Planning	42
Pregnancy Rates, Fertility and Abortion.....	44
THE PERINATAL PERIOD.....	48
Births.....	48
Place of Delivery and Attendant at Birth	49
Paying for Delivery.....	49
Low Birth Weight and Preterm Deliveries	50

Multiple Births	52
C-Sections	52
Maternal Deaths.....	53
Stillbirths	53
Infant Mortality	54
Breastfeeding.....	55
Perinatal Periods of Risk.....	57
Prenatal Care.....	62
Oral Health.....	64
Maternal Weight Gain	64
Substance Use During Pregnancy	65
Post Partum Depression	66
CHILDREN AND ADOLESCENTS.....	68
General Health.....	68
Insurance	68
Primary and Preventive Care	69
Unmet Need and Barriers to Care.....	70
Obesity, Physical Activity and Nutrition	71
Chronic Conditions.....	75
Oral Health.....	77
Childcare, Home, and School Environments.....	80
Mental/Behavioral Health.....	83
Substance Abuse.....	85
Teen Sexual Behaviors and Outcomes.....	87
Teen Pregnancy.....	88
Sexually Transmitted Disease and HIV/AIDS (15-19).....	92
Mortality Rates and Major Causes of Death.....	94
Nonfatal Injury and Poisoning	98
CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS	102
C/YSHCN Methodology	102
Health Care System Capacity	106
Infrastructure System Capacity	112
Prevalence and Distribution	113
National Survey of Children with Special Health Care Needs	116
Impact of Special Needs on the Child and Family.....	117
Types of Special Health Care Needs	119
Arizona Department of Education Data.....	120
Traumatic Brain Injury.....	121
Children’s Rehabilitative Services (CRS).....	123
Assessment of the Needs	124
Identified Needs	140
Other Unmet Needs	149
TITLE V PRIORITY NEEDS.....	151
Appendix A - OCSHCN Analytic Results	156
Appendix B - OCSHCN Partnerships	164

INTRODUCTION

Title V of the Social Security Act of 1935 is a federal program that focuses on improving the health of all mothers and children. The Maternal and Child Health (MCH) Services Block Grant was created in 1981, consolidating several former categorical child health programs into a single program of formula grants to states. The block grant serves three populations: pregnant women and infants, children, and children with special health care needs. Each year, states apply for the block grant in an application that includes a plan for meeting needs identified through a statewide needs assessment, and a description of how the funds allotted to the state will be used.

Every five years, state Title V MCH agencies are required to conduct comprehensive needs assessments to identify state MCH needs and prioritize them for strategic planning. While needs assessment is always part of an ongoing planning cycle, the five-year needs assessment is an opportunity to formally examine trends and issues, review progress, and set priorities for the next five years. The statewide needs assessment identifies the need for:

- preventive and primary care services for pregnant women, mothers, and infants up to age one year;
- preventive and primary care services for children; and
- family-centered, community-based services for children with special health care needs and their families.

The five-year needs assessment may be seen as a point in an ongoing planning cycle. The cycle begins with assessing problems, needs, assets and strengths. From these, priorities are established, strategies are developed, and resources are allocated. Indicators in the form of state performance measures are developed to evaluate activities and monitor performance each year within the five-year cycle and reported in the annual block grant application.

Needs assessments are data driven, but appreciate that resource allocation depends upon policy-making and program development. Consequently, the 2005 needs assessment process went beyond quantitative analysis and involved the community of interest, or stakeholders, not only in setting priorities, but also in defining strategies. Priorities were established that the community and the MCH agency jointly identified as important and are within their capability to address. The result of this process is a plan for directing limited resources to those priorities that are seen as most important, and a plan to measure progress in addressing them.

This document presents information on issues that affect the health status of the MCH population and the state's ability to address them, and an articulation of the priority needs that were identified through the needs assessment process.

NEEDS ASSESSMENT METHODOLOGY

The needs assessment process was both qualitative and quantitative. Mortality, morbidity, and health care utilization data were analyzed, and need was indicated by any of the following:

1. A trend in Arizona that is moving in an undesirable direction,
2. Arizona compares unfavorably to the nation on a measure,
3. Disparity among subgroups of the population (e.g. racial/ethnic groups, geographic location, age group),
4. Arizona measure falling short of a defined standard or target (e.g., Healthy People 2010 goals), and
5. Partner/stakeholder input.

PUBLIC INPUT

Several avenues were pursued to seek input from stakeholders, both to help identify and understand emerging issues and to help set priorities. The home page of the Office of Women's and Children's Health website, as well as other forms of electronic communications such as emails and newsletters were used to disseminate information about the needs assessment process, issues, and findings, and to seek input. Program managers and staff who directly work with the public, contractors, and community partners, also brought the perspective of those stakeholders to the process.

Four formal public input sessions were held around the state. One session was scheduled to coincide with the Arizona chapter of the American Public Health Association meeting held in Tucson, in the southern part of the state. Another session was held in more centrally located Phoenix. A third session coincided with the Arizona Local Health Officers Association Conference, and was held in Prescott, in the northern part of the state. Finally, a session was held in Phoenix, which focused specifically on American Indians. Each of these sessions were structured to present information on health trends and issues, and to gather input on community concerns, priorities, and preferred strategies. All of the sessions were well attended.

During the public input sessions, information was presented on health issues and trends in Arizona before attendees participated in facilitated group discussion about concerns in their communities, priorities, and strategies. In identifying priorities, public-input participants were asked to consider the size and seriousness of problems, as well as the availability and effectiveness of interventions and resources to carry them out. In addition to the facilitated group discussion, comment sheets were made available for later review.

Another valuable source of public input was the Governor's Commission on the Health Status of Women and Families. Title V funds a position in the Governor's office to staff the Commission, contributing to an infrastructure for public input and planning. Key leaders in the public and private sector serve on the Commission, and their recommendations, issued in May of 2005, were considered in developing priorities.

Some issues that were discussed during public comment may not be reflected in the Title V Priorities section of this document. This should not be construed to indicate a lack of interest in the issue, nor even a lack of programmatic activity. The top priorities presented at the end of this document reflect those needs that participants believed were most important in terms of size and seriousness, and which the Title V maternal-child health program has the capacity to influence. Public input will continue, even after submission of this document, as partners participate in dialogues to refine understanding of issues and develop strategies.

DATA SOURCES

VITAL STATISTICS

Arizona Health Status and Vital Statistics is compiled every year by the Arizona Department of Health Services Bureau of Health Statistics. This document contains birth and death statistics, reported diseases, and data on birth outcomes, such as complications in labor and delivery, preterm delivery rates and low birth weight rates, as well as information on certain maternal risk factors and prenatal care. Statistics are presented by various racial and maternal risk factors and prenatal care. In addition to published data, birth and death certificates were analyzed to evaluate perinatal periods of risk.

A major strength of vital statistics data is that they are comprehensive, population-based statewide data, and there are sufficient cases to break the data down by geographic region, ethnicity, or other subcategories and retain reliability. Some weaknesses have been noted with birth data as it relates to identifying risk factors and some diagnostic information because short hospital stays make it difficult to identify conditions before mothers and their babies are discharged. Some problems may not emerge until after hospital discharge, such as certain complications or birth defects.

INPATIENT HOSPITAL DISCHARGE DATABASE AND OUTPATIENT EMERGENCY ROOM DATABASE

All acute-care hospitals in Arizona, with the exception of federal hospitals (military and Indian Health Services), are required to submit inpatient hospital discharge data to the Arizona Department of Health Services (ADHS) twice a year. For the first half of 2003, some small hospitals did not submit data;

however, the data that were submitted represented 95 percent of the expected record volume for the entire state. All of the hospitals submitted data for the second half of the year.

The hospital discharge database is a rich source of data, containing medical and financial data. However, problems with coding have led to problems with reliability of data. Auditing procedures have been implemented to improve data quality, and beginning with data from the second half of 2003, hospitals were required to correct and resubmit data that did not meet standards. At the time data were compiled for this needs assessment, the most current data available was for inpatient hospitalizations occurring in 2003. Outpatient emergency room data has also recently become available. This needs assessment includes emergency room data for the 2004 calendar year.

THE NATIONAL SURVEY OF CHILDREN'S HEALTH (NSCH)

The National Survey of Children's Health is a module of the State and Local Area Integrated Telephone Survey, conducted by the National Center for Health Statistics, Centers for Disease Control and Prevention (CDC). This survey was designed to produce national and state-specific prevalence estimates for a variety of physical, emotional, and behavioral health indicators and measures of children's experiences with the health care system, parents' health status, stress and coping behaviors, family activities, and perceptions of neighborhoods. A random-digit-dial sample of households with children less than 18 years of age was selected from each of the 50 states and the District of Columbia, and the survey was conducted during 2003. One child was randomly selected from all children in each identified household to be the subject of the survey. The respondent was the parent or guardian who knew the most about the child's health and health care. The weighted overall response rate was 55.3 percent. The strength of this data is that estimates based on the sampling weights generalize to the non-institutionalized population of children in each state and nationwide. A weakness of any telephone survey is that it is biased against children living in households with no telephone, and who are likely to be in the lowest income categories. Estimates of unmet need and barriers to care may underestimate the actual burden felt by these families. Another weakness of this data source is that there are often not enough cases to allow for subgroup comparisons and cross-tabulations.¹

THE YOUTH RISK BEHAVIOR SURVEILLANCE SYSTEM (YRBSS)

The Youth Risk Behavior Surveillance System is an epidemiologic surveillance system that was established by the CDC to monitor the prevalence of youth behaviors that most influence health. The YRBS focuses on priority health-risk

¹ Blumberg, Stephen J. et al. [Design and Operation of the National Survey of Children's Health, 2003](http://www.cdc.gov/nchs/data/slait/NSCH_Methodology_Report.pdf). Hyattsville, MD: Centers for Disease Control and Prevention, (March 1, 2005): Internet. http://www.cdc.gov/nchs/data/slait/NSCH_Methodology_Report.pdf.

behaviors established during youth that result in the most significant mortality, morbidity, disability, and social problems during both youth and adulthood. YRBS procedures were designed to protect the students' privacy by allowing for anonymous and voluntary participation. Students complete the self-administered questionnaire in their classrooms during a regular class period, and record their responses directly on a computer-scannable booklet or answer sheet. Local parental permission procedures are followed before survey administration.

The 2003 national school-based survey employed a three-stage cluster sample designed to produce a nationally representative sample of students in grades 9-12. More details on the methodology can be found on the CDC's web site.² Arizona also conducted a statewide Youth Risk Behavior Survey in 2003 allowing for Arizona-specific analysis and comparison to the rest of the nation. Unless otherwise cited, most of the YRBS results that are presented in this document come from the CDC's Morbidity and Mortality Weekly Report,³ which contains comparisons of individual states with national data. However, this publication excluded charter school students, which comprise 10 percent of the public school population in Arizona. Consequently, results may not be representative of all public high school students in Arizona.

BEHAVIOR RISK FACTOR SURVEILLANCE SYSTEM (BRFSS)

The Behavior Risk Factor Surveillance System is comprised of survey data from all 50 states and the District of Columbia. The system consists of a series of cross-sectional telephone surveys conducted by state health departments with the assistance of the CDC. BRFSS uses a multistage design based on random-digit-dialing methods to select a representative sample from each state's non-institutionalized civilian population aged 18 years and older. The BRFSS questionnaire consists primarily of questions about personal behaviors that increase risk for one or more of the ten leading causes of death in the United States. Arizona has been participating in the BRFSS since 1982 to monitor the health behaviors of its adult population. The most recent year for which BRFSS data are available on women in Arizona is 2004. For comparisons between Arizona and the nation, data is presented for the year 2003, which is the most recent year for which data are available nationally and locally.

CHILD FATALITY REVIEW

In 1994 the Arizona legislature mandated a statewide team to provide oversight of Arizona's Child Fatality Review Program, develop a data collection system,

² United States. Centers for Disease Control and Prevention. 2003 National School-Based Youth Risk Survey Public-use Data Documentation. Internet. <http://www.cdc.gov/HealthyYouth/yrbs/data/2003/yrbs2003codebook.txt> June 17, 2005.

³ United States. Centers for Disease Control and Prevention. "Youth Risk Behavior Surveillance – United States, 2003." Morbidity and Mortality Weekly Report 53.SS-2 (May 21, 2004).

and produce an annual report summarizing their findings. By statute, the state team includes representatives of the Arizona Chapter of the American Academy of Pediatrics, Indian Health Service, law enforcement, a prosecuting attorney's office, a county health department, a military advocacy program, child protective services, American Indian agencies, and a county medical examiner's office. The Child Fatality Review Program is responsible for reviewing as many of the deaths in children under the age of 18 as possible to determine whether or not the death was preventable. To accomplish this, local teams review documents related to the circumstances of each child's death and make assessments of the preventability. A child's death is classified as preventable if an individual or the community could reasonably have done something that would have changed the circumstances that led to the child's death. Standardized data sheets that include extensive information regarding the circumstances surrounding the death and the team's findings are completed and entered into the Child Fatality Review database for analysis. Eighty-nine percent of the deaths (937 of the 1,053) occurring in Arizona were reviewed for 2003.

HEALTH SYSTEMS DEVELOPMENT DATABASE

The ADHS Bureau of Health Systems Development maintains a database based on primary care areas. This database contains information on population size, geographic area, demographics, and on primary and specialty health care providers. Analysis of these data allows an evaluation of underserved areas and provides a picture of resource distribution among the population.

SAFE AND DRUG FREE SCHOOLS

In Arizona schools, violent and criminal behavior occurring on school grounds is reported to the Arizona Department of Education through the Safe and Drug Free Schools Report. Data for this report is collected through a web-based survey, and is required for all schools receiving federal funds for education. Ninety-eight percent of all public schools receiving federal funds completed a Safe and Drug Free Schools Report for the 2003 school year. A total of 77,810 incidents, ranging from bullying to use of firearms were reported to have occurred on school grounds. All incidents occurring on campus are included in the Safe and Drug Free School Reports, regardless of whether or not the incident occurred during school hours. Incidents involving students and non-students are included in the report.

NATIONAL SURVEY OF CHILDREN WITH SPECIAL HEALTH CARE NEEDS (NSCSHCN)

The National Survey of Children with Special Health Care Needs (NSCSHCN) is conducted as a module of the State and Local Area Integrated Telephone Survey (SLAITS). The NSCSHCN was designed to produce national and state-specific prevalence estimates of children/youths with special health care needs

(C/YSHCN), to describe the types of services they need and use, assess aspects of the systems of care, and provide health care coverage estimates. The NSCSHCN was conducted from October 2000 to April 2001 as part of the National Immunization Program's large-scale random digital-dial telephone survey and included a household file, a screener file, and an interview file. In Arizona, there were 8,542 children screened from 4,276 households to identify 774 C/YSHCN. For the analyses presented in this Needs Assessment, data was used from all three files. The screener file contained data on race and ethnicity; the household file included state of residence, metropolitan status, and household income relative to poverty; and the interview file contained most of our variables of interest, such as the child's age, gender, mother's education, and severity of child's health condition. The results of the analysis of the Arizona data is available on the ADHS website at www.dhs.az.gov.

ARIZONA SURVEY OF CHILDREN WITH SPECIAL HEALTH CARE NEEDS (AZSCSHCN)

To allow for a comparison of the data from the NSCSHCN with a non-random sample of Arizona families who have children with clearly defined special health care needs, Office of Children with Special Health Care Needs utilized the core questions from the National Survey of Children with Special Health Care Needs. These questionnaires were distributed in family focus groups and public input sessions, and were delivered to advocacy groups throughout the state. There were 99 completed surveys; 20 from the families in the focus groups, 10 from the public input sessions, and 67 from advocacy groups. The typical respondent was a White, non-Hispanic (76 percent) mother (79 percent) who had more than a high school education (71 percent), and who worked outside of the home (49 percent). The respondents typically had children who attended school (71 percent) and were in preschool or an elementary grade (52 percent).

ARIZONA OCSHCN PROVIDER SURVEY

To compare the perceived needs of the families of C/YSHCN with those of the provider community, OCSHCN constructed a survey for providers that mirrored the needs questions contained in the NSCSHCN. In addition, the providers were asked to rate many issues in the systems of care development for C/YSHCN, such as Medical Home, Transition Issues, etc. The providers were asked if the issue had been adequately addressed in their community, and whether the activity had been adequately implemented. They were then asked their perceptions on a series of needs within the C/YSHCN community and adequacy with which these perceived needs were met. In the final section, providers were asked to rank the importance of some basic public health education needs for C/YSHCN. While this survey was distributed to a variety of providers throughout Arizona, the data presented here utilizes only the results obtained from Child Rehabilitative Services providers.

CHILDREN'S REHABILITATIVE SERVICES, FAMILY CENTERED SURVEY, 2004.

OCSHCN surveys families enrolled in Children's Rehabilitative Services (CRS) every two years to assess their satisfaction with the services received and to measure the degree to which the families perceive the services as family-centered. In 2004, a simple random sample of 1,350 CRS members who had received at least one service in FY 2003 were selected with a confidence level of 95 percent, relative margin of error of 0.05, and a probability of outcome 0.5. Surveys were mailed to the home addresses with a reminder card and a second survey was mailed 30 days later to non-respondents. All surveys were in English and Spanish. The survey contained 21 questions that were designed to measure whether or not: 1) child received family-centered care, 2) family received effective care coordination, and 3) the child had a usual source of care. The response rate was 23 percent. Respondents were more likely to be the mother (77 percent) from the Phoenix regional clinic (61 percent). The children were fairly evenly divided among the four age groups; 30 percent were between birth and 5 years, 22 percent were between 6 and 11 years of age, 19 percent were 12 to 16 years of age and 29 percent were between 17 and 21 years of age. There were an equivalent number of male and female children (51 percent and 49 percent, respectively). Eighty-two percent of the respondents were covered by AHCCCS. The results of this survey are available on the ADHS website at www.dhs.as.gov.

SURVEY OF ARIZONA SCHOOLS REGARDING ASTHMA POLICIES AND PROGRAMS

A statewide survey was mailed to a random sample of 671 elementary schools and 452 high schools in Spring 2001 (sample selection was determined based on a 95 percent confidence level and a power of 80 percent). The response rate was very good--68 percent for the elementary schools and 56 percent for the high schools.

OFFICE OF ORAL HEALTH, SURVEY OF THE WORKFORCE, DISTRIBUTION AND COMPOSITION OF ARIZONA'S WORKFORCE AND PRACTICE PATTERNS

The ADHS Office of Oral Health conducted a statewide telephone survey of dentists licensed and practicing in Arizona during the months of July 2000 through September 2001. Telephone surveys were conducted with the 2,584 licensed dental practices throughout Arizona. The adjusted response rate was 64 percent consisting of 1,648 unique providers representing 1,317 practice sites.

BREATHING EASIER IN ARIZONA: AN ACTION PLAN FOR CHANGE. A REPORT PREPARED BY THE ARIZONA ASTHMA COALITION, FEBRUARY 2005

This report, funded by ADHS OCSHCN, provides information to the public about the prevalence of asthma in Arizona, environmental triggers, treatment barriers, and recommended solutions. The report also profiles innovative programs for the treatment of asthma. The report is available at www.azasthma.org.

OVERVIEW OF THE STATE

POPULATION GROWTH

Arizona is the second-fastest growing state in the nation, with an estimated population of 5,832,150 in 2004. The state population grew by nearly 1.9 million people in the period between 1993 and 2004, representing an increase of 48 percent. An estimated 200,000 undocumented immigrants moved to the state during the past five years, and Arizona now has the fifth-largest population of undocumented immigrants in the United States, with an estimated undocumented population of 500,000.⁴

Since the last five-year maternal child health (MCH) needs assessment in the year 2000, there has been a 14 percent increase in Arizona's population, while the population growth within the nation as a whole for the same time period was only 4.3 percent.⁵ Over the next 25 years, the U.S. Census projects that Arizona will grow by five million people, doubling by the year 2030.⁶ By 2004, the maternal-child population included 2,797,421 women of childbearing age and children under age 21.

There are 15 counties in Arizona; however, 77 percent of the state's population resides in either Maricopa or Pima Counties. Maricopa County alone added 500,000 people since 2000, more than any other county, making it the third largest county in the United States.⁷ Overall, three of every four Arizonans lives in an urban area, one in five lives in a rural area; 2 percent live in a frontier area, and 3 percent live on Indian reservations.

RACE/ETHNICITY

Twenty-one American Indian tribes reside in Arizona, each representing a sovereign nation with its own language and culture. Tribal lands span the state and even beyond state borders, with the Navajo Reservation crossing into New

⁴ Passel, Jeffrey S. Estimates of the Size and Characteristics of the Undocumented Population. (March 21, 2005): Internet. <http://pewhispanic.org/reports/report.php?ReportID=44> May 31, 2005

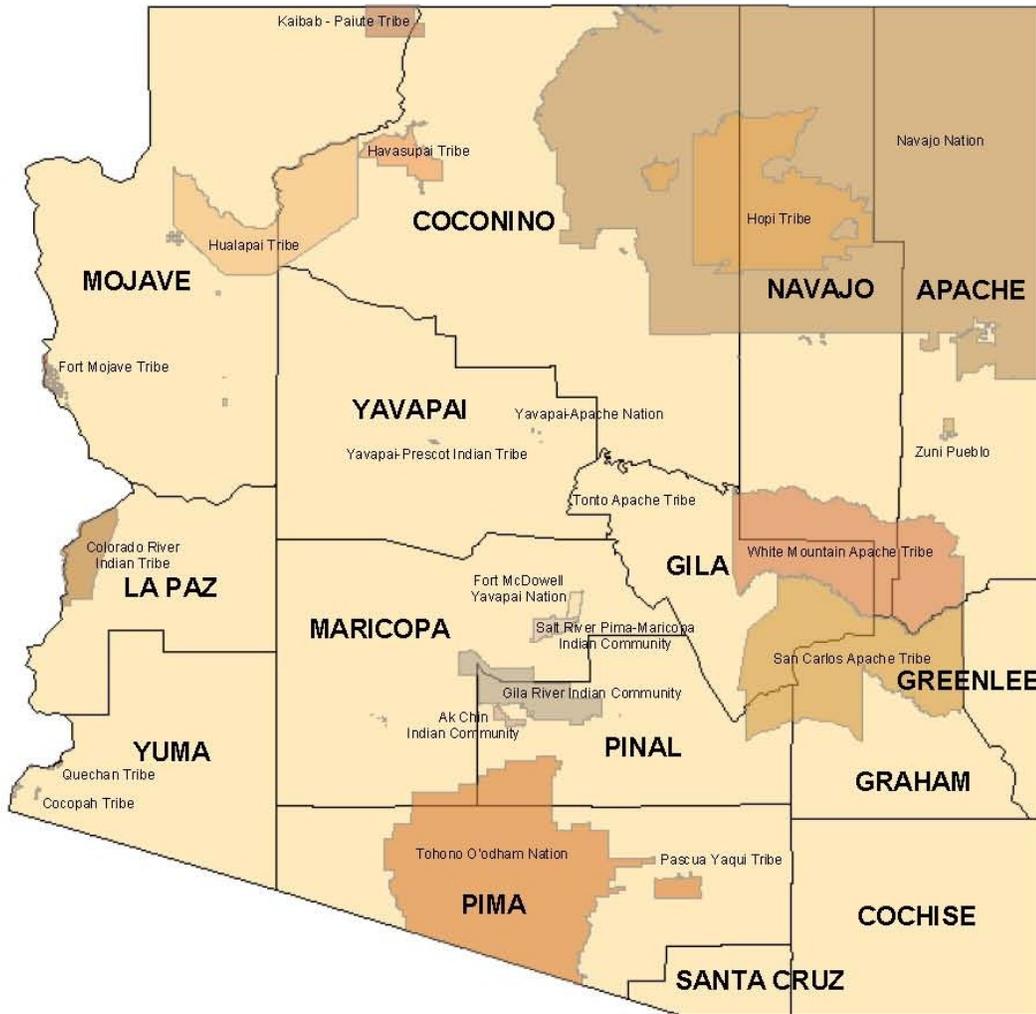
⁵ U.S. Census Bureau, Population Division, Projections Branch. Annual Estimates of the Population for the United States and States, and for Puerto Rico: April 1, 2000 to July 1, 2004. (April 21, 2005): Internet. <http://www.census.gov/popest/states/tables/NST-EST2004-01.xls> May 13, 2005.

⁶ U.S. Census Bureau, Population Division, Projections Branch. State Interim Population Projections by Age and Sex: 2004 - 2030. (April 21, 2005): Internet. <http://www.census.gov/population/www/projections/projectionsagesex.html> May 31, 2005.

⁷ U.S. Census Bureau, Population Division, Projections Branch. Population Estimates for the 100 Largest U.S. Counties Based on July 1, 2004 Population Estimates: April 14, 2000 to July 1, 2004. (April 21, 2005): Internet. <http://www.census.gov/popest/counties/CO-EST2004-08.html> May 10, 2005.

Mexico and Colorado, and the Tohono O’odham Reservation crossing international boundaries into Mexico. Figure 1 is a map showing Arizona’s counties and tribal lands.

Figure 1. Arizona’s Counties and Tribal Lands⁸



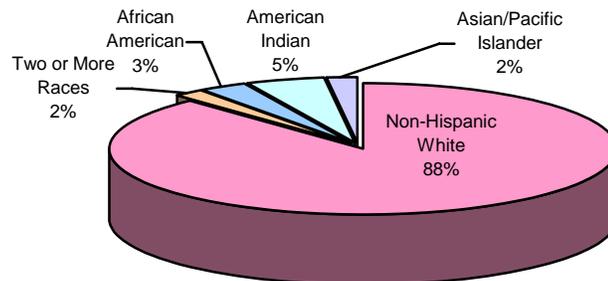
Approximately 18 percent of tribal members reside on tribal lands while 82 percent are considered urban. Some counties have high proportions of American Indians among their population. Seventy-seven percent of Apache County, 48 percent of Navajo County, and 29 percent of Coconino County residents are American Indians.

Four counties border Mexico, and Arizona has an increasing Hispanic population, with a higher proportion of Hispanics (28 percent) compared to the nation (13

⁸ Inter Tribal Council of Arizona. Map of Tribal Homelands. (2003): Internet. <http://www.itcaonline.com/map.html> June 17, 2005.

percent). An even higher percentage of children are Hispanic (39 percent in Arizona, compared to 19 percent nationally). In 2003, the number of births to Hispanic mothers surpassed Anglos for the first time. Arizona has a smaller percentage of African Americans than the nation (3 percent compared to 13 percent) and a higher proportion of Whites (88 percent compared to 81 percent nationally).⁹ Figure 2 shows Arizona's demographic composition in 2004.

Figure 2. Racial/Ethnic Distribution, Arizona 2004



LANGUAGE SPOKEN

Arizona residents are more likely to speak a language other than English at home (26 percent in Arizona compared to 18 percent nationally), and more likely to report speaking English “less than very well” (11 percent in Arizona compared to 8 percent nationally). Among Arizona residents who spoke English “less than very well,” 85 percent spoke Spanish, while the other 15 percent spoke one of many other languages.¹⁰

ECONOMY

Arizona is second in the nation in generating jobs; however, wages and personal income lag behind the rest of the nation. Arizona's main economic sectors include services, trade and manufacturing, and most of the fastest growing jobs in Arizona are jobs with relatively low wages and few benefits (such as health insurance). The average per capita personal income in Arizona ranked 38th among the 50 states, at \$27,232 in 2003.¹¹ Although the cost of living in Arizona mirrors national averages, the per-employee compensation tends to be lower.

⁹ US Census Bureau, Population Division. Table 4: Annual Estimates of the Population by Race Alone and Hispanic or Latino Origin for the United States and States: July 1, 2003 (SC-EST2003-04) (September 30,2004): Internet. <http://www.census.gov/popest/states/asrh/tables/SC-EST2003-04.xls> . March 21,2005.

¹⁰ U.S. Census Bureau, 2003 American Community Survey. (2003): Internet. http://factfinder.census.gov/servlet/ADPTable?_bm=y&-geo_id=04000US04&-qr_name=ACS_2003_EST_G00_DP2&-ds_name=ACS_2003_EST_G00_&-_lang=en&-_sse=on. May 2 2005.

¹¹ United States. Department of Commerce, Bureau of Economic Analysis. State per Capita Personal Income. (March 28,2005): Internet. <http://www.bea.gov/bea/newsrel/SQPINewsRelease.htm> May 13, 2005.

The average Arizona compensation was \$42,100 in Arizona, which was 8 percent lower than the national average.¹²

Based on the 2003 U.S. Census three-year average estimate of 2001-2003, 13.9 percent of Arizona's population earned incomes below the federal poverty line, while the national rate was 12.1 percent. In Arizona, 21 percent of children under the age of 18 years lived in poverty in 2003, relative to 17 percent children in the nation as a whole. Children continue to constitute a large proportion of the poor population (45 percent) while representing only 30 percent of the total population. In 2001, 26 percent of Arizona children lived in families in which no parent had full-time, year round employment, and 29 percent lived in families headed by a single parent.¹³ These families bear an increased risk for living in poverty.

Hispanic and American Indian children were more likely to live in poverty than other racial and ethnic groups. A study recently released by the Harvard Project on American Indian Economic Development determined that American Indians, who are among the poorest minorities in the United States, made gains during the 1990s in income, educational attainment, housing, poverty and unemployment, and Arizona tribes shared in those gains. The report cautioned that substantial gaps remain between American Indians and the rest of the United States.¹⁴

HOMELESSNESS

In Arizona, "homeless" means the individual has no permanent place of residence where a lease or mortgage agreement exists. Determining the number of homeless individuals is a significant challenge because they are difficult to locate and/or identify. The best approximation is from an Urban Institute study, which states that about 3.5 million people nationwide, 1.35 million of them children, are likely to experience homelessness in a given year.¹⁵ Based on actual shelter and street accounts in 2004, approximately 22,000 people are homeless on any given day in Arizona.¹⁶

¹² Rex, Tom R. Job Quality in Arizona. Arizona State University, W.P. Carey School of Business. March 2005.

¹³ United States. Census Bureau. United States and States-R11. Percent of Related Children Under 18 Years Below Poverty Level. (2003): Internet. http://factfinder.census.gov/servlet/GRTTable?_bm=y&-geo_id=D&-box_head_nbr=R11&-ds_name=ACS_2003_EST_G00_&-lang=en&-redoLog=false&-format=US-30&-mt_name=ACS_2002_EST_G00_R11_US30 June 14, 2005.

¹⁴ Taylor, Jonathan B and Kalt, Joseph P. American Indians on Reservations: A Databook of Socioeconomic Change Between the 1990 and 2000 Censuses. (January, 2005) Internet. <http://pewhispanic.org/files/reports/44.pdf> May 31, 2005.

¹⁵ Urban Institute 2000

¹⁶ State of Arizona. Homeless Coordination Office. The Current Status of Homelessness in Arizona and Efforts to Prevent and Alleviate Homelessness. Nov. 2004, 13th ed.

There are many factors that contribute to homelessness, including poverty, domestic violence, gender (the majority of homeless adults are males), substance abuse, mental illness, lack of affordable housing, decreases in public assistance, low wages, and lack of affordable health care. Families, specifically women with children, are the fastest-growing subpopulation of people who are homeless. Twenty-seven percent of homeless women, children, and teens came from a domestic violence situation. In spite of an overall positive economic picture in the state, the large number of households earning less than a livable wage and a disproportionate rise in housing costs versus incomes points to increasing numbers of homeless persons.¹⁷

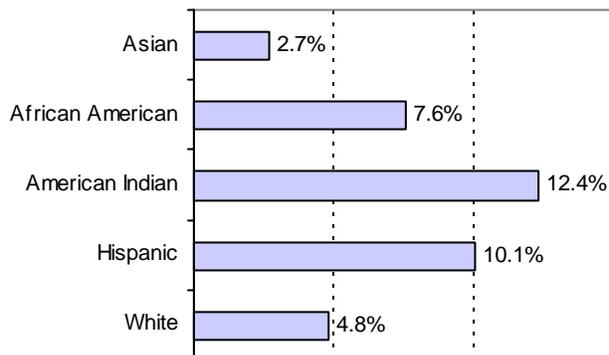
EDUCATION

Arizona has more than 583 school districts, which includes 364 charter holders. Arizona's has 2,270 schools and the largest number of charter schools in the nation. According to the National Educational Association, Arizona per pupil spending is among the lowest in the nation. In a national study of reading proficiency, nearly half of Arizona's 4th graders (46 percent) read below proficiency, compared to 38 percent in the rest of the nation.¹⁸

Among Arizona's population age 25 and older, 84 percent graduated from high school, and 24 percent have a college degree, similar to the proportions of all United States residents.

However, Arizona has one of the highest high-school dropout rates in the nation. During the 2003-2004 school year, the statewide dropout rate was 7.4 percent. For American Indians and Hispanic students, the dropout rates were even higher (see figure 3).

Figure 3. 2003-2004 Arizona High-School Dropout Rates



Arizona adopted high stakes testing requiring students to pass proficiency tests in reading, writing, and mathematics in order to earn a high school diploma. The Arizona Instrument to Measure Standards (AIMS) has been administered annually in recent years. Although passing the test has not yet been required to earn a high school diploma, students have been taking AIMS for purposes of evaluating school performance. High proportions of students across the state, and even

¹⁷ *Ibid.*

¹⁸ National Center for Education Statistics, National Assessment of Educational Progress. The Nation's Report Card: State Reading 2003 Snapshot Report. (2004): Internet. <http://nces.ed.gov/nationsreportcard/pdf/stt2003/2004456AZ4.pdf>. March 21, 2005.

higher proportions of minority students, have failed to meet AIMS standards for graduation. Implementation of the requirement to pass the AIMS before receiving a diploma was postponed in order to give schools time to align their curriculum to testing standards. The class of 2006 will be the first graduating class required to pass the test in order to graduate. In 2005, legislation was passed to allow students to apply points towards their AIMS scores for some classes in which they earned As, Bs, or Cs.

According to the Annie E. Casey Foundation Kids Count 2004 study, a disconnected youth is defined as a teen that is not in school or working. Currently, there are an estimated 3.8 million (15 percent) young adults nationally who are neither in school nor working. In Arizona, 12 percent of teens age 16 to 19 are not in school or working. Referred to as “disconnected youth,” they lack the skills, support and education to make a successful transition to adulthood. This study determined that the most disconnected youth were the teens in foster care, youth involved in the juvenile justice system, teens that have children of their own, and those who have never finished high school. These subgroups were determined to need the most urgent attention.¹⁹

JUVENILE DELINQUENCY

The proportion of violent crimes attributed to juveniles by law enforcement has declined in recent years, while drug and alcohol-related arrests have increased. Between 1993 and 2002, there were substantial declines in juvenile arrests for murder (64 percent), motor vehicle theft (50 percent), and weapons law violations (47 percent) and major increases in juvenile arrests for drug abuse violations (59 percent) and driving under the influence (46 percent).²⁰ Fourteen percent of all arrests in Arizona were juveniles under age 18, compared to 16 percent nationally, and 71 percent of the arrests were male.²¹ Of the arrests of Arizona juveniles ages 8 through 17 in 2003, 16 percent of those offenses were larceny/theft. Runaways, drug violations, and assaults each make up 10 percent of the total number of juvenile offenses, and liquor law violations made up 9 percent of the total violations.

¹⁹ Annie E Casey Foundation. 2004 Kids Count Data Book, Moving Youth From Risk To Opportunity. Baltimore, MD: Annie E Casey Foundation, 2004.

²⁰ Snyder, Howard. OJJDP Bulletin—September 2004—Juvenile Arrests 2002. (September 2004): Internet. www.ncjrs.org/html/ojjdp/204608/contents.html May 9, 2005.

²¹ United States. Federal Bureau of Investigation. Crime in the United States 2003. (October 27, 2004): Internet. http://www.fbi.gov/ucr/cius_03/pdf/toc03.pdf May 9, 2005.

Health Care Systems

HEALTH INSURANCE

Eighty-three percent of Arizona residents have some kind of health insurance, according to 2003 United States Census data. Many people have more than one kind of insurance: 64 percent of people have private insurance—either employment-based (55 percent) or direct purchase (9 percent); and 30 percent had some kind of government-sponsored insurance—such as Medicaid, (13 percent), Medicare (14 percent), or military health insurance (6 percent).²²

Ninety-three percent of all businesses in Arizona are small businesses with 50 or fewer employees. There are more than 100,000 small businesses in Arizona, and each year, small businesses add more workers to the workforce than large businesses. One of their top challenges is to offer competitive benefits. Only 28 percent of Arizona small businesses offer employer-sponsored health coverage, and cost is the primary barrier.²³ For many Arizonans, healthcare remains unaffordable.

Recognizing the importance of affordable health care, the Healthcare Group was created in 1985 by the Arizona State Legislature with the support of the Robert Wood Johnson Foundation. It is a state-sponsored, guaranteed issue health insurance program for small businesses and public servants. The Arizona Health Care Cost Containment System (AHCCCS), Arizona's Medicaid agency, oversees and administers the program, although it will receive no state subsidies after July of 2005. Over 4,000 businesses participate in Healthcare Group, covering more than 12,000 Arizona residents.

The very concept of health insurance must be redefined as it applies to American Indians, who are entitled to healthcare through treaties with the United States government. However, tribal members face significant barriers to accessing care, including provider shortages and sometimes a confusing array of barriers when accessing services.

MANAGED CARE

The health care delivery system and its financing has dramatically changed in the last 25 years, and managed care has played a dominant role in its evolution. Approximately 70 percent of the population in the United States under age 65

²² United States. U.S. Census Bureau. Historical Health Insurance Tables. (Dec. 7, 2004): Internet. www.census.gov/hhes/hlthins/historic June 15, 2005.

²³ State of Arizona. AHCCCS. State Coverage Initiatives (June 28, 2004): Internet. <http://www.statecoverage.net/0604/rodgers.ppt> June 15, 2005.

currently has private health insurance, the majority of which is managed care based and obtained through the workplace. Under the managed care umbrella, health maintenance organizations have become a major source of health care for beneficiaries of both employer-funded care and publicly funded programs, Medicaid, and Medicare. Seventy-two million people in the United States had health insurance through a health maintenance organization in 2003. Participation rapidly increased until hitting peak enrollment in 1999; however, it has dropped by 9 million enrollees by 2003.²⁴

ARIZONA HEALTH CARE COST CONTAINMENT SYSTEM

Arizona was the last state in the nation to implement a Title XIX Medicaid program. After much debate, the legislature rejected traditional fee-for-service financing arrangements in favor of an innovative plan for Medicaid managed care. In October 1982, the nation's first Section 1115 demonstration waiver for a statewide Medicaid managed care program was approved and AHCCCS was created. AHCCCS is a prepaid managed care Medicaid program that has become a national model.

From the beginning the AHCCCS program was envisioned as a partnership, which would use private and public managed health care health plans to mainstream Medicaid recipients into private physician offices. This arrangement opened the private physician network to Medicaid recipients and allowed AHCCCS members to choose a health plan and a primary care provider who can be a physician, nurse practitioner or physician assistant. Primary care providers manage all aspects of medical care for members. There are a limited number of plans available in the rural areas, making fewer choices available to rural beneficiaries.

Fully medically necessary health care services are covered for individuals who qualify for Medicaid, including comprehensive dental coverage for children under the age of 21 and emergency dental care (extractions) for adults 21 years of age and older. For individuals who qualify for the Federal Emergency Service (FES) and State Emergency Services (SES) programs, AHCCCS health care coverage includes only emergency services.

In 1998, KidsCare became Arizona's Title XXI Children's Health Insurance Program (CHIP). It is a federal and state program administered by AHCCCS to provide health care services for children under the age of 19 living in families with a gross income at or below 200 percent of the Federal Poverty Level (FPL). Since KidsCare began, enrollments have steadily risen. The outreach efforts undertaken to identify children eligible for KidsCare have also resulted in

²⁴ United States. Centers for Disease Control and Prevention. Health, United States, 2004; with Chartbook on Trends in the Health of Americans. (2004): Internet. <http://www.cdc.gov/nchs/data/hus/hus04acc.pdf> June 14, 2005.

identifying additional children who are eligible for Medicaid. The KidsCare application is short, clear, and relatively easy to use, and allows individuals to apply for health care coverage without having to go through the longer and more detailed application process that is needed for Temporary Assistance for Needy Families (TANF) cash assistance, food stamps, and other family assistance programs.

The passing of Proposition 204 in 2001 expanded eligibility from 34 percent of the federal poverty level to 100 percent. Expanded eligibility, together with Arizona's growing population, increased enrollment in AHCCCS and KidsCare more than 40 percent—from 411,152 enrollees in federal fiscal year 2001 to 579,640 enrollees in federal fiscal year 2003. By May 2005, enrollment in KidsCare increased from 3,710 in December 1998 to 50,682 and AHCCCS was providing health care coverage to 1,054,558 eligible members, approximately 18 percent of Arizona's population.

The state budget passed in 2003 directed AHCCCS to increase the premiums paid by families with children enrolled in KidsCare. The new premiums are based on a sliding scale depending on family income and the number of children. Before July of 2003, the scale ranged from \$0 to \$20, depending on income. As of July 2004 the premiums increased to a range of \$10 to \$35.

GENERAL AND SPECIAL HOSPITALS

According to the Arizona Department of Health Services Division of Licensing Services, there were 59 general acute care hospitals in the State of Arizona in 2004, with 11,235 beds and 25 specialty hospitals with 1,790 beds. There are two children's hospitals, both of which are located in the Phoenix metropolitan area. The state overall has 1.9 inpatient beds per 1,000 population, one-third fewer beds per population than the national average of 2.8 per 1,000.²⁵ According to the United States Department of Health and Human Services, Arizona ranks 45 in the number of hospital beds per 100,000 population.

PROFESSIONAL HEALTH CARE PROVIDERS

Arizona has 12,121 physicians, representing 208 doctors per 100,000 residents. Although the number of doctors practicing medicine in Arizona has grown faster than the population, the physician-to-population ratio in Arizona remains far below the national average of 283. Eighty-six percent of physicians practice in either Maricopa or Pima County, and the physician-to-population ratios range from a high of 277 in Pima County per 100,000 to a low of 48 per 100,000 in

²⁵ Health Forum LLC and affiliate of the American Hospital Association. "Arizona-Table 6_ Utilization, Personnel, revenue and Expenses, Community Health Indicators 1998-2002." [Hospital Statistics](#) 53 (2004).

Apache County.²⁶ Arizona has 606 registered nurses per 100,000 population, compared to 784 nationally, and ranks 48 in the number of employed registered nurses per capita.²⁷

Federal regulations establish health professional shortage areas based on three criteria: the area must be rational for the delivery of health services, more than 3,500 people per physician or 3,000 people per physician if the area has high need, and healthcare resources in surrounding areas must be unavailable because of distance, over-utilization, or access barriers.

Since 2000, there has been a 25 percent increase in the number of federally designated health professional shortage areas in Arizona. There are 60 areas that are federally designated shortage areas in Arizona. Twelve of these areas are considered frontier, 35 are non-metropolitan, and 13 are in metropolitan areas.

Arizona has developed its own designation system for identifying under-served areas. All federally designated shortage areas are automatically designated as Arizona shortage areas. In addition, Arizona's system involves the application of an index which weights 14 indicators such as providers to population ratios, travel time, percent of population below poverty, and adequacy of prenatal care. There are 13 state designated Arizona Medically Under-Served Areas. A recent survey of State Title V Directors on pediatric provider capacity for children with special health care needs (CSHCN) pointed out network concerns specific to CSHCN. The most commonly identified significant access barrier in this survey was the uneven distribution of pediatric providers.²⁸

Arizona has only one state medical school and a college of osteopathic medicine. As a result, Arizona trains fewer of its own providers than do most other states and many Arizona medical graduates leave to practice in other parts of the country. Arizona also has a higher percentage of older physicians than the national average, and more physicians are retiring earlier as well.²⁹ These factors all affect Arizona's ability to develop and maintain an adequate provider network.

²⁶ Johnson, William, et al. Arizona Physician Workforce Study, Part I, The Numbers of Practicing Physicians 1992-2004. Arizona State University William C. Carey School of Business and the University of Arizona Health Sciences Center, June 12 2005.

²⁷ Anderson, Dan. The Economic Impact of Arizona's Healthcare Industry. Arizona Board of Regents, January 19, 2005.

²⁸ Limb S., M. McManus, and H. Fox. Pediatric Provider Capacity for Children with Special Health Care Needs: Results from a National Survey of State Title V Directors. U.S. Department of Health Services, Health Resources and Services Administration, Maternal and Child Health Bureau, MCH Policy Research Center, March 2001.

²⁹ Nolan L, et al. An Assessment of the Safety Net in Phoenix, Arizona". Urgent Matters. The George Washington University Medical Center School of Public Health and Health Services, Department of Health Policy, March 2004.

The American Academy of Pediatrics recommends one pediatrician per 10,000 people. Of the 14 counties in Arizona that have a population of at least 10,000, only Coconino, Maricopa and Pima Counties meet this recommendation and 107 of the state's 109 pediatric specialists all practice in these same three counties. The other two specialists practice in Yuma County.

According to the National Center for Vital Statistics, the percentage of midwife-attended births has gradually increased from 1 percent in 1975, to 8 percent in 2002. Arizona reached a high of 10 percent of births being attended by a midwife in 1997. However, since 1997 there has been a gradual decrease in the percentage of midwife-attended births to 7 percent in 2003. However, nearly one in three American Indian births continue to be attended by midwives. As reported by the Arizona Department of Health Services Licensing Division, as of April 2005, there were a total of 34 licensed midwives, and 150 certified nurse midwives.

Although midwifery is a recognized alternative to the medical model of prenatal care, it is faced with a number of challenges. Hospitals that admit women and babies who received midwifery services use the same protocols as if the women had not received any prenatal care and most insurance plans do not cover midwifery services. AHCCCS rules allow coverage for midwife services, and most of the AHCCCS-contracted health plans contract with them.

PERINATAL SYSTEM

Arizona is the home of a unique perinatal regional system. Voluntary participation by the ADHS, AHCCCS, the Arizona Perinatal Trust, private physicians, hospitals, and transport providers result in a statewide comprehensive system that is considered a model nationally.

The Arizona Perinatal Trust endorses a voluntary program that certifies levels of perinatal care provided at hospitals throughout Arizona. Level I perinatal care centers provide services for low risk obstetrical patients and newborns, including caesarean deliveries. Level II facilities provide services for low risk obstetrical patients and newborns plus selected high-risk maternity and complicated newborn patients. Level II EQ facilities provide expanded services of level II perinatal care centers for defined maternal and neonatal problems through a process of enhanced qualifications. These facilities do not meet level III criteria, but have the capacity to care for infants on ventilators. Level III centers provide all levels of perinatal care and treatment or referral of all perinatal and neonatal patients.

The perinatal system reduces neonatal mortality by transporting critically ill newborns from rural hospitals to urban intensive care centers that are equipped to provide higher levels of nursing and medical care during acute phases of

illness. Neonatologists provide 24-hour consultation and medical direction for transport, and the ADHS Newborn Intensive Care Program serves as payer of last resort for families with no insurance for care delivered at Arizona Perinatal Trust certified facilities. The regional system has expanded and changed over the years. Currently services are available to all Arizona residents from the first identification of a high risk condition in pregnancy through post discharge and until the child is three years old.

ORAL HEALTH

Arizona has 15 counties that have been subdivided into 94 Dental Care Areas, which are geographic areas defined by the State of Arizona based on aggregates of census tracts. These Dental Care Areas are considered rational service areas for dental care by the State and are used for Federal Dental Health Professions Shortage Area designations. Thirty of the 94 areas are designated by the federal government as Dental Health Professional Shortage Areas. An area may also be designated as a “vulnerable population” if it is in the top quartile of any of the following: percent of the population less than 200 percent of the federal poverty level, percent of population that is Hispanic, or percent of the population that is American Indian.

The Center for California Health Workforce Studies at the University of California, San Francisco, in collaboration with the ADHS Bureau of Health Systems Development, analyzed dental workforce data on the distribution of dental providers and the availability of dental care services in Arizona. The project focused on profiling the statewide distribution of dental services in order to inform oral health policy in Arizona. Data were collected by the ADHS Office of Oral Health through a statewide telephone survey of dentists licensed and practicing in Arizona during the months of July 2000 through September 2001.

According to the survey, 58 percent of dental practices had at least one staff member that could translate for non-English speaking patients, while 63 percent said that they had patients who needed that service. Among office staff who could translate, 80 percent spoke Spanish, and a total of 28 different languages were spoken. Vulnerable populations were more likely to need translation services and were less able to meet the need. While 5 percent of practices overall said that their staff were rarely or never able to meet translation needs, 12 percent of practices in high Hispanic areas rarely or never met the need.³⁰

From 2000 to 2004, there was a net increase of 590 dentists and 999 dental hygienists licensed in Arizona. By September 30, 2004, 2,854 dentists and 2,439

³⁰ Mertz, E. and K. Grumbach. The Distribution and Composition of Arizona's Dental Workforce and Practice Patterns: Implications for Access to Care. A survey conducted for the Arizona Department of Health Services, Office of Oral Health by the Center for California Health Workforce Studies, July 2004.

dental hygienists had a license and address in Arizona. In 2003, the Governor signed a bill into law that creates a new opportunity for dentists and dental hygienists to expand the traditional walls of a dental practice through the creation of an affiliated practice relationship, expanding the scope of practice for dental assistants. Through an affiliated practice relationship, hygienists can provide preventive oral health services (e.g., fluoride, cleanings, sealants) to children in a variety of community-based health and educational settings without a prior examination by a dentist. It allows underserved children access to preventive services at an earlier age in a convenient setting, such as a Head Start Program or a school. It also provides an opportunity for early referral to dental services.

In 2004, legislation was passed to allow licensure by credentials, which provides a method for dentists and dental hygienists licensed in other states to receive an Arizona license without a clinical examination. Although it is expected that this change will increase the number of licensed dental professionals in the state, the impact on access to care in underserved areas is yet to be realized.

In 2003, the Arizona School of Dentistry and Oral Health opened its doors in Mesa to 54 dental students as Arizona's first dental school. Students there will earn the Doctor of Dental Medicine degree and a Certificate in Public Health Management. The school specifically recruits students to work in rural and underserved dental areas. In 2004, Mohave Community College in Bullhead City accepted 18 students into its new Dental Hygiene Program. Students will provide preventive therapies to this rural community as part of their educational experience. Two colleges in Maricopa County are pursuing accreditation for dental hygiene programs.

BEHAVIORAL HEALTH

The Arizona Department of Health Services Division of Behavioral Health Services (BHS) has reorganized permanent statutory authority to operate the state's behavioral health system, including planning, administration, and regulation and monitoring of all facets of the state behavioral health system. The division's focus is to promote healthy development and to provide effective prevention, evaluation, treatment, and intervention services to people in need who would otherwise go unserved.

Behavioral health services are delivered through community-based and tribal contractors, known as Regional Behavioral Health Authorities (RBHAs). Contractors are private organizations that function in a similar fashion to a health maintenance organization, managing networks of providers to deliver a full range of behavioral health care supports and services.

At this time there are six active Regional Behavioral Health Authorities: one serving northern Arizona, one serving Yuma, La Paz, Gila, and Pinal Counties,

one serving Maricopa County, one serving Graham, Greenlee, Cochise, Santa Cruz, and Pima Counties, one serving the Gila River Indian Community, and one serving the Pascua Yaqui tribe. In addition to other state and federal funds, clinics receive funds from Title XIX and Title XXI. BHS also has Intergovernmental Agreements with two additional American Indian Tribes to deliver behavioral health services to persons living on the reservation. These tribes are the Colorado River Indian Tribe and Navajo Nation.

BHS's strategic plan recognizes that the promotion of mental health in infants and toddlers is key to the prevention and mitigation of mental disorders throughout the lifespan. With the participation of Tribal and Regional Behavioral Health Authorities (T/RBHAs), and the involvement of other child-serving agencies, specialists in infant mental health, and parent advocates, a uniform new approach to assessments and service planning has been developed and will be implemented across Arizona effective October 1, 2005.

The ADHS Birth to Five assessment and service planning process differs from the system's strength-based assessment process for all other persons in two ways: first, it focuses not on any particular attribute of a child, but on the context of the child's life, seeing the child as a product of the environment in which he/she is immersed. Second, service plans must be written to support and reinforce normalized child development; to promote and reinforce health-promoting parenting and child rearing skills; to enhance child/parent attachment and bonding; and to reduce the long-term effects of any trauma. In regards to infants and toddlers, then, behavioral health interventions will include preventive as well as corrective measures, and like the assessment, will target the family, as well as the individual.

ARIZONA IMMUNIZATION PROGRAM

The ADHS Arizona Immunization Program provides funding, vaccines, and training support to public immunization clinics and private providers throughout Arizona. The program works to increase public awareness by providing educational materials to county health departments and community health centers and through partnerships with local and statewide coalitions. The program monitors immunization levels of children in Arizona, performs disease surveillance and outbreak control, provides information and education, and enforces the state's immunization laws. The Arizona State Immunization Information System collects, stores, analyzes and reports immunization data through a central registry maintained at ADHS.

In 1992 ADHS founded the Arizona Partnership for Infant Immunization (TAPI) as part of Arizona's federal Immunization Action Plan. TAPI is a non-profit statewide coalition of more than 400 members. TAPI was formed in response to the alarming fact that in 1993, only 43 percent of Arizona's two-year-olds were

fully immunized against preventable childhood diseases like measles, mumps, polio and whooping cough. Through the efforts of TAPI's partners from public and private sectors, immunization coverage rates in Arizona have dramatically improved, with more than three in four children fully immunized by age two. The goal of TAPI is to deliver age appropriate immunizations by the year 2010 to at least 90 percent of Arizona's two-year-old children before their second birthday and to encourage appropriate immunizations through the lifespan.

MEDICAL HOME PROJECT

The Medical Home Project, administered through the Arizona chapter of the American Academy of Pediatrics, was designed to increase access to and utilization of primary care services for Arizona's uninsured children from low-income families. The Medical Home Project provides delivery of medical services in participating physicians' offices to children without health insurance and to those who do not qualify (or are in the process of qualifying) for public assistance. The Medical Home Project creates a system of linkages between medical providers and school nurses to assist with health care provision to the target population. School nurses identify children who are eligible to participate in the Medical Home Project and facilitate their enrollment. To be eligible for the Medical Home Project a child must have no health insurance; must not be eligible for AHCCCS, KidsCare, or Indian Health Services; and must have a household income less than 185 percent of the federal poverty level. If a child appears to be eligible for AHCCCS or KidsCare, the school nurse is encouraged to identify resources to assist the family with the application process. A child with an acute illness may be seen through the Medical Home Project while in the qualifying process. The child is provided with a referral form to a participating health care provider and the school nurse makes the appointment.

A network of physicians (pediatricians, family practice physicians and specialists) provides care to children qualifying for the Medical Home Project for an office visit fee of either \$5 or \$10 as payment-in-full. The health care providers agree to provide a certain number of appointment slots to Medical Home Project children each month. Development of the provider network has been an ongoing effort since the beginning of the project in 1993. In addition, prescription medications, diagnostic laboratory services, and eyeglasses are provided as necessary to qualifying children.

Funding for the Medical Home Project has been provided by a number of entities. ADHS Office of Women's and Children's Health has had a contract with the Arizona chapter of the American Academy of Pediatrics since 1993 to fund the project management. Other sources of funds include the Robert Wood Johnson Foundation, St. Luke's Charitable Health Trust, Arizona Diamondbacks Charities, Diamond Foundation, as well as many others. In addition to the primary care providers, a variety of specialist providers (e.g. cardiology, dermatology, ear,

nose and throat, orthopedics, and pulmonology) have donated their services to children in need of care.

The Medical Home Project is currently operating in seven Arizona counties involving school nurses from 834 schools (representing 61 school districts). The primary care provider network consists of 20 pediatric group practices, 38 individual pediatricians, 6 family practice groups, and an additional 17 individual family practitioners.

COMMUNITY HEALTH CENTERS

Community health centers were established in the 1960s by federal law to treat and provide primary care to all patients regardless of their ability to pay. The Arizona Association of Community Health Centers reports that their membership includes 35 community health centers with more than 100 satellite locations statewide, serving more than 400,000 people in 2002. The Association represents health centers statewide and provides advocacy, professional education programs, financial services, and programs for health centers to improve and ensure clinical excellence.³¹

SCHOOL-BASED HEALTH CENTERS

There were 100 school-based or school-linked health care clinics in Arizona, delivering more than 45,000 medical visits to over 14,000 children during the 2002-2003 school year. Most of the children served had no health insurance (79 percent).³² Thirty-five percent of the centers operate in rural areas, and six operate on tribal lands. These clinics offer access to health care in communities where there is a significant provider shortage and transportation to health care services may be problematic.

School-based and school-linked health centers allow students to have immediate access to health care providers for problems ranging from minor aches and scrapes to acute illnesses. They are staffed with nurse practitioners and physician assistants who work closely with a medical director. For many students, these centers are the only source of medical care.

Most school-based clinics are affiliated with a hospital-based outpatient department that provides on-call services and after-hours coverage when the school-based clinic is closed. This configuration not only offers a location for the

³¹ Arizona Association of Community Health Centers. Programs Overview. Internet. <http://www.aachc.org/programs.html> June 14, 2005.

³² Arizona School-Based Health Care Council. 2003 Annual Report Summary. (March 29, 2005): Internet. http://www.azschoolhealthcouncil.org/2003_Council_Summary_Report.pdf June 15, 2005.

child to go at times when the school clinic is not open, but the affiliated location is also available as a medical home for all family members. All of the clinics encourage parental involvement and parental consent is required before any services are provided. The clinics support the philosophy of the parent participating as a partner in the decision making process.

OTHER PROJECTS TO INCREASE ACCESS TO CARE

Health-e-Arizona is a web-based electronic screening and application process for public health insurance. It was initiated by El Rio Community Health Center in Pima County and piloted there beginning in June 2002. It is now used in most federally designated community health centers throughout Arizona, as well as in several hospitals. Since its inception, 32,000 people have submitted electronic applications for processing by AHCCCS. The electronic application has many advantages over the paper application. The electronic version requires full and complete information before the application could be submitted, resulting in more complete and accurate applications. As a result, the approval rate of electronic applications is much higher. The electronic application process automatically screens for eligibility for a number of programs, thus helping to link patients with health care coverage; a total of 95 percent of those seeking health care coverage through Health-e-Arizona have been linked to some health program.

Another community-based program, the Pima County Access Project (P-CAP) and Healthcare Connect in Maricopa County are offering discounted health care to those not eligible for public health insurance and unable to afford commercial insurance products. With federal grant funding, the project recruited the participation of medical providers who are willing to charge discounted rates to enrolled patients. P-CAP has 8,000 patients enrolled and Maricopa County Healthcare Connect began enrolling patients in June 2004.

TELEMEDICINE

Telemedicine is the practice of medicine using a telecommunication system to provide clinical services at a geographically separate site. Service can be delivered “real-time” using interactive video conferencing or through “store and forward” which relies on the transmission of images for review immediately or at a later time.

The University of Arizona Telemedicine Program is a statewide program intended to increase access to healthcare to all residents in Arizona using telemedicine technologies. The use of telemedicine enhances the rural health infrastructure and reduces the need for rural patients and their families to travel to urban centers for health services. The program’s telecommunications network spans the entire state and serves as a hub for linking all of the telemedicine networks in

Arizona. Arizona's telemedicine network serves three functions: health care delivery, education and training, and videoconferencing administrative meetings. The complete telemedicine network is shown in figure 4.

CULTURAL COMPETENCE

As racial and ethnic disparities in health outcomes and access to care persist, there has been much interest in the concept of cultural competence. A recent study evaluated states not on disparities in health outcomes, but on their efforts, leadership, capacity, and infrastructure that would be sensitive to direct policy intervention to create state minority health policy report cards. Four measures were defined: insurance coverage disparity, diversity ratio, offices of minority health, and number of race/ethnicity vital statistics categories.³³

Insurance coverage among people whose incomes fell below 200 percent of the federal poverty level is correlated with state Medicaid policy. The authors used data from the 2001 and 2002 Current Population Surveys to examine the states' low-income populations. By dividing each state's percentage of low-income non-elderly minorities by its percentage of low-income non-elderly Whites, they calculated the insurance ratio. The insurance gap is the relative risk of uninsurance for minorities compared to Whites among non-elderly poor, with low scores representing lower relative risk levels for minorities. Arizona's insurance gap was 1.52, meaning that minorities in Arizona were 52 percent more likely to be uninsured than Whites. Delaware had the lowest insurance gap, at 0.74, and Idaho had the highest gap, at 2.13.

The diversity ratio is a measure of the degree to which the demographic composition of a state's physicians matches the demographic composition of the state as a whole. The ratio is calculated by first dividing the total state minority population by the number of minority physicians in the state. This number is then divided by the ratio of the total state White population to the number of White physicians in the state. The diversity ratio is the factor by which underrepresented minority physicians must be increased to reach population parity with Whites. Arizona scored a 5.70 on this measure. The state with the best ratio was Maine, with a score of 0.94. Illinois was worst, at 11.53.

³³ Trivedi, Amal N. et al. "Creating a State Minority Health Policy Report Card." Health Affairs 24.2 (March/April 2005): 388-396.

The office of minority health measure is a simple yes or no field. At the time of the analysis, Arizona had discontinued its office. There were 27 states with minority health offices. Since the time of the study, a Center for Minority Health in the Office of Health Systems Development was reestablished.

The number of race/ethnicity vital statistics categories measures how precisely states record race/ethnicity. For example, a state with two categories may break it down by “White/other” or “African American/White,” while a state with three may say “African American/White/other.” Arizona tied with 16 other states that used five categories. Three states only used one category.

The Center for Minority Health is currently conducting its own infrastructure assessment within the ADHS to determine minority health resources existing within the agency, examine the capacity of the agency to identify and address health disparities and barriers to access to care among minority groups and vulnerable populations, and to establish an inventory and directory of minority health resources.

WOMEN OF CHILDBEARING YEARS

An estimated 1,235,274 women of childbearing age (15 through 44 years) resided in Arizona in 2004. The Behavioral Risk Factor Surveillance System (BRFSS) collects health behavior information for adults 18 years and older, and tracks a number of measures designed to monitor behavioral patterns that affect morbidity and mortality. Arizona has been participating in it since 1982 to monitor the health behaviors of its adult population.

BRFSS respondents were asked to rate their general health. The overwhelming majority of women (88 percent) in Arizona reported that their health was excellent or good with only 12 percent reporting that their health was either fair or poor.

ACCESS TO CARE

Women of childbearing years in Arizona are less likely to have health insurance, less likely to have a personal doctor or nurse, and more likely to experience cost as a barrier to needed care than women in the rest of the nation. Twenty-three percent of women of childbearing age in the BRFSS survey in 2003 said that they have no health insurance, compared to only 19 percent in the nation; 71 percent said that they had either one or more doctor or nurse, compared to 79 percent of women in the nation; and 15 percent of women in Arizona indicated that there was a time in the past year when they needed to see a doctor but could not because of costs, compared to 13 percent of women nationally.

MORTALITY AND MORBIDITY

Mortality rates have generally declined among women of childbearing years in Arizona over the past decade (see figure 5).

Figure 5. Mortality per 100,000 Arizona Women Age 15-44

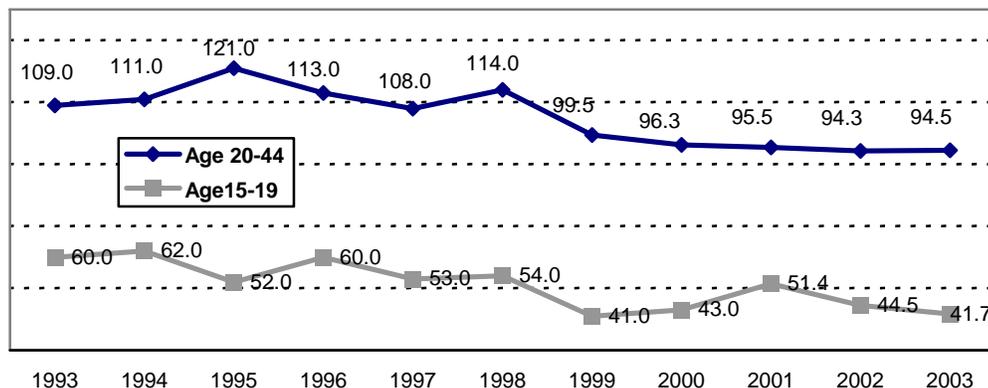
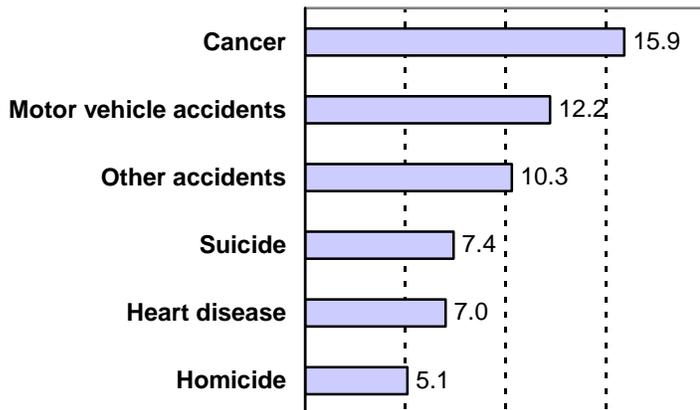


Figure 6. Leading Causes of Death per 100,000 Arizona Women Age 15-44



The same six leading causes of death account for most deaths among teenage girls and women from 1993 through 2003, although their relative importance changes between groups. In 2003, car accidents were the single largest killer of teenage girls, followed by suicide, homicide, and other accidents.

Table 1 shows the mortality rates for the leading causes of death among teenage girls from 1993 through 2003.

Table 1. Mortality Rates for the Leading Causes of Death per 100,000 Women Age 15-19 1993-2003											
Cause	1993	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003
Unintentional Injuries	30.5	25.8	26.5	28.3	21.4	27.7	19.9	23.7	22.9	22.2	19.1
<i>Motor Vehicle Accidents</i>	25.6	24.2	23.6	24.9	18.1	22.6	16.8	20.3	18.6	18.0	15.5
<i>Other Accidents</i>	4.8	1.6	2.9	3.5	3.3	5.2	3.1	3.4	4.3	4.2	3.6
Homicide	9.6	7.8	8.8	4.8	6.7	8.4	5.6	5.6	2.2	3.2	4.1
Suicide	8.0	5.5	3.7	3.5	8.0	3.9	3.1	2.8	5.5	2.1	4.1
Cancer	3.2	7.8	2.9	2.8	2.0	3.9	5.0	1.1	4.9	3.2	2.6
Heart Disease	3.2	1.6	0	3.5	2.0	1.3	0.0	1.1	1.1	21.1	0.5

Cancers accounted for most deaths among women age 20-44 in 2003, followed by motor vehicle and other accidents, suicide, heart disease, and homicide. Table 2 shows the mortality rates for the leading causes of death among women age 20-44 from 1993 through 2003.

Table 2. Mortality Rates for the Leading Causes of Death per 100,000 Women Age 20-44 1993 through 2003											
Cause	1993	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003
Cancer	25.9	22.4	23.1	22.9	22.8	25.0	21.0	21.0	21.2	18.7	15.9
Unintentional Injuries	20.3	22.9	23.0	24.7	22.4	24.4	23.4	16.7	22.0	21.9	22.5
<i>Motor Vehicle Accidents</i>	13.7	14.5	15.4	16.5	13.6	15.5	14.0	10.1	10.5	12.0	12.2
<i>Other Accidents</i>	6.6	8.4	7.6	8.2	8.8	8.9	9.4	6.6	11.5	9.9	10.3
Suicide	8.6	9.0	11.8	9.6	8.7	9.7	7.8	7.2	4.3	6.2	7.4
Heart Disease	7.4	9.0	9.2	8.7	8.4	8.2	7.5	6.2	7.6	7.3	7.0
Homicide	7.4	6.8	8.0	5.6	6.6	7.1	7.3	4.5	6.2	3.9	5.1

Among the leading causes of death for women of childbearing years, only two, cancer and heart disease, have medical causes. The remaining causes all relate to either unintentional harm (accidents), or intentional harm (suicide or homicide). BRFSS data has tracked the percentage of women who use seatbelts over time, and no substantial increases have occurred since 1997. In 2002, 85 percent of women said they always used a seatbelt, and another 8 percent said they nearly always did.

INJURY AND POISONING

There were 6,198 inpatient hospitalizations for non-fatal injuries and poisonings among women of childbearing years in 2003. Many more women who are injured are cared for on an outpatient basis in the emergency room. In 2004, there were 77,678 non-fatal outpatient emergency room visits among women age 15-44.

Most of the injuries (87 percent) were unintentional, 4 percent were self-inflicted, and 6 percent were the result of an assault. For 3 percent of the emergency room visits, the manner was either undetermined, or some other classification. Looking only at those injuries, which were intentional, 39 percent were self-inflicted. However, among adolescent girls, 53 percent of injuries were self-inflicted. Table 3 shows the number of nonfatal emergency room visits for injury and poisoning by cause and manner among women of childbearing age in 2004.

Table 3. Emergency Room Visits for Nonfatal Injuries and Poisonings
By Mechanism and Manner
Women Age 15-44, Arizona 2004

	Unintentional	Self-Inflicted	Assault	Undetermined /Other	Total	Percent
Cut/Pierce	6,340	731	180	43	7,294	9.4%
Drowning/Submersion	15				15	0.0%
Fall	9,371	6	4	30	9,411	12.1%
Fire/Hot Object	1,409	8	4	3	1,424	1.8%
Firearm	33	2	31	10	76	0.1%
Machinery	139				139	0.2%
Motor-vehicle Traffic	16,613	5	14	1	16,633	21.4%
Pedacyclist	486				486	0.6%
Pedestrian	65				65	0.1%
Transport	1,479				1,479	1.9%
Natural/Environment	3,926	1			3927	5.1%
Overexertion	10,019				10,019	12.9%
Poisoning	1,003	2,034	9	542	3,588	4.6%
Struck by, Against	8,271		2,000	63	10,334	13.3%
Suffocation	7	14	12	1	34	0.0%
Other and Unspecified	8,463	81	2,214	1,996	10,862	14.0%
Total	67,639	2,882	4,468	2,689	77,678	
Percent	87.1%	3.7%	5.8%	3.4%		

The leading cause of unintentional injury was motor vehicle accidents, which accounted for 25 percent of nonfatal unintentional injuries, followed by overexertion (15 percent) and falls (14 percent). When women are seen in the emergency room for self-inflicted injuries, the cause is most often poisoning (71 percent) or cutting and piercing (25 percent).

VIOLENCE AGAINST WOMEN

During 2003, 1,825 rapes were reported in Arizona, and 226 arrests were made. The rate of reported rapes in Arizona mirrored that of the nation with 33 per 100,000 people in Arizona (32 per 100,000 U.S.). Women in Arizona appear to be at greater risk for being the victim of a homicide than women in the rest of the nation. In 2003, the homicide rate for women 20 to 44 in Arizona was 5.4 per 100,000 women (54 homicides) compared to 3.3 per 100,000, nationally.

There were 110,369 calls to law enforcement for domestic violence in 2003. One in five of them resulted in an arrest, and minors were present at one in four cases. Requests for domestic violence shelters collected by the Arizona Department of Economic Security for 2003-2004 indicate that only 39 percent of those requesting shelter were given a bed that night. More than 15,500 requests for shelter were unmet.

There were 365 inpatient hospitalizations for which a diagnosis code indicating violence against women was recorded in 2003. These cases represent the tip of the iceberg, as they capture only those cases that were severe enough to be admitted into the hospital and only those cases in which the cause of the injury was recognized as due to abuse.

For the first time in 2004, emergency room data became available for analysis. There were 4,246 emergency room visits for which a diagnosis code indicated abuse, and in which the patient was not admitted into the hospital, representing a rate of 380.0 emergency visits for violence per 100,000 women age 18-44. The rate for women age 18-30 was considerably higher than the rate for women age 31-44 (471.0 per 100,000 women age 18-30 compared to 299.3 per 100,000 women age 31-44).

MENTAL HEALTH

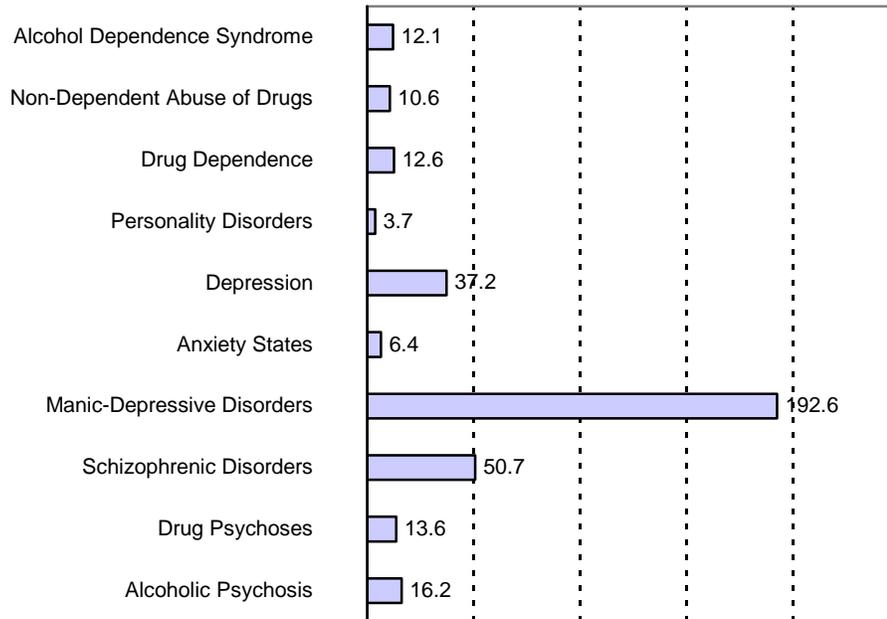
A broad range of mental health issues – including depressive disorders, anxiety disorders, eating disorders, schizophrenia, symptoms related to premenstrual syndrome, and postpartum depression – affect women of childbearing years. Recent research has shown that depression, which is the number one cause of disability in women, affects twice as many women as men and is the second leading cause of hospitalizations after pregnancy-related hospitalizations. This gender difference occurs after puberty and decreases after menopause, leading researchers to hypothesize that hormonal factors are involved in the increased risk for depression in women.³⁴

There were 4,920 inpatient hospital admissions for mental disorders among women of childbearing age in Arizona during 2003, representing 9 percent on non-pregnancy related hospitalizations among women age 15-44. These hospitalizations represent only those cases in which the principle reason for the hospital admission was a mental disorder. However, mental disorders also are present as complications and co-morbidities of other hospitalizations. There were 18,400 additional hospitalizations in which a mental disorder was identified as a complication or co-morbidities.

Manic-depressive disorders were the most common reason that women were hospitalized for a mental disorder in Arizona during 2003, with 192.6 per 100,000 women age 15-44 hospitalized. The second most common reason was for schizophrenic disorders, followed by depression. Figure 7 shows hospitalization rates for mental disorders per 100,000 women age 15-44 in 2003.

³⁴ United States. Substance Abuse and Mental Health Services Administration. Mental Health Topics. Internet. <http://www.mentalhealth.samhsa.gov/topics/explore/womenmen/> May 17, 2005.

Figure 7. Mental Health-Related Hospitalizations per 100,000 Women Age 15-44, Arizona 2003



The BRFSS asked respondents to think about their mental health, including stress, depression, and problems with emotions, and to say how many of the last 30 days their mental health was not good. Well more than half (57 percent) of respondents stated that they did not have any days in the previous month in which they experienced mental health problems, and another 13 percent reported poor mental health on one or two days. However, 5 percent of women said that their mental health was not good on all 30 days of the previous month. On average, women of childbearing years in Arizona reported that their mental health was not good for 4 out of the preceding 30 days.

Premenstrual syndrome (PMS) is estimated to affect 40 percent of menstruating women. Five to ten percent of women suffer from severe PMS symptoms including depression and anxiety.³⁵

PREVENTIVE HEALTH CARE

Utilization of health screening exams can be used as a proxy for access to health care. However, the main purpose of health screening exams is early detection of devastating diseases to prevent morbidity and mortality. Some examples of preventive health screenings are Pap tests (use to screen for cervical cancer), mammography, and breast exams, which are utilized to detect breast cancer.

³⁵ United States. The National Women's Health Information Center. Premenstrual Syndrome. (2002): Internet. <http://www.4woman.gov/faq/pms.htm> May 17, 2005.

Following skin cancer, breast cancer is the most commonly diagnosed cancer among women. It follows lung cancer as the second leading cause of cancer-related deaths. During 2003, nearly 300 women died of breast cancer in Arizona; 45 of them (16 percent) were of childbearing age. When breast cancer is diagnosed at an early stage, the survival rate is 97 percent.³⁶

In order to detect breast cancer early, the American Cancer Society recommends that all women age 40 and older receive an annual mammogram and that, starting in their twenties, women receive a clinical breast exam about every three years and then yearly in their forties. (The American Cancer Society no longer includes self-breast exams in its recommendations.)

According to the 2002 BRFSS, nine percent of women of childbearing age in Arizona said that they had never had a clinical breast exam. Sixty-five percent reported that they had received one during the past year.

Figure 8. Clinical Breast Exams Women Age 18 and Older in 2002

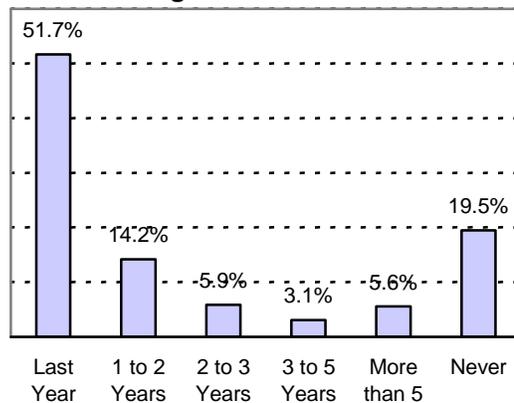
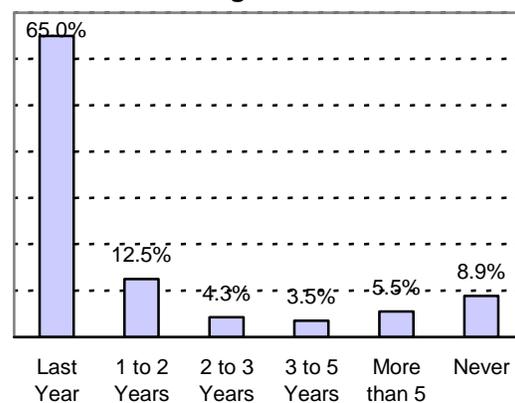


Figure 9. Mammograms in Arizona Women Age 40-49 in 2002



The 2000 National Health Interview Survey showed that overall, 55 percent of women 40 years and older had a mammogram in the last year. Women with 16 or more years of education were more likely to have had a mammogram (65 percent) and women with no health insurance were less likely (28 percent). In Arizona, BRFSS data for 2002 indicate that 9 percent of adult women (18 and older) had never had a clinical breast exam and 20 percent of women over the age of forty had never had a mammogram. Approximately half (52 percent) of women met the American Cancer Society recommendation to have a mammogram within the past year.

The American Cancer Society recommends that all women have their first Pap test (to screen for cervical cancer) within three years of becoming sexually active or no later than 21 years of age. After the first test, recommendations vary

³⁶ American Cancer Society, Inc. *Cancer Prevention & Early Detection Facts & Figures 2004*. (2004): Internet. <http://www.cancer.org/downloads/STT/CPED2004PWSecured.pdf> May 18, 2005.

depending on the test being used, risk factors, the woman's health history, and her age. According to the 2002 BRFSS, 4 percent of women in Arizona have never had a Pap test and 72 percent had one in the last year.

ORAL HEALTH

Having one's teeth cleaned and checked regularly is important to maintaining good oral health. In addition, an appointment with a dentist or dental hygienist provides an opportunity for updates on oral health disease prevention. Prevention, early detection, and treatment of any periodontal (gum) disease and dental cavities during routine dental visits are important to a woman's health and may be important to the health of her children. Research suggests that some pregnant women with advanced periodontal disease may be more likely to deliver pre-term, low birth weight babies.^{37,38} After birth, the bacteria that cause dental cavities (recognized as a transmissible, infectious disease) may be passed from mother to child.^{39,40,41}

According to the 2004 BRFSS, more than 40 percent of women age 18-34 and more than 30 percent of women age 35-44 in Arizona reported that they had not had their teeth cleaned in the last year. In fact, 11 percent of 18-24 year-old women and 7 percent of 25-44 year-old women had not seen a dentist in five or more years.

PHYSICAL ACTIVITY, NUTRITION, WEIGHT, AND RISK BEHAVIORS

Cancer and heart disease were among the leading causes of death in women of childbearing years in Arizona. Sedentary lifestyle is a risk factor, while maintaining a healthy weight through healthy eating patterns and physical activity is a critical component of chronic disease prevention. Over the last decade, strides have been made in increasing the level of physical activity and healthy eating. However, the proportion of the population that maintained a healthy weight has moved in the wrong direction.

WEIGHT

During the 1990s obesity reached epidemic proportions, affecting all regions and demographic groups in the United States. The Healthy People 2010 goal for obesity is to reduce its prevalence among adults to 15 percent. In Arizona, as in

³⁷ Jeffcoat, M.K. et al. "Current Evidence Regarding Periodontal Disease as a Risk Factor in Preterm Birth." *Annals of Periodontology* Dec. 2001:183-8.

³⁸ Offenbacher S, et al. "Periodontal infection as a possible risk factor for preterm low birth weight." *Journal of Periodontology* Oct. 1996: 1103-13.

³⁹ Slavkin HC. Streptococcus mutans, early childhood caries and new opportunities. *Journal of the American Dental Association* Dec. 1999: 1787-91.

⁴⁰ Jeffcoat, M.K., loc. cit.

⁴¹ Offenbacher S., loc. cit.

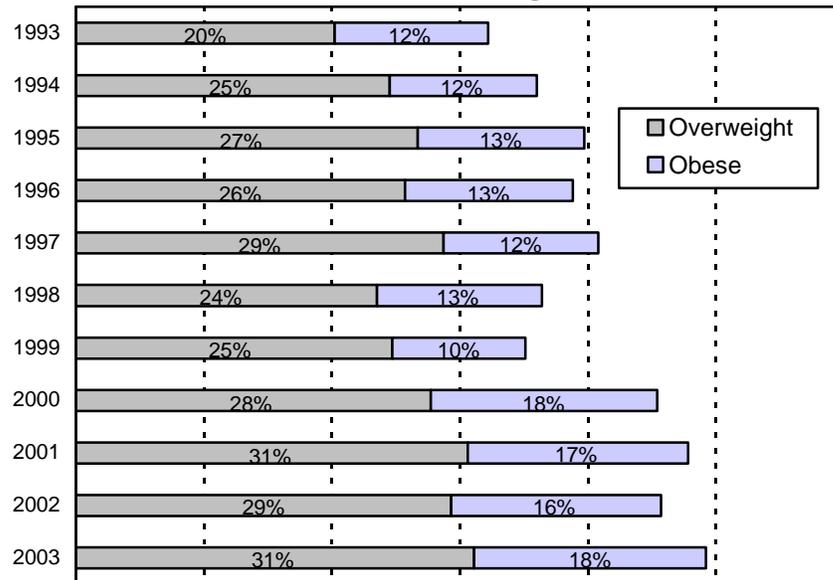
the nation, the trend is moving in the wrong direction. BRFSS data indicate that in 1993, 32.2 percent of females in Arizona were obese or overweight, compared to 40.2 percent, nationally. In 2003, those numbers jumped to 49 percent of women in Arizona and 51.5 percent of women, nationally.

The 2003 BRFSS sample was not large enough to analyze weight for all racial/ethnic groups of women of childbearing years. However, there was a sufficient sample to separately analyze White, non-Hispanic women and Hispanic women. 2003 BRFSS data indicate that Hispanic women of childbearing years are more likely to be overweight with 55 percent having body mass index that indicated that they were obese or overweight compared to 47 percent of White women.

All estimates of obesity and overweight depend upon women accurately reporting their height and weight. It is interesting to note that 12 percent of women in Arizona either did not know or refused to report either their height or weight, compared to only 8 percent of women, nationally. Figure 10 shows the number of women in Arizona whose body mass index indicates they were overweight or obese during the last decade.

Forty-six percent of women age 18-44 in Arizona said they were trying to lose weight, and 10 percent said they received information regarding weight loss from their health care providers in the last 12 months.

**Figure 10. Percent of Overweight and Obesity
Arizona Women 1993 through 2003**

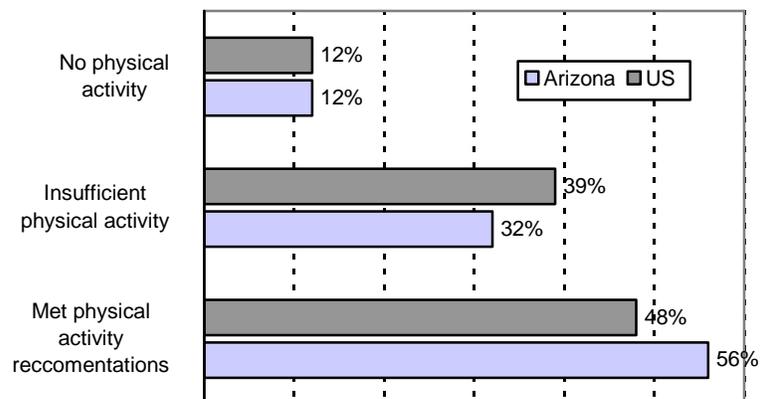


DIET

Consuming a diet high in fruits and vegetables is associated with lower risks for numerous chronic diseases, including cancer and cardiovascular disease. The CDC's National Center for Chronic Disease Prevention and Health Promotion recommends consuming at least five fruits and vegetables per day for optimum health. Several questions on the consumption of fruits and vegetables were asked on the 2003 BRFSS.

Both nationally and in Arizona, only one in four women reported eating at least five servings of fruits and vegetables per day. Six percent of women in Arizona reported that they ate less than one serving of fruits and vegetables per day, and over the last decade, fruit and vegetable consumption levels have not changed. In 1993, 70.9 percent of women reported not getting enough fruits and vegetables compared to 71.6 percent in 2003.

Figure 11. Physical Activity of Women 18-44 BRFSS-Defined Recommendations, 2003



EXERCISE

Exercise is a critical component of chronic disease prevention and an important tool in weight management. Many health problems affecting women of childbearing years can be prevented or improved through regular physical activity. In addition to improving general health, exercise reduces symptoms of anxiety and depression. Physical activity need not be strenuous to be beneficial. People of all ages benefit from participating in regular, moderate-intensity physical activity, such as thirty minutes of brisk walking five or more times a week.⁴²

Although 12 percent of women of childbearing years reported no physical activity in the 2003 BRFSS, more women in Arizona reported sufficient levels of physical activity than the rest of the nation.

⁴² United States. Centers for Disease Control and Prevention. Physical Activity – The Importance of Physical Activity. (April 14, 2005): Internet. <http://www.cdc.gov/nccdphp/dnpa/physical/importance/index.htm> May 17, 2005.

TOBACCO

Smoking is the single most preventable cause of death and disease in the United States. It is a major contributor to lung cancer, oral cancer and heart disease and has been causally linked to respiratory illness among non-smokers. The CDC reports that smoking causes 440,000 (one in five) deaths per year.⁴³

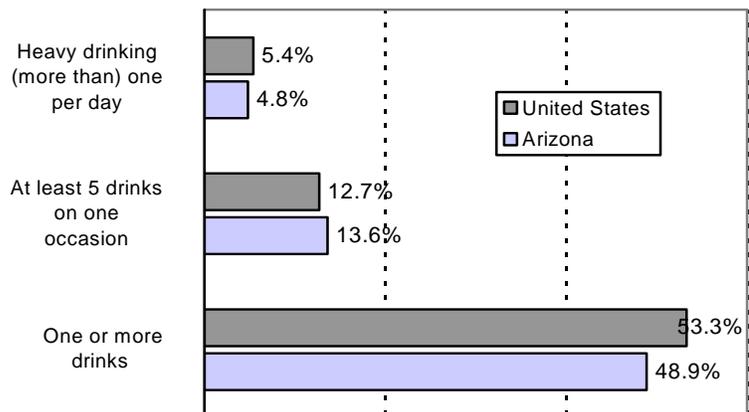
Fewer women of childbearing age smoke in Arizona than in the rest of the nation. Nationally, 23 percent of females under the age of 45 reported that they are current smokers (either daily or sometimes), compared to 19 percent of women in Arizona in 2003, according to BRFSS data.

ALCOHOL

Excessive drinking has numerous negative health effects, including liver cirrhosis (damage to liver cells), pancreatitis (inflammation of the pancreas), various cancers, high blood pressure, and psychological disorders. Acute health consequences of excessive drinking can include motor vehicle injuries, falls, domestic violence, rape, and child abuse.⁴⁴

The BRFSS asked women about their alcohol consumption within the last 30 days. Approximately half of the women of childbearing age in Arizona (49 percent) reported that they had had at least one drink during the last 30 days. Fourteen percent had five or more drinks on at least one occasion, and five percent could be described as drinking heavily, consuming more than one drink per day during the last 30 days. Figure 12 shows alcohol consumption among women of childbearing age in the United States and Arizona.

**Figure 12. Alcohol Consumption
Women 15 through 44 Years of Age, 2003**



⁴³ Fellows, JL, PhD. "Annual Smoking-Attributable Mortality, Years of Potential Life Lost, and Economic Costs --- United States, 1995--1999." Centers for Disease Control, Morbidity and Mortality Weekly Report. 51.14 (April 12, 2002): 300.

⁴⁴ United States. Centers for Disease Control and Prevention. Alcohol – FAQs. (Sept. 23, 2004): Internet. <http://www.cdc.gov/alcohol/faqs.htm> May 17, 2005.

SEXUALLY TRANSMITTED DISEASE (STD)

Sexually transmitted diseases can cause an array of health problems for women. Chlamydia (the most commonly reported infectious disease in the country) and gonorrhea can cause pelvic inflammatory disease, infertility, ectopic pregnancy, and chronic, long-term pelvic pain. In pregnant women, these diseases can cause premature delivery and other complications. Other common STDs include syphilis, genital warts, and genital herpes. Syphilis can cause damage to the heart, brain, and other organ systems, as well as prematurity and stillbirth. Genital warts can cause genital cancers, and genital herpes can cause spontaneous abortion and prematurity, birth defects, mental retardation, and brain damage in infants. Chlamydia, syphilis, herpes, and gonorrhea are treatable, although antibiotic-resistant strains of gonorrhea are becoming more common.⁴⁵ In Arizona, the BRFSS shows that only 25 percent of women talked to their doctor about preventing STDs through condom use.

Figures 13 and 14 provide information on STD rates among women ages 20 and older by race/ethnicity. In general, teens, younger women, and racial and ethnic minorities have higher STD rates than older White women. (STD rates for teens are presented in the Children and Adolescent section of this document).

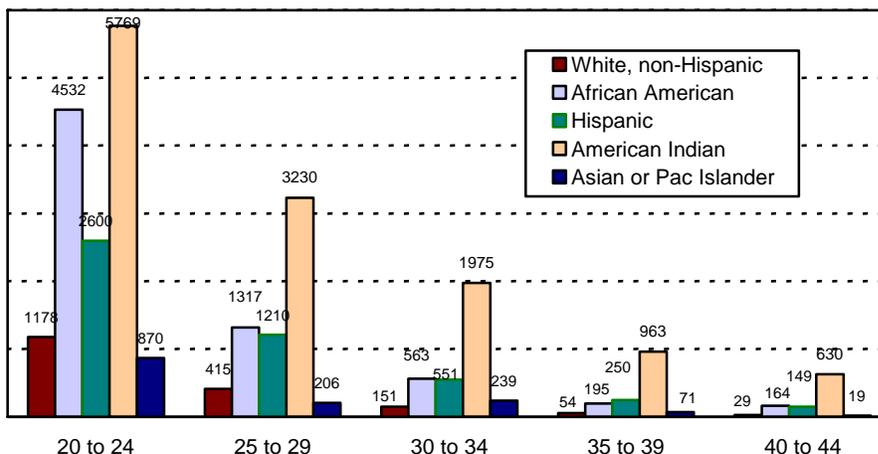
CHLAMYDIA

According to the CDC, Chlamydia rates in Arizona mirrored those of the nation in 2002, with 296 cases per 100,000 population reported nationally and 292 reported in Arizona.⁴⁶ In 2004, women of childbearing years in Arizona had an overall Chlamydia rate of 1,023 cases per 100,000 women. Chlamydia rates within this population varied widely by race, ethnicity, and age group. Figure 13 shows that American Indian women ages 20 to 24 had the highest Chlamydia rate with 5,769 cases of Chlamydia reported per 100,000. The lowest Chlamydia rate was in Asian women 40 through 44 years of age with 19 reported cases per 100,000 women of childbearing years.

⁴⁵ Washington State. Dept. of Health. STD Fact Sheets. (March 3, 2005): Internet. <http://www.doh.wa.gov/cfh/STD/factsheet.htm> May 16, 2005.

⁴⁶ United States. Centers for Disease Control and Prevention. Table 3. Chlamydia – Reported Cases and Rates by State/Area, Ranked by Rates: United States 2002. Internet. <http://www.cdc.gov/std/stats02/tables/table3.htm> May 17, 2005.

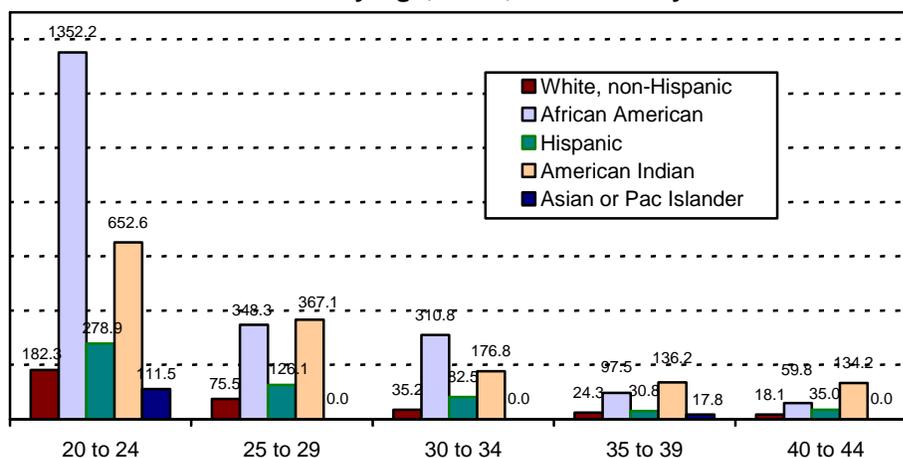
Figure 13. 2004 Chlamydia Rates per 100,000 Women by Age, Race, and Ethnicity



GONORRHEA

Overall gonorrhea rates were lower in Arizona than the national average in 2002 (74 per 100,000 population in Arizona versus 125 for the nation), but were still much higher than the Healthy People 2010 goal of 19 per 100,000.⁴⁷ As with Chlamydia, there are huge disparities in gonorrhea rates among women of childbearing ages with a rate of 1,352 cases per 100,000 African American women ages 20 to 24 compared to Asian women with 112 cases reported per 100,000 in the same age group.

Figure 14. 2004 Gonorrhea Rates per 100,000 Women by Age, Race, and Ethnicity



⁴⁷ United States. Centers for Disease Control and Prevention. Table 13. Gonorrhea — Reported cases and rates by state/area, ranked by rates: United States, 2002. Internet. <http://www.cdc.gov/std/stats02/tables/table13.htm> May 17, 2005.

SYPHILIS

In the year 2000, the rate of syphilis was the lowest it has ever been since reporting began in 1941.⁴⁸ However, over the last decade in Arizona, syphilis has become a growing concern. In 1993, there were a total of 556 cases of syphilis reported in Arizona. In 2003, nearly twice as many cases (1,094) were reported. Untreated early syphilis in pregnant women results in perinatal death in up to 40 percent of cases, and if acquired during the four years preceding pregnancy, leads to infection of the fetus in more than 70 percent of cases. Twenty-one people have died as a result of syphilis infections in Arizona from 1993 through 2003.

HIV/AIDS

In addition to the sexually transmitted diseases mentioned above, there were 1,586 women diagnosed with HIV or AIDS as of June 2004 in Arizona. The number of newly diagnosed cases of HIV/AIDS has remained fairly stable over the last decade with highs of 108 cases reported in each of 1995 and 1996 and a low of 79 cases reported in 2003.

FAMILY PLANNING

Family planning is the conscious effort to regulate the number and spacing of births through contraception. It plays an integral role in bolstering the health and well being of women and children. Family planning plays an important role in reducing maternal and infant mortality rates. Additionally, with the ability to plan their pregnancies, women gain more flexibility in education and employment opportunities. Healthy People 2010 Family Planning Objective #1 is to increase to at least 70 percent, the proportion of all pregnancies among women age 15 through 44 that are planned.

During the 1990s, several developments have affected women's ability to plan pregnancies. A wide variety of effective hormonal birth control methods became available that do not require the user to adhere to daily regimens, like birth control pills do (e.g., transdermal patches and the vaginal ring). In addition, in 1998, the Food and Drug Administration approved the first emergency contraceptive for post-coital contraception available via prescription in the United States. Emergency contraception, which contains the same hormones that are used in birth control pills, is estimated to be 75 percent effective in preventing pregnancy if taken within 72 hours of unprotected sex.

⁴⁸ United States. Centers for Disease Control and Prevention. 2002 National STD Surveillance Report. (Sept. 27, 2004): Internet. <http://www.cdc.gov/std/stats02/syphilis.htm>. May 17, 2005.

In an effort to provide a timely and reasonable estimate of the need for family planning services in Arizona, the Arizona Family Planning Council conducts an annual needs assessment. The needs assessment compares the number of low-income women who are potentially in need of family planning services (women 15 through 44 with an income at or below 200 percent federal poverty level who are fertile) to the number of these women reported to receive free or subsidized family planning services through publicly funded resources.⁴⁹ Publicly funded service networks⁵⁰ work collaboratively with Arizona Family Planning Council to provide data for this report.

The most recent Arizona Family Planning Council report⁵¹ found that of the 250,834 women in the target group, 135,139 (54 percent) received no publicly funded family planning services in 2003. The Arizona Family Planning Council report concluded that several factors influence access to family planning services, including demand exceeding resources, nursing shortages, and logistical barriers. The most recent report also found that underutilization of existing resources may be a contributing factor. This finding should be interpreted with caution, as some of the service networks include obstetric providers whose focus is on prenatal care and delivery rather than family planning. Some providers focus on illness rather than prevention, and for them, family planning is not a priority. Finally, family planning services may be under reported in the data.

Another way to measure the need for family planning is to examine rates of pregnancy intention. Unintended pregnancies may be seen as an indication of a need for family planning. In the late 1980s, the Centers for Disease Control and Prevention designed the Pregnancy Risk Assessment Monitoring System (PRAMS) to monitor maternal attitudes and experiences prior to, during, and immediately following pregnancy. Maricopa County Department of Public Health used this system in 1999 and 2000 in their effort to reduce health disparities in South Phoenix.

Among other topics, the PRAMS questionnaire asked mothers who had recently delivered babies if the pregnancy was intended. Results from the survey showed that about half of the South Phoenix mothers who were surveyed said the pregnancy was not intended. Mothers who were not trying to get pregnant and were not using any form of birth control were asked, "What were your or your husband's or partner's reasons for not doing anything to keep from getting pregnant?" While 30 percent of these women indicated that they did not mind

⁴⁹ Networks include AHCCCS, the Arizona Family Planning Council, Arizona Department of Health Services Office of Women's and Children's Health, community health centers, local county governments, and state funded primary care.

⁵⁰ Data from IHS were not available for the Arizona Family Planning Council report. Consequently, American Indian women were removed from estimates of both the target population and when possible, from the service data that calculations are based on.

⁵¹ Arizona Family Planning Council. *Status Report on Family Planning in Arizona*. (2003): Internet. <http://www.azfpc.org/PDFfiles/2003Status%20Report-webpage.pdf> May 17, 2005.

being pregnant, 31 percent thought they could not get pregnant at the time; 22 percent said their husband or partner did not want to use birth control; 11 percent said they had problems getting birth control; and another 11 percent said they had side effects from birth control.⁵²

Family planning is not the only reproductive health need of women. Other unmet needs related to reproductive health include a lack of low cost colposcopy, cryosurgery, and other treatments when low-income, uninsured women have abnormal Pap tests. During the 2003 calendar year, the Office of Women’s and Children’s Health Reproductive Health Program provided 5,278 clients with full reproductive health exams. Family planning clinics are often the only source of preventive health care for low-income women.

PREGNANCY RATES, FERTILITY AND ABORTION

Pregnancy rates are made up of fertility rates (sometimes referred to as birth rates), abortion rates, and fetal death rates. Fertility rates⁵³ in Arizona have been declining for the past decade, although they remain considerably higher than national rates (76.3 births per 1,000 women in Arizona, compared to 66.1 births per 1,000 women nationally). Between 1993 and 2003, pregnancy rates⁵⁴ declined from 92.3 to 85.3 per 1,000 women of childbearing age, representing a decrease of 7.6 percent. The decline occurred in all three components that make up the pregnancy rate: the live birth rate (fertility rate), the abortion rate, and the fetal death rate. (See table 4). However, because of rapid population growth, the actual number of pregnancies in Arizona increased by 25 percent from 81,445 to 101,476 during the same time period.

Table 4. Pregnancies by Outcome: 1993 through 2003											
Total Number	1993	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003
Pregnancies	81,445	83,663	84,261	86,445	87,256	93,148	91,761	95,268	94,142	98,548	101,476
Births	69,037	70,896	72,386	75,094	75,563	77,940	80,505	84,985	85,213	87,379	90,783
Abortions	11,852	12,260	11,738	10,868	11,056	14,606	10,656	9,631	8,226	10,397	10,154
Fetal Deaths	556	507	497	483	637	530	563	532	566	556	539
Rates per 1,000 Women Age 15-44	1993	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003
Pregnancy Rate	92.3	93.4	93.3	89.0	87.9	92.2	87.7	87.8	83.9	85.2	85.3
Fertility Rate	78.3	79.2	79.8	77.3	76.1	77.1	77.0	78.4	75.9	75.5	76.3
Abortion Rate	13.4	13.7	13.0	11.2	11.1	14.5	10.2	8.9	7.3	9.0	8.5

Source: Arizona Health Status and Vital Statistics, 1993-2003 Table 1A

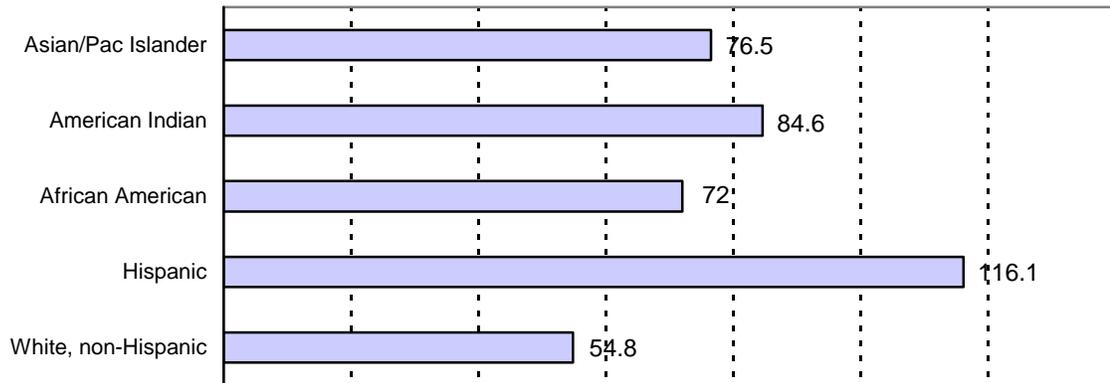
⁵² Maricopa County. Dept. of Public Health. 2001 Maricopa County Maternal and Child Health Needs Assessment. Internet. http://www.maricopa.gov/public_health/epi/pdf/MCH_Section5_South_Phoenix.pdf May 16, 2005.

⁵³ Fertility rate is the number of births for women of all ages per 1,000 women age 15-44.

⁵⁴ Pregnancy rate is the number of pregnancies per 1,000 women of childbearing years

Pregnancy, birth, fetal death and abortion rates vary widely by race, ethnicity and age group. Typically in the United States, women 25 to 29 have the highest birth rates of any age group. However, in Arizona, it is the 20 through 24 year-old age group that consistently has the highest birth rate with rates ranging from 136 to 145 per 1,000 over the last decade. Figure 15 shows that, in Arizona in 2003 the pregnancy rate for Hispanics (127.1 per 1,000) was twice the rate of White, non-Hispanics (61.9 per 1,000). Abortion rates ranged from 5.1 per 1,000 women of childbearing years in the American Indian population to 11.8 for African American women.

Figure 15. Birth rate per 1,000 Women by Race/Ethnicity, 2003

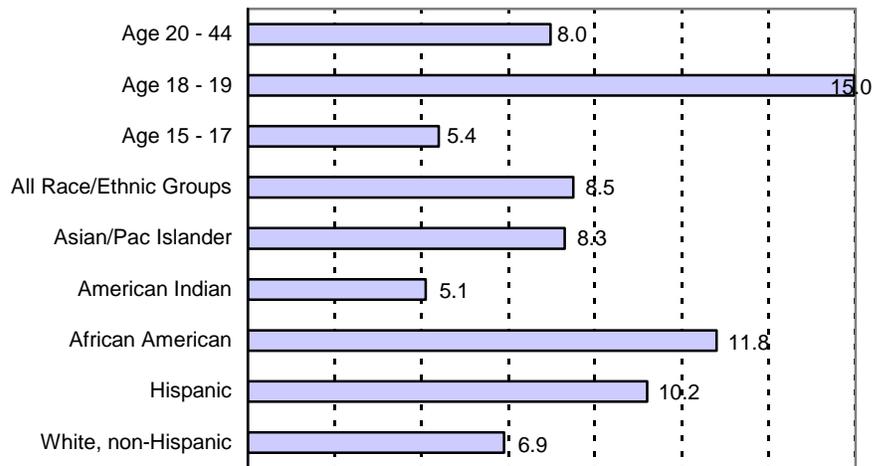


While pregnancy rates have declined over the last decade, national data shows that many pregnancies continue to be either mistimed or unwanted. The 2002 National Survey of Family Growth data shows that age at conception is an important determinant of how wanted a pregnancy is. Three-fourths of women 25 through 44 years of age intended their pregnancy, while less than one-fourth (22 percent) of women under the age of 20 indicated that their pregnancy was intended. For those women under the age of 20, 57 percent said that the pregnancy was mistimed and 22 percent said that it was unwanted.⁵⁵

The abortion rate in Arizona in 2003 was 8.5 per 100,000 women of childbearing age. As shown in figure 16, teenagers age 18 and 19 have higher abortion rates than the statewide average, as do African American and Hispanic women.

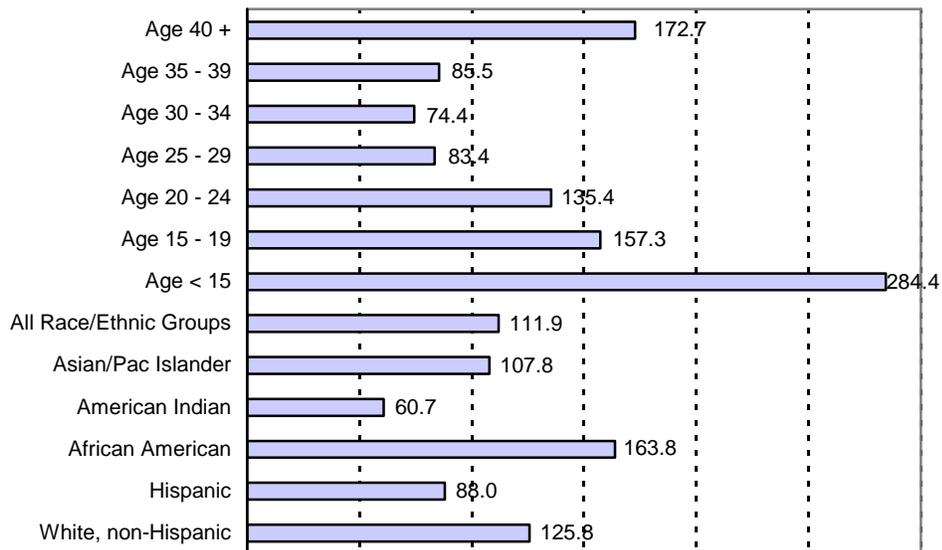
⁵⁵ United States. Dept. of Health and Human Services. Teenagers in the United States: Sexual Activity, Contraceptive Use, and Childbearing, 2002. Dec. 2004: 12.

Figure 16. Abortion Rates by Age and Race/Ethnicity Arizona, 2003



While the abortion rate is based on the number of women of childbearing age, the abortion ratio is the number of abortions per 1,000 women giving birth. Since 1993, the abortion ratio in Arizona has declined by 35 percent from 171.7 abortions per 1,000 women giving birth in 1993 to 111.8 in 2003. Teenage girls, especially those under age 15, women age 40 or older, and African American women are most likely to have pregnancies that end in abortion. Figure 17 shows the abortion ratios by race, ethnicity and age group for 2003.

Figure 17. Number of Abortions per 1,000 Live Births (Abortion Ratio) by Age and Race/Ethnicity Arizona, 2003



In November of 2000, the Food and Drug Administration approved a combination of two medications for non-surgical abortions. The drugs are effective if taken within 63 days after the first day of the last menstrual cycle, and this method is

95-98 percent effective with few complications. In 2003, non-surgical abortions accounted for nearly one in four abortions (24 percent) performed in Arizona. When obtaining an abortion, African American and American Indian women were the least likely to have medical abortions (17 percent and 16.8 percent of abortions, respectively).

In 2003, abortion services were only available in three of the 15 counties in Arizona making it logistically difficult for many women to obtain abortion services. The abortion rate for the state was 8.5 abortions per 1,000 women of childbearing years. The abortion rate varied widely from a high of 10.6 per 1,000 in Pima County (one of the three counties where abortion services are available) to a low of 0.2 per 1,000 women of childbearing years in Mohave County where services are not available.

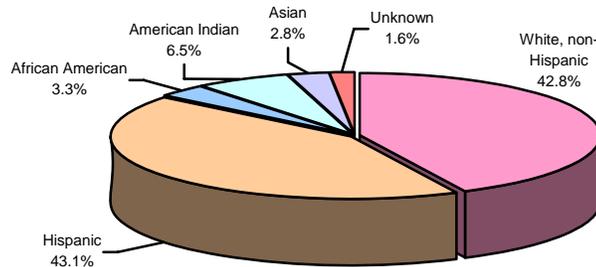
The Perinatal Period

BIRTHS

The number of live births in Arizona continues to increase even though the birth rate per 100,000 women of childbearing years has decreased. In 2003, 90,783 infants were born in Arizona, compared to 69,037 in 1993, representing an increase of 31 percent.

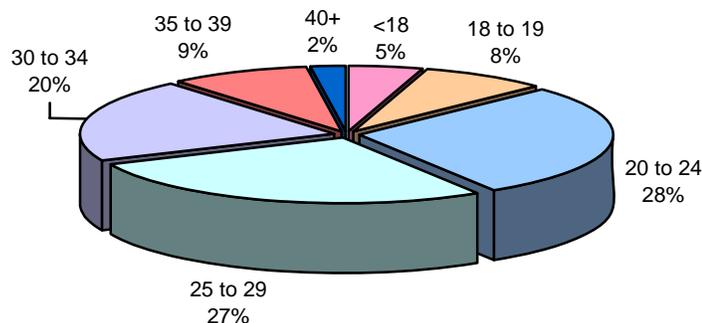
The most striking change in the demographic composition of live births in Arizona over the last decade is in the proportion of infants born to Hispanic and White, non-Hispanic women. In 1993, more than half of the infants born in Arizona were born to White, non-Hispanic women (54 percent versus 32 percent to Hispanics). In 2003, the number of infants born to Hispanic mothers surpassed the number born to White, non-Hispanic women. Figure 17 shows the percent of births in 2003 by race/ethnicity of the mother.

Figure 17. Mother's Race/Ethnicity, Arizona 2003



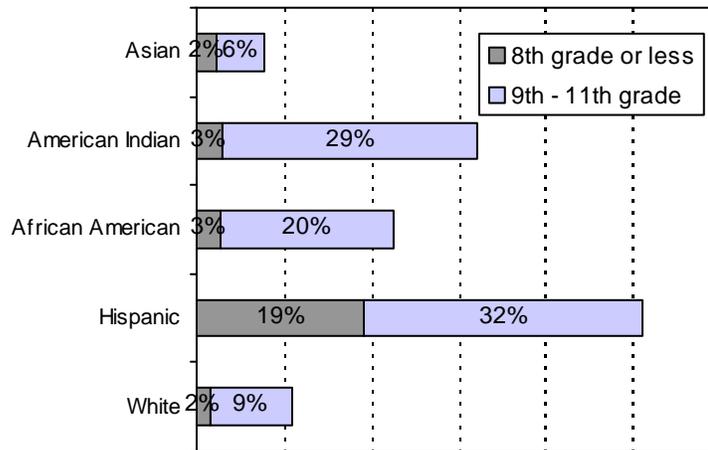
Over the last decade, women in their twenties have consistently given birth to the majority of infants in Arizona. However, the proportion of births to teen mothers and women of advanced maternal age has changed. Teen births decreased from 15 percent of all births in 1993 to 13 percent of births in 2003. Births to women age 35 and older increased from 9 percent of births in 1993 to 12 percent in 2003. In 2003, 28 percent of births were to 20 to 24 year-olds, 27 percent were to 25 to 29 year-olds, and 20 percent were to 30 to 35 year-olds (figure 18).

Figure 18. Mother's Age, Arizona 2003



Thirty-one percent of women giving birth in Arizona in 2003 had less than a high school education, 29 percent had 12 years of education, and 40 percent had at least some college. However, educational attainment level of women giving birth in 2003 varied by race/ethnicity. African American, American Indian and Hispanic women were less likely to have received a high school education before giving birth than White, non-Hispanic and Asian women (see figure 19).

Figure 19. Percent of Women in Arizona Giving Birth in 2003 with Less Than a High School Education



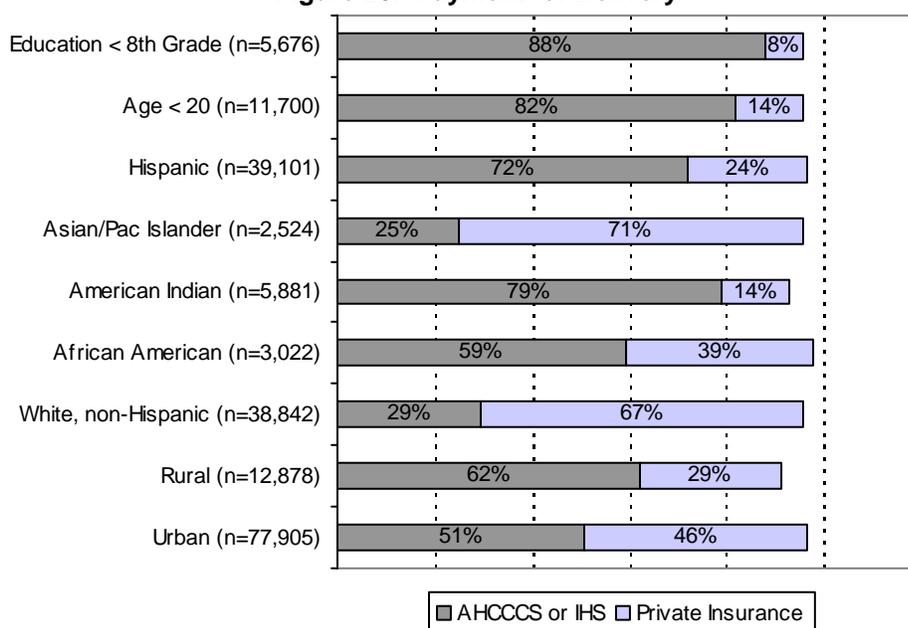
PLACE OF DELIVERY AND ATTENDANT AT BIRTH

Ninety-nine percent of births in Arizona occur in hospitals, clinics, medical centers, or maternity homes. Over the last few years, the percent of births attended by a midwife has dropped from a high of 10 percent in 1997 to 7 percent in 2003. Births attended by midwives have consistently been lower in rural areas of the state (with a high of 4 percent of births in 1993, and a decline to 2 percent of births in 2003). However, 32 percent of births to American Indians were attended by a midwife in 2003. Although this rate is considerably higher than rates for other racial and ethnic groups in the state, the proportion of births attended by midwives has also declined in the American Indian population over the last decade.

PAYING FOR DELIVERY

The share of deliveries paid for by AHCCCS has increased from 42 percent of deliveries in 1998 to approximately half (51 percent) of all deliveries in 2003. Payment for delivery varies by race and ethnicity, location of birth (urban versus rural), education level, and age group. Figure 20 shows that women with less than an eighth grade education, women under the age of 20, and Hispanics were more likely to have births that were paid for through AHCCCS, while White women and Asian/Pacific Islanders were more likely to have private health insurance.

Figure 20. Payment for Delivery



LOW BIRTH WEIGHT AND PRETERM DELIVERIES

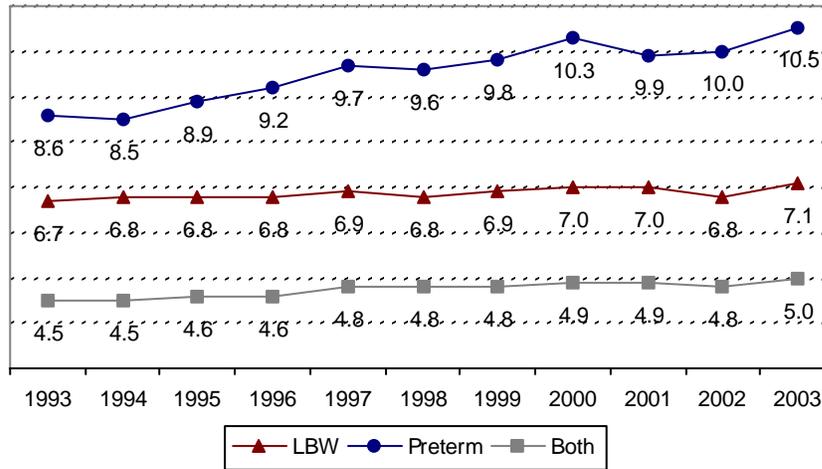
Babies born with a low birth weight are at an increased risk for infant mortality.⁵⁶ Infants born before 37 weeks gestation are considered to be preterm, and are at a higher risk to be born with a low birth weight.

In Arizona in 2003, 7 percent of births were below 2,500 grams (approximately 5 pounds, 8 ounces), and were considered to have low birth weight, and 10.5 percent were born preterm. Rates of low birth weight and preterm deliveries have been gradually increasing in Arizona and in the nation.⁵⁷ Figure 21 shows the rate of low birth weight, preterm deliveries, and the rate of babies who were born preterm and with low birth weight from 1993 through 2003 in Arizona.

⁵⁶ McCormic, M.C. "The Contribution of Low Birthweight to Infant Mortality." *The New England Journal of Medicine*. 312.2 (Jan. 10, 1985): 82-90.

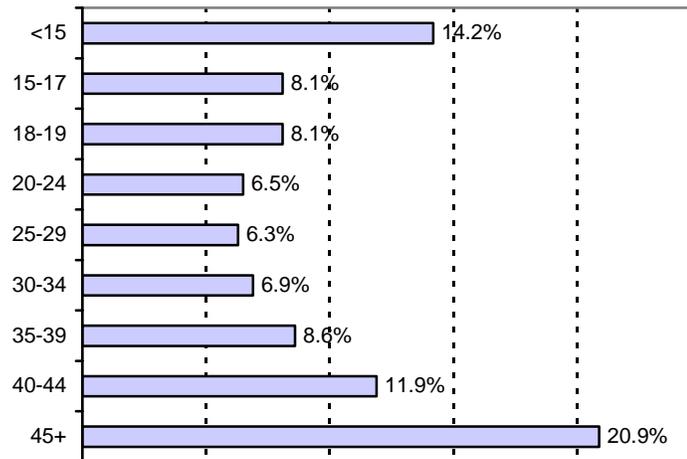
⁵⁷ Hamilton, Brady. "Births: Preliminary Data." *National Vital Statistics Reports*. 53.9 (Nov. 23, 2004): Internet. http://www.cdc.gov/nchs/data/nvsr/nvsr53/nvsr53_09.pdf June 13, 2005.

Figure 21. Low Birth Weight and Preterm Births per 100 Live Births



African Americans had a low birth weight rate of 11.7 percent, 65 percent higher than the statewide rate of 7.1 percent. Asian infants were also more likely to have low birth weights, with 8.5 percent weighing less than 2,500 grams. The likelihood of delivering a low birth weight baby increases for women younger than age 20 and older than age 34, as shown in figure 22. Women age 45 and older had nearly three times the risk, and girls under age 15 had twice the risk of women generally of delivering a low birth weight baby.

Figure 22. Percent of Low Birth Weight Within Age Groups, 2003



Women who had no prenatal care before delivering were at a higher risk for delivering low birth weight babies (12.6 percent). Only 6.6 percent of women with private insurance and 5.3 percent of women whose deliveries were paid for by Indian Health Services had low birth weight babies, while 7.4 percent of women whose deliveries were paid for by AHCCCS, as well as 7.4 percent of women who paid for their own deliveries had low birth weight babies.

MULTIPLE BIRTHS

Nationally and in Arizona, the number and proportion of babies born in multiple deliveries has increased dramatically over the last two decades. In 2003, there were a record 2,581 multiple birth events in Arizona, and 2,400 of these were twins. The remaining 181 were triplets and quadruplets. The rise in the number of twin deliveries represents a 67 percent increase from 1993 to 2003, while the rise in triplet or higher births represents an increase of 162 percent over the same time period.

The rise in multiple births has been associated with two related trends: advances in, and greater access to, assisted reproductive technology; and the older age of childbearing (women in their thirties and beyond are more likely to have a multiple birth even without the use of fertility therapies). While only 1.3 percent of infants born to mothers under the age of 20 were multiples, one in four of those born to mothers 45 years of age and older were twins, triplets, or quadruplets.

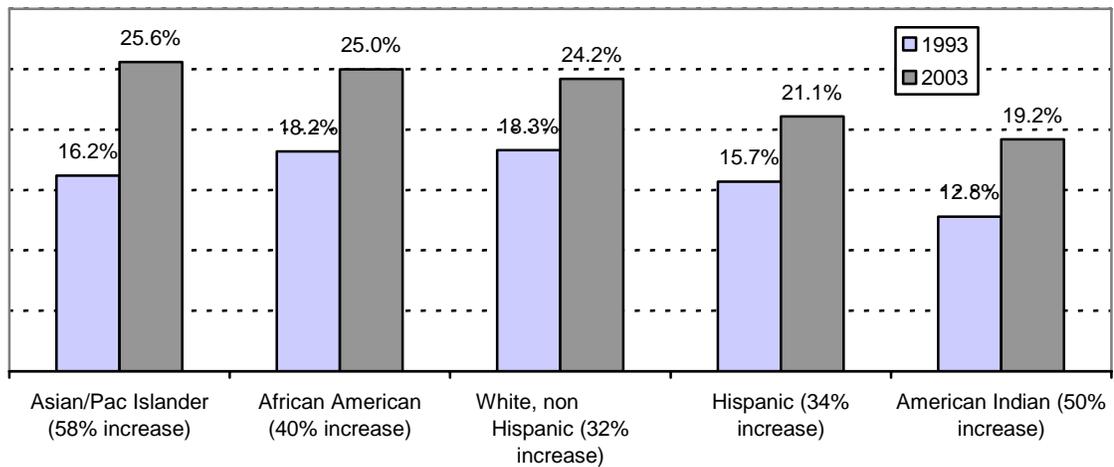
Infants born in multiple deliveries tend to be born at short gestations and are smaller than those born in singleton deliveries. Of singleton births in Arizona in 2003, 9 percent were born preterm (less than 37 weeks gestation) compared to 65 percent of multiples. Approximately six percent of singleton infants weighed less than 2,500 grams (considered low birth weight) compared to more than half (58 percent) of multiples.

C-SECTIONS

During the period of 1989 through 1996, cesarean section (c-section) rates declined nationally and in Arizona. However, the c-section rate has been rising since 1996 and hit an all time high in 2003, with 27.6 percent of all births being delivered by c-section nationally and 22.6 percent in Arizona. In analyzing c-section rates, two statistics are often presented: the primary cesarean rate (percent of cesareans sections among women with no previous cesarean delivery), and repeat c-section rates. The distinction is important because once a woman has had a primary c-section, her chances of having a subsequent pregnancy delivered by c-section are greatly increased.

In 2003, the primary c-section rate in Arizona was 16 percent, while the national rate was 19 percent. Since 1993, the combination of primary and repeat c-section rates in Arizona increased by 33 percent from 17 percent to 22 percent. While most c-sections that are performed are done due to medical necessity, over the last decade there has been an increasing trend to perform c-sections for non-medical reasons. Twenty-six percent of women with health insurance had a c-section compared to 16 percent of those who paid for their own deliveries. Figure 23 shows the proportion of Arizona births that were either primary or repeat c-section deliveries in 1993 and 2003 by race and ethnicity.

**Figure 23. Percent of Pregnancies Delivered by C-Section
Arizona 1993 and 2003**



MATERNAL DEATHS

Maternal deaths, as reported in Vital Statistics, do not include all deaths occurring to pregnant women, but only those deaths assigned to causes related to, or aggravated by, pregnancy or pregnancy management. From 1993 through 2003, a total of 51 maternal deaths were reported in Arizona, or less than 5 per year on average (a range from zero to eight). Complications of pregnancy and complications following childbirth each accounted for 16 maternal deaths during this period. Complications of delivery accounted for seven deaths, ectopic pregnancy caused three deaths, and nine deaths were caused by other factors.

STILLBIRTHS

Stillbirths are defined as unintended fetal deaths that occur after the twentieth week of pregnancy. In 2003 in Arizona, 539 infants were stillborn, representing a rate of 5.9 per 1,000 pregnancies. The stillbirth rate has remained relatively stable over the last few years, and does not substantially differ from the national rate. During the last decade of the twentieth century, the US fetal death rate declined from 7.5 in 1990 to 6.6 per 1,000 in 2000.⁵⁸

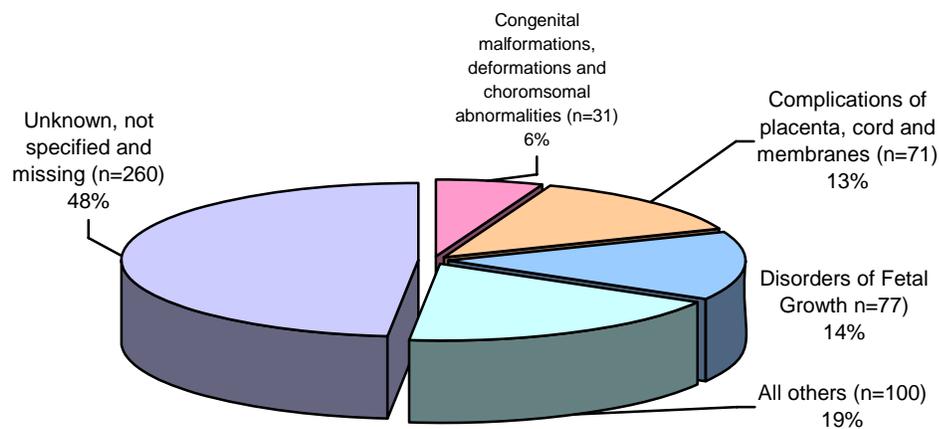
Stillbirth rates in Arizona in 2003 varied by racial and ethnic group, maternal age, and educational attainment level. African American women and older women had more than twice the rate of stillbirths than other women in Arizona (13.4 and 12.0 stillbirths per 1,000 pregnancies, respectively). Other groups with higher

⁵⁸ United States. Centers for Disease Control and Prevention. *Morbidity and Mortality Weekly Report*. (June 25, 2004): Internet. <http://www.cdc.gov/mmwr/pdf/wk/mm5324.pdf> June 13, 2005.

rates of stillbirths than the statewide rate of 5.9 per 1,000 pregnancies included women under age 20 (7.6), American Indians (6.9) women with 12 or fewer years of education (6.6) and Hispanics (6.3).

In 2003, the cause of death was listed on the death certificate as either unknown, not specified, or missing for nearly half of reported stillbirths (48 percent). Disorders of fetal growth was listed as the cause on 14 percent of fetal death certificates, complications of the placenta, cord and membranes on 13 percent, and congenital malformations, and deformations and chromosomal abnormalities on 6 percent. Figure 24 shows the causes of stillborn deaths in Arizona in 2003.

Figure 24. Causes of Stillborn Deaths, Arizona 2003

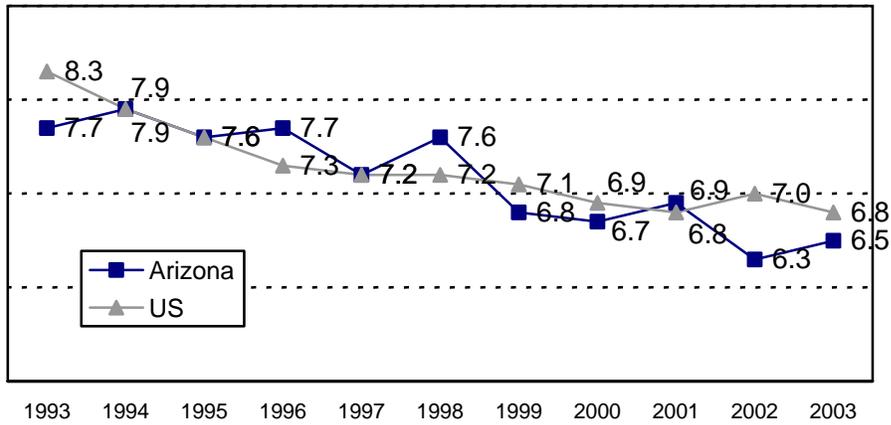


INFANT MORTALITY

The infant mortality rate is the number of deaths within the first 365 days of life per 1,000 live births. In 2003, 586 infants died in Arizona before reaching their first birthday, with 388 deaths occurring during the neonatal period (birth through the 27th day of life) and 198 dying during the postneonatal period (from the 28th day of life through the first year). The overall infant mortality rate was 6.5 infant deaths per 1,000 live births, the second lowest recorded infant mortality rate since 1950. The lowest infant mortality rate for Arizona was in 2002, with 6.3 deaths per 1,000 live births. Figure 25 shows that Arizona's infant death rate does not differ substantially from the national rate. However, it should be noted that the United States, with a rate of 6.5 deaths per 1,000 live births, ranks number 42nd in terms of infant mortality internationally, far behind countries such as Singapore (2.29), Sweden (2.77), Hong Kong (2.97), and Japan (3.26).⁵⁹

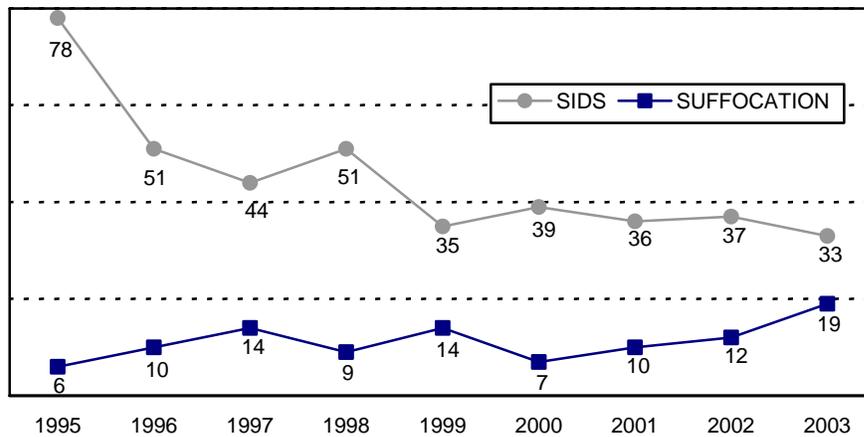
⁵⁹ United States. Central Intelligence Agency. The World Factbook. (June 2, 2005): Internet. www.cia.gov/cia/publications/factbook/rankorder/2091rank.html June 13, 2005.

Figure 25. Infant Deaths per 1,000 live births Arizona 2003



In 2003, 33 children died of SIDS and 19 died of suffocation. The number of deaths due to SIDS in Arizona continues to decrease whereas the deaths due to suffocation have been increasing (see figure 26). One reason for the decrease in SIDS deaths may be the American Academy of Pediatrics “Back to Sleep” Campaign, which encourages parents to put their infants to sleep on their back rather than on their stomach. Part of the increase may also be due to increased identification of deaths due to suffocation that may have previously been attributed to SIDS.

Figure 26. SIDS and Suffocation Deaths in Infants: 1995-2003



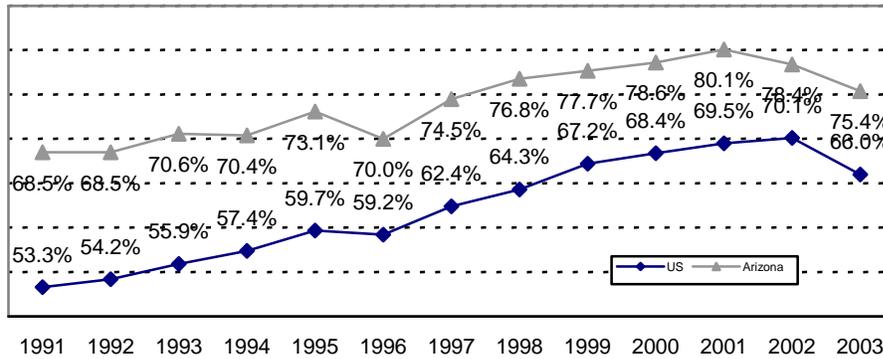
BREASTFEEDING

Children who are breastfed have a 20 percent lower risk of dying during the postneonatal period than children who were not breastfed, and longer breastfeeding has been associated with lower risk. Breastfed babies have lower rates of morbidity, especially from infectious disease.⁶⁰

⁶⁰ Chen, Aimin and Walter Rogan. “Breastfeeding and the Risk of Postneonatal Death in the United States.” *Pediatrics*. 113.5 (May 2004): 435-439.

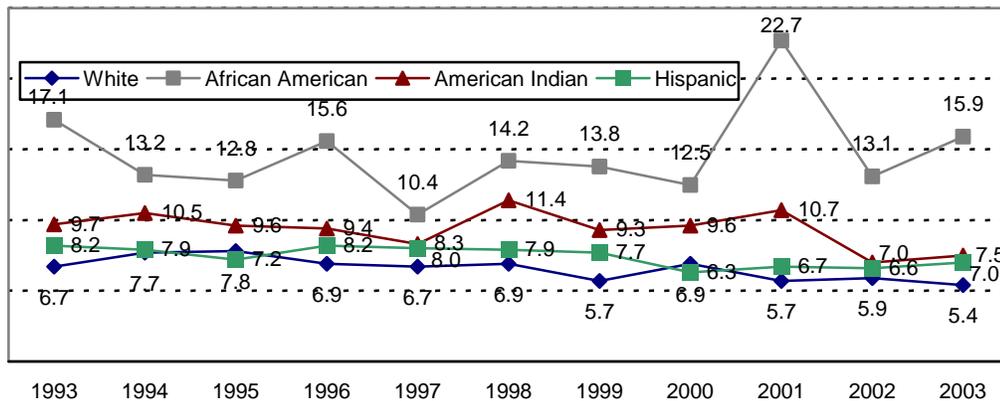
The percent of mothers breastfeeding at hospital discharge climbed steadily in Arizona and nationally during the 1990s, but has been declining in Arizona since reaching a high of 80.1 percent in 2001 (ten points higher than the highest national rate of 70.1 percent in 2002). Breastfeeding appears to be declining in the most recent years, and was back down to its 1997 rate of 75.4 percent in 2003 (see figure 27). Only 34.8 percent continued to breastfeed at six months among all Arizona women, and only 19.5 percent of WIC participants continued to breastfeed at six months.⁶¹

Figure 27. Percent of Mothers Who Breastfeed Their Infants at Hospital Discharge



Although infant mortality in Arizona has declined, disparities remain in the rates of death among various subgroups of the population. African American, American Indian, and Hispanic infants die at higher rates than White infants, as do infants born to less educated women and teens. In 2003, African American infants were approximately three times more likely to die within their first year of life than non-Hispanic White infants. (See figure 28.)

Figure 28. Infant Mortality per 1,000 Live Births by Race and Ethnicity in Arizona



⁶¹ Ross Laboratories. Mothers Survey, Ross Products Division of Abbott.

PERINATAL PERIODS OF RISK

Perinatal Periods of Risk is an analytic technique developed by the CDC that is used to strategically target interventions based on which phase of the perinatal period accounts for the most excess deaths. The model recognizes that not all mortality is preventable. Death rates in a reference group known to have relatively good birth outcomes are calculated and compared to target subpopulations in order to identify excessive death rates.

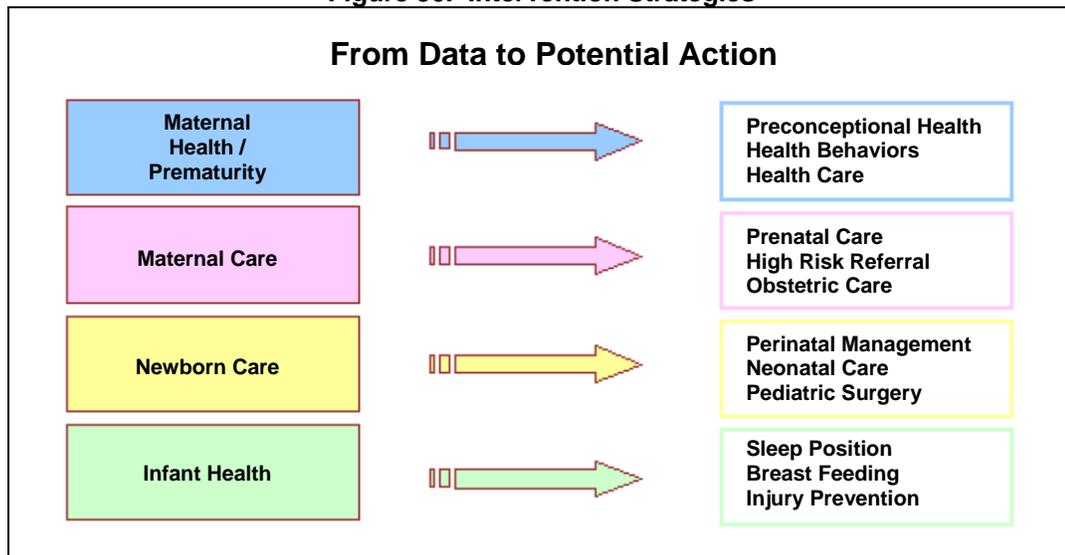
The Periods of Risk analysis begins with a categorization of fetal and infant deaths into one of four periods by weight and age at death as shown in figure 29. All births and fetal deaths weighing between 500 and 1,499 grams are classified as maternal health/prematurity, regardless of age at death. Fetuses weighing more than 1,499 grams are classified as relating to maternal care. Deaths occurring to infants weighing more than 1,499 grams and dying before the twenty-eighth day of life are classified in the newborn care period, and infant weighing more than 1,499 grams and dying between 28 and 365 days are classified as infant health deaths.

Figure 29. Map of Feto-Infant Mortality

	Fetal	Neonatal (Death at <28 Days)	Post-Neonatal (Death at 28 – 365 Days)
500-1,499 grams	Maternal Health / Prematurity		
1,500+ grams	Maternal Care	Newborn Care	Infant Health

Each of these periods is associated with different risk factors, and suggests different strategies for intervention, as shown in figure 30.

Figure 30. Intervention Strategies



MATERNAL HEALTH PERIOD

Deaths attributed to the maternal health period are associated with the general state of the mother's health, maternal nutrition, anemia, infections before and during pregnancy, stress, previous pregnancy outcomes, pre-pregnancy conditions (e.g., diabetes) and tobacco and alcohol use.

MATERNAL CARE PERIOD

Deaths in the maternal care period are associated with preconception care, prenatal care, nutrition during pregnancy, infections during pregnancy, recognition and management of early labor, care in a hospital providing an appropriate level of perinatal care, monitoring during labor and obstetrical expertise.

NEWBORN CARE PERIOD

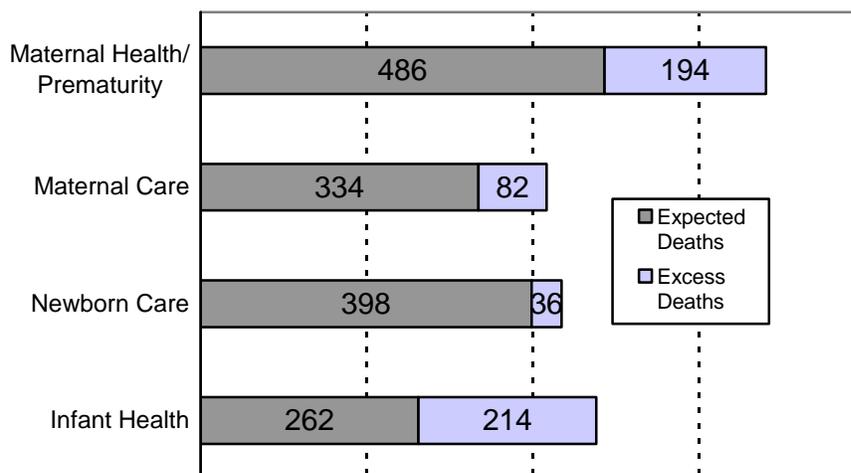
Deaths in the newborn care period are associated with quality and appropriateness of the level of hospital care, including neonatal intensive care, obstetrical and pediatric expertise, feeding, prevention of infections, and the recognition of emergencies.

INFANT HEALTH

Factors influencing deaths attributed to the infant health period are associated with preventing and diagnosing infection and injury, recognition of birth defects and developmental abnormalities, prevention of sudden infant death syndrome, and breastfeeding. Using this model, information on 2,006 stillbirths and infants delivered in Arizona during the years 2000 through 2002 were combined for analysis. Excess death rates were calculated statewide and for targeted subgroups of the population by comparing the mortality rate within each period for the target to an Arizona reference group of White, non-Hispanic women age 20 or older with 13 or more years of education.

Twenty-six percent of the overall fetal and infant deaths from 2000 through 2002 were preventable. Figure 31 shows the number of expected and excess deaths associated with each period of risk across the state. While the highest number of deaths was associated with the maternal health/prematurity period of risk, the infant health period accounted for the highest number of preventable deaths. Of the 476 deaths attributed to the infant health period, 214 (or 45 percent) were preventable. Of the 680 deaths attributed to the maternal health/prematurity period, 194 (or 29 percent) were preventable. Eighty-two excess deaths occurred in the maternal care category, representing 20 percent of deaths in that category, and 36 excess deaths were attributed to the newborn care category, representing 8 percent of newborn care deaths.

Figure 31. Expected and Excess Deaths by Periods of Risk, Arizona 2000-2002



African Americans and American Indians have higher overall excess death rates than Whites and Hispanics. Women who were younger than 20 and women who were older than 35 also delivered babies with higher mortality rates, as did women with 12 or fewer years of education. (See figure 32.) Table 5 on the following page shows the number of deaths for specific subgroups of the population and shows the number expected and excess.

Figure 32. Excess Deaths as a Percent of Overall Infant Mortality Arizona 2000-2002

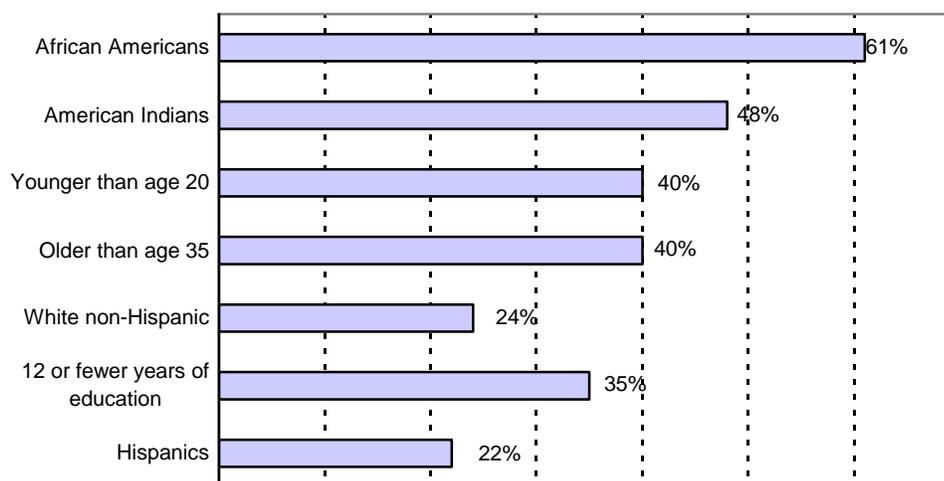


Table 5. Perinatal Periods of Risk Findings for Select Subgroups				
	Total	Expected	Excess	Excess as
	Deaths			% of Total
Statewide	2006	1480	526	26%
Maternal Health/Prematurity	680	486	194	29%
Maternal Care	416	334	82	20%
Newborn Care	434	398	36	8%
Infant Health	476	262	214	45%
Hispanics	785	609	176	22%
Maternal Health/Prematurity	272	204	68	25%
Maternal Care	166	141	25	15%
Newborn Care	184	153	31	17%
Infant Health	163	111	52	32%
African Americans	117	46	71	61%
Maternal Health/Prematurity	42	15	27	64%
Maternal Care	20	11	9	45%
Newborn Care	22	12	10	45%
Infant Health	33	8	25	76%
American Indians	180	94	86	48%
Maternal Health/Prematurity	53	31	22	42%
Maternal Care	36	22	14	39%
Newborn Care	25	24	1	4%
Infant Health	66	17	49	74%
Whites	1642	1245	397	24%
Maternal Health	564	417	147	26%
Maternal Care	345	289	56	16%
Newborn Care	373	313	60	16%
Infant Health	360	226	134	37%
12 years of less of education	1308	847	461	35%
Maternal Health/Prematurity	448	284	164	37%
Maternal Care	264	196	68	26%
Newborn Care	248	213	35	14%
Infant Health	348	154	194	56%
Younger than age 20	270	160	110	41%
Maternal Health	97	54	43	44%
Maternal Care	52	37	15	29%
Newborn Care	52	40	12	23%
Infant Health	69	29	40	58%
Older than age 35	241	143	98	41%
Maternal Health/Prematurity	93	48	45	48%
Maternal Care	65	33	32	49%
Newborn Care	51	36	15	29%
Infant Health	32	26	6	19%

There were 117 deaths among infants born to African American women, and 61 percent of them were potentially preventable, with excess deaths spread among all four periods of risk. The highest number of preventable deaths were attributable to the maternal health/prematurity period (n=27), representing 64 percent of the deaths in this period. The infant health period accounted for another 25 excess deaths, or 76 percent of the deaths during the infant health period. The maternal care period accounted for nine excess deaths, and the newborn care period for another ten deaths, each representing 45 percent of the deaths in those periods of risk.

There were 180 deaths among infants born to American Indian women, with 48 percent of them potentially preventable. Forty-nine excess deaths were attributable to the infant health period, representing 74 percent of the deaths in that period. Another 22 excess deaths were categorized to the maternal health/prematurity period, and 14 excess deaths were attributed to maternal care, representing 42 percent and 39 percent of the deaths in these periods, respectively. Only one of the 25 deaths in the newborn care period was determined to be excess.

Infants born to Hispanic women had a lower excess mortality rate than the statewide rate. Among Hispanics, there were 785 infant deaths, only 22 percent of which were potentially preventable. The maternal health/prematurity period of risk accounted for the most excess deaths in terms of numbers, with 68 of the deaths associated with this period determined to be excess, representing 25 percent of maternal health/prematurity deaths. A smaller number, but a higher percentage of deaths, were determined to be excess within the infant health period, with 52 or 32 percent determined to be potentially preventable. Finally, 31 of the newborn care deaths were determined to be excess, representing 17 percent of newborn care deaths.

Infants born to White women had a lower excess mortality rate than the statewide rate, with 24 percent of deaths overall identified as excess. The highest number of excess deaths were the 147 deaths attributed to the maternal health period, representing 26 percent of deaths. The highest percentage of excess deaths were the 134 deaths, attributed to the infant health period of risk, representing 37 percent of deaths. There were 56 excess maternal care deaths and 60 newborn care deaths, each representing 16 percent of the deaths attributed to those periods of risk.

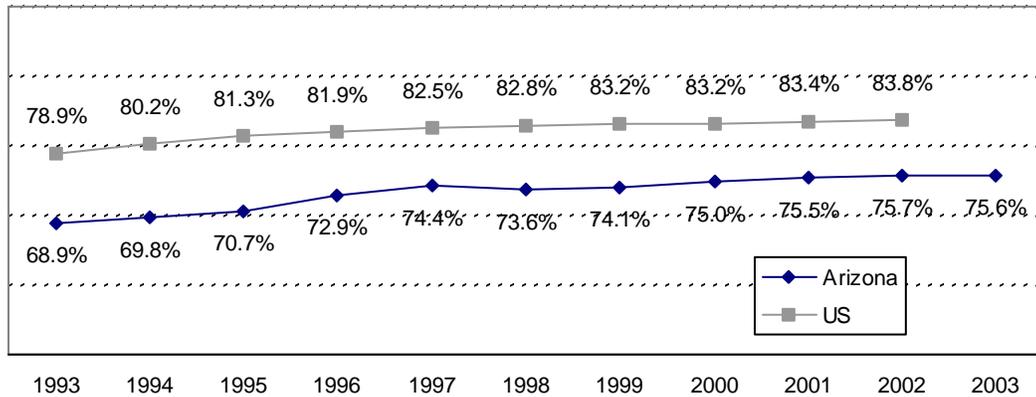
Among women with 12 years of education or less, there were 1,308 infant deaths, 35 percent of which were potentially preventable. The greatest number of deaths in terms of numbers and percentages were attributed to the infant health period, with 194 (or 56 percent) of the deaths being potentially preventable. Another 164 excess deaths were attributed to maternal health/prematurity, accounting for 37 percent of the deaths in the maternal health/prematurity period. Maternal care accounted for 68, or 26 percent of the deaths in the maternal care period, and 35 of the deaths attributed to newborn care, or 14 percent, were determined to be excess.

PRENATAL CARE

Prenatal care is an opportunity to identify risks and mitigate their impact on pregnancy outcomes through medical management. Prenatal visits also offer an opportunity for education and counseling on proper nutrition and risk factors, such as smoking and alcohol use during pregnancy. Prenatal care is more effective when women enter care early in their pregnancy.⁶²

There has been a steady upward trend in the proportion of women receiving prenatal care in their first trimester of pregnancy in Arizona and nationally, although Arizona continues to lag behind the rest of the nation (see figure 33). In 2003, 76 percent of women received prenatal care in Arizona compared to 84 percent nationally.

Figure 33. Percent of Women Receiving First Trimester Prenatal Care Arizona and United States 1993-2003

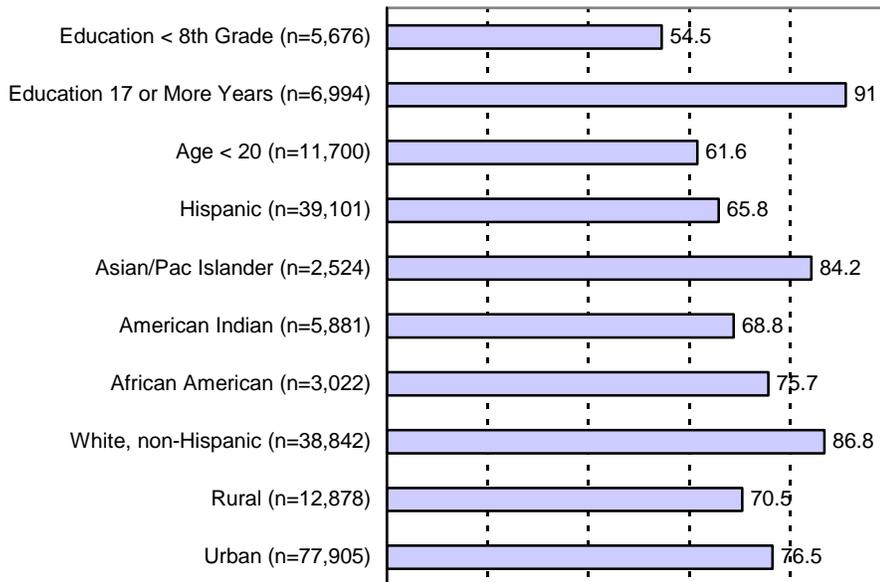


Healthy People 2010 set a goal for 90 percent of women to enter prenatal care in their first trimester. At least one group of women in Arizona has reached this goal. Ninety percent of women with private health insurance received prenatal care in their first trimester in 2003. The proportion of women who enter prenatal care early in their pregnancies varies according to race, ethnicity, education, and source of payment for delivery. Only 60 to 65 percent of women with pay sources other than private insurance (e.g., self-pay, AHCCCS, Indian Health Services) received early prenatal care.

Figure 34 shows the percentage of women receiving prenatal care during their first trimester by selected characteristics of the mother. White, non-Hispanic women and Asian women were more likely to receive early prenatal care than other racial or ethnic groups. The likelihood of receiving early prenatal care also increases with higher levels of education. Only 55 percent of women with less than an eighth grade education received prenatal care, compared to 91 percent of those with 17 or more years of education.

⁶² United States. Healthy People 2010. *Maternal, Infant, and Child Health*. http://www.healthypeople.gov/document/html/volume2/16mich.htm#_Toc494699663 May 18, 2005.

Figure 34. Percent of Women Receiving Early Prenatal Care (1st Trimester) 2003



Prenatal care also varies geographically. Only two counties in 2003 had more than 76 percent of births delivered by women who entered prenatal care early in their pregnancies. Only 56 percent of women in La Paz County received prenatal care in the first trimester, followed by 61 percent in Apache, 62 percent in Gila and Yuma, 66 percent in Santa Cruz, 68 percent in Mohave, Navajo and Greenlee, and 70 percent in Cochise.

Among all births in Arizona in 2003, 3 percent were born to women who received no prenatal care at all. Some subgroups of the population were particularly at risk for receiving no prenatal care. Fourteen percent of women who paid for their own deliveries, 5 percent of teens under the age of 18, and 7 percent of women with less than 9 years of education gave birth after not receiving any prenatal care.

Health Start is an outreach program designed to get high-risk women into prenatal care early. There are 15 sites around the state that use lay health workers to identify women early in their pregnancy and facilitate their entry into prenatal care. Participants must have an identified risk factor in order to enroll. Of the women enrolled in Health Start in 2004, 66 percent were Hispanic, 19 percent were White, non-Hispanic, 8 percent were American Indian, 5 percent identified their race as other, and African Americans and Asians each account for 1 percent of Health Start enrollees.

Forty-five percent of pregnant women enrolled in Health Start during 2004 had no access to regular medical care, and 36 percent were either under age 19 or older than 35. Thirty-eight percent of Health Start participants had a medical risk factor such as anemia, high blood pressure, heart problems, diabetes or

gestational diabetes, HIV, STD, Sickle Cell Disease, kidney disease, vaginal bleeding, or were pregnant with a multiple pregnancy. Twenty-six percent had previously experienced problems with pregnancies, including preterm or low birth weight deliveries, miscarriages, or other complications. Fifteen percent of enrollees disclosed using tobacco, alcohol and other substances, and 5 percent of enrollees disclosed that they had experienced domestic violence.

ORAL HEALTH

Pregnant women with advanced periodontal disease may be more likely to deliver pre-term, low birth weight babies.^{63,64} After birth, the bacteria that cause dental cavities (recognized as a transmissible, infectious disease) may be passed from mother to child.^{65,66,67}

A phone survey was conducted by the Arizona Department of Health Services Office of Oral Health with 400 women with an infant or toddler under three years old. Ninety percent of survey respondents thought that oral health and baby teeth were either important or very important, but only 25 percent said the child's first dental visit should come before one and a half years of age. Fifty-two percent of respondents said they had never taken their infant or toddler to the dentist. The survey asked a series of questions related to knowledge and behaviors about transmission of cavity-causing bacteria. Twenty-four percent said they had cleaned a pacifier by licking it, and more than 75 percent had shared eating utensils. Fifty-four percent of respondents said that they would be very likely to change their behavior if they knew about bacterial transmission.

MATERNAL WEIGHT GAIN

Maternal weight before pregnancy and weight gain during pregnancy are important determinants of infant birth weight.⁶⁸ Interpreting appropriate weight gain from birth certificate data is difficult as guidelines call for different levels of weight gain depending on the women's pre-pregnancy body mass index (BMI), based on her height and weight, which is not collected on the birth certificate.

⁶³ Jeffcoat, M.K. et al. "Current Evidence Regarding Periodontal Disease as a Risk Factor in Preterm Birth." *Annals of Periodontology* Dec. 2001:183-8.

⁶⁴ Offenbacher S, et al. "Periodontal infection as a possible risk factor for preterm low birth weight." *Journal of Periodontology* Oct. 1996: 1103-13.

⁶⁵ Slavkin HC. Streptococcus mutans, early childhood caries and new opportunities. *Journal of the American Dental Association* Dec. 1999: 1787-91.

⁶⁶ Jeffcoat, M.K., loc. cit.

⁶⁷ Offenbacher S., loc. cit.

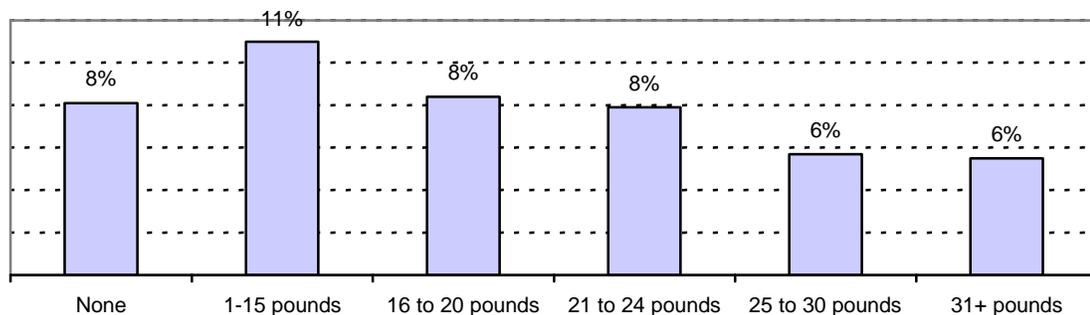
⁶⁸ Canada. Health Products and Food Branch. *Nutrition for a Healthy Pregnancy - National Guidelines for the Childbearing Years*. (Oct. 24, 2004): Internet. http://www.hc-sc.gc.ca/hpfb-dgpsa/onpp-bppn/national_guidelines_06b_e.html May 18, 2005

While birth certificate records do not have a field for the mother's pre-pregnancy BMI, they do contain information on the amount of weight the mother reports gaining during her pregnancy. For women who are neither overweight nor underweight, the Institute of Medicine recommends a weight gain of 25 to 35 pounds (35 to 45 for twins).

Overall, 60 percent of women who gave birth in Arizona in 2003 gained at least 25 pounds. White and Asian women were more likely to gain at least 25 pounds (68 percent and 64 percent respectively). Just over half of African American, Hispanic and American Indian women gained at least 25 pounds.

Figure 35 shows that women who gained at least 25 pounds were less likely to deliver low birth weight babies. The proportion of low birth weight births was twice as high (11 percent) among women who gained 1 to 15 pounds compared women who gained at least 31 pounds (6 percent).

Figure 35. Percent of Women Delivering Low Birth Weight Infants by Maternal Weight Gain Arizona, 2003



SUBSTANCE USE DURING PREGNANCY

Community members identified substance abuse during pregnancy as a threat to the health and well being of women and children. Tobacco, alcohol, and other drug use are well documented to have negative impacts on pregnancy outcomes.

Birth certificate data indicate that there has been a sharp decline in the proportion of women who report smoking cigarettes and the proportion of women who report drinking alcohol during pregnancy. Data on smoking during pregnancy first became available in 1989. At that time, 15.2 percent of women reported smoking during pregnancy. In 1998, only 7.5 percent of women reported smoking during pregnancy, and in 2003, 5.8 percent reported tobacco use. It is unclear whether the reduction in reported tobacco use means that women giving birth in Arizona are using tobacco less than previously, or if they are less likely to report it.

Reported tobacco use varied widely by county of residence in 2003. None of the 1,222 women residing in Graham, Greenlee and Santa Cruz Counties who gave birth in 2003 reported smoking cigarettes during pregnancy compared to 17 percent of Gila County residents, 15 percent of Yavapai County residents, and 15 percent of Mohave County residents. Reported tobacco use also varied by race and ethnicity, though not to the extent that it did by county of residence. Ten percent of White women, 9 percent of African American women, 3 percent of Asian, and 2 percent of American Indian women, and two percent of Hispanic women reported smoking during pregnancy.

In 2003, just under 1 percent of live births were to mothers who reported alcohol use. The most notable effect of heavy maternal drinking during pregnancy is fetal alcohol syndrome, which is caused by drinking alcohol during pregnancy. Fetal alcohol syndrome is characterized by abnormal facial features, growth retardation, and central nervous system problems. Children with the condition may have physical disabilities and problems with learning, memory, attention, problem solving, and social and behavioral problems.⁶⁹ Although there is a field in the Arizona Birth Certificate database to report fetal alcohol syndrome, there were no cases reported in 2003.

POST PARTUM DEPRESSION

Many women experience baby blues, marked by feelings of being sad, afraid, angry, or anxious. Women may cry for no clear reason; have trouble sleeping, eating and making choices; and question whether they can handle taking care of the baby. For most women, these feelings tend to go away after a few days with or without treatment.⁷⁰

Postpartum depression lasts longer and is more intense than the baby blues that most women experience. Women with postpartum depression have trouble coping with their daily tasks and often require treatment, without which, depression may become worse or last longer.⁷¹ The majority of new mothers with postpartum depression suffer with this illness for more than six months.⁷² Postpartum depression negatively impacts the cognitive and emotional development of children up to age five. Children of depressed mothers see their primary care physicians more often and have higher rates of prescription medications and hospitalizations than children of non-depressed mothers.

⁶⁹ United States. Centers for Disease Control and Prevention. Fetal Alcohol Syndrome. (Sept. 23, 2004): Internet. <http://www.cdc.gov/ncbddd/fas> May 17, 2005.

⁷⁰ The American College of Obstetricians and Gynecologists. ACOG Education Pamphlet AP091—Postpartum Depression. http://www.acog.org/from_home/wellness/PEP091.cfm 5/30/2005.

⁷¹ *Ibid.*

⁷² Blue Cross Blue Shield of Texas. Postpartum Depression and House Bill 341. (2005): Internet. <http://www.bcbstx.com/provider/postpartum.htm>, June 1, 2005.

Serious consequences can occur as a result of postpartum depression, including, in the worst cases, suicide, infanticide, and non-accidental injury to the child.⁷³ Postpartum depression can be present with or without psychotic features. Postpartum psychosis affects about 1 out of 1,000 women who have given birth, and there is a seven-fold increase in the risk of psychiatric hospitalization for women following childbirth.⁷⁴

The American College of Obstetricians and Gynecologists estimates that 10 percent of women experience postpartum depression.⁷⁵ As part of the 2000 Pregnancy Risk Assessment Monitoring System (PRAMS), women in seven states were asked if they were depressed in the months following their pregnancy. Seven percent reported severe depression after delivery and more than half reported low to moderate depression.⁷⁶ Arizona does not participate in PRAMS, but 17 percent of participants in the Health Start Program women who enrolled postpartum during 2004 had postpartum depression. The Academy of Pediatrics and the American College of Obstetricians and Gynecologists recommend that pregnant women be educated about postpartum depression during the third trimester and that obstetricians consult with their patients about their risk for psychiatric illness during the postpartum period. Despite this recommendation, postpartum depression is often undiagnosed and untreated.⁷⁷

⁷³ Blue Cross Blue Shield, *loc. cit.*

⁷⁴ Blue Cross Blue Shield, *loc. cit.*

⁷⁵ The American College of Obstetricians and Gynecologists, *loc. cit.*

⁷⁶ United States. Centers for Disease Control and Prevention. Pregnancy Risk Assessment Monitoring System (PRAMS): PRAMS and Postpartum Depression. (May 6, 2004): Internet. http://www.cdc.gov/reproductivehealth/prams/pramsFS_PD.htm 5/21/2005

⁷⁷ Blue Cross Blue Shield, *loc. cit.*

CHILDREN AND ADOLESCENTS

GENERAL HEALTH

According to the National Survey of Children's Health, 81 percent of caregivers in Arizona perceive their children's health to be either excellent (59 percent) or very good (22 percent). Another 16 percent said their children's health was good, and 3 percent said it was fair. A very small percentage said that their children's health was poor (0.2 percent). Twenty-one percent of children had not missed any school due to injury or illness in the past year, 57 percent missed one to five days, 16 percent missed six to ten days, and five percent missed more than ten days. (Responses were excluded from analysis if children were home schooled or did not attend school.)

INSURANCE

Substantial progress has been made in recent years related to health insurance for children. Before Arizona adopted KidsCare as Arizona's Title XXI Children's Health Insurance Program (CHIP), United States Census figures estimated that in 1997, 27 percent of children in Arizona had no health insurance, compared to 15 percent of children nationally.⁷⁸ Adopted in 1998, KidsCare is a federal and state program administered by AHCCCS to provide health care services for children below 200 percent of the federal poverty level. Since KidsCare was implemented, enrollments have risen steadily, and outreach efforts undertaken to identify children eligible for KidsCare have also resulted in identifying additional children who are eligible for Medicaid. In 2001, Arizona voters approved Proposition 204, which expanded eligibility in Medicaid from 34 percent of the federal poverty level to 100 percent.

Since the implementation of KidsCare, the percent of children who were uninsured in Arizona declined by 45 percent, from 26 percent in 1998 to 15 percent in 2003.⁷⁹ During that same time period, the national rate of uninsured children declined from 20 percent to 11 percent. However, the state budget passed in 2003 directed AHCCCS to increase the premiums paid by families with children enrolled in KidsCare, and it is too early to measure the impact of this change on insurance coverage levels. Premiums are based on a sliding scale, and had ranged from \$0 to \$20. As of July 2004 the premiums increased to a range of \$10 to \$35.

⁷⁸ United States. Census Bureau. *Historical Health Insurance Tables*. (March, 2003): Internet. <http://www.census.gov/hhes/www/hlthins/historic/hihist5.html> May 10,2005.

⁷⁹ *Ibid.*

According to data from the National Children Health Survey, nearly one in four (23 percent) of children in Arizona either currently did not have health insurance or did not have insurance for some period in the last year, compared to 15 percent nationally.⁸⁰ Sixteen percent of children in Arizona were reported to have no health insurance at the time of the survey, compared to 9 percent nationally. The percentage of children who were insured through Medicaid or the CHIP program was similar in Arizona (26 percent) to the national figure (27 percent).

MEDICAL HOME

The American Academy of Pediatrics defines a medical home as primary care that is accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective. It is not a building, house, or hospital, but rather an approach to providing comprehensive primary care.⁸¹ Using this definition, results from the National Survey of Children's Health indicate that fewer children in Arizona had a medical home (36 percent) than children nationally (46 percent) in 2003.⁸²

PRIMARY AND PREVENTIVE CARE

According to the National Survey of Children's Health, eighty percent of children in Arizona saw a health professional in the last year. Of the 20 percent who did not, 98 percent indicated that they did not need any care. Seventy percent of children in Arizona saw a health care provider in the last 12 months for preventive care (compared to 78 percent nationally), and only 52 percent received medical and dental preventive care (compared to 59 percent nationally).

IMMUNIZATIONS

Prevention of disease through the use of vaccines is one of the great success stories of public health in the United States.⁸³ In 2004, 78 percent of children 19 to 35 months old had received the full schedule of age-appropriate immunizations against measles, mumps, rubella, polio, diphtheria, tetanus, pertussis, Haemophilus influenzae, and hepatitis B, up from the 67 percent who had completed the series in 2000.

⁸⁰ National Survey of Children's Health, Data Resource Center on Child and Adolescent Health. Child and Adolescent Health Measurement Initiative.(2005): Internet.

<http://nschdata.org/DesktopDefault.aspx?topic=stateprevalence&geo=Arizona>. June 5,2005.

⁸¹ American Academy of Pediatrics. The National Center of Medical Home Initiatives. (June 9, 2005): Internet. <http://www.medicalhomeinfo.org> June 4, 2005.

⁸² National Survey of Children's Health, Data Resource Center on Child and Adolescent Health. Child and Adolescent Health Measurement Initiative.(2005): Internet.

<http://nschdata.org/DesktopDefault.aspx?topic=stateprevalence&geo=Arizona>. June 5,2005.

⁸³ Hinman, A.R. (1990). "Immunizations in the United States." Pediatrics 86, 1-64-1066.

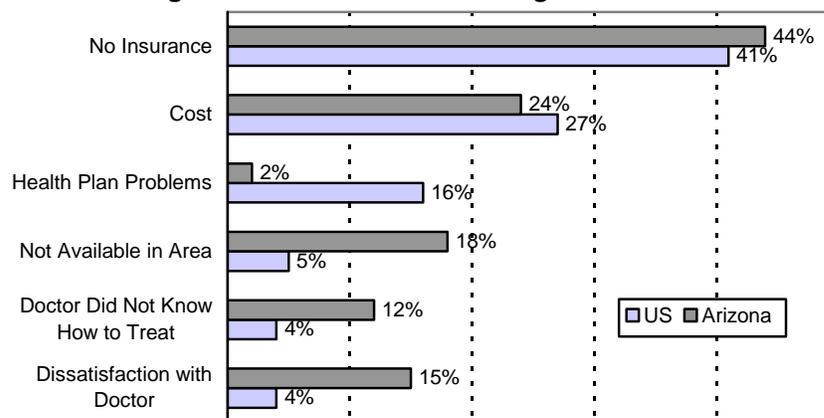
From the year 2000 through 2003, there were only two cases of measles and ten cases of mumps reported. However, outbreaks of vaccine-preventable diseases continue to occur. At the time of this writing, Arizona is experiencing one such outbreak with pertussis, also known as whooping cough. The pertussis vaccination became available in the 1940s. Since the vaccine was introduced, the United States has seen a 98 percent decline in the number of cases reported annually.⁸⁴

An average of 278 cases of pertussis were reported in Arizona from 2000 to 2004. As of June 9, 2005, 474 cases had been reported. Because infants are at increased risk for complications of pertussis, and at increased risk of dying from the disease, the Arizona Department of Health Services is recommending that adolescents who live with infants receive a booster vaccine and that the infant immunization schedule be accelerated so that infants can be protected earlier.

UNMET NEED AND BARRIERS TO CARE

Two percent of NSCH respondents indicated that their child had some need for health care over the past year that was not met. Of those who had an unmet need, caregivers were asked to indicate why the child had not received the needed care. No health insurance and the cost of care were the two most frequently cited reasons for not obtaining needed health care nationally and in Arizona (see figure 36). Eighteen percent said that the needed healthcare was not available in their area (compared to 5 percent nationally). Dissatisfaction with the doctor kept 15 percent from obtaining the needed care (compared to 4 percent nationally), and 12 percent stated that the doctor did not know how to treat the health problem that the child had (compared to 4 percent nationally). Only 2 percent of respondents in Arizona said that health plan problems were the barrier to obtaining needed healthcare, compared to 16 percent nationally.

Figure 36. Barriers to Obtaining Health Care

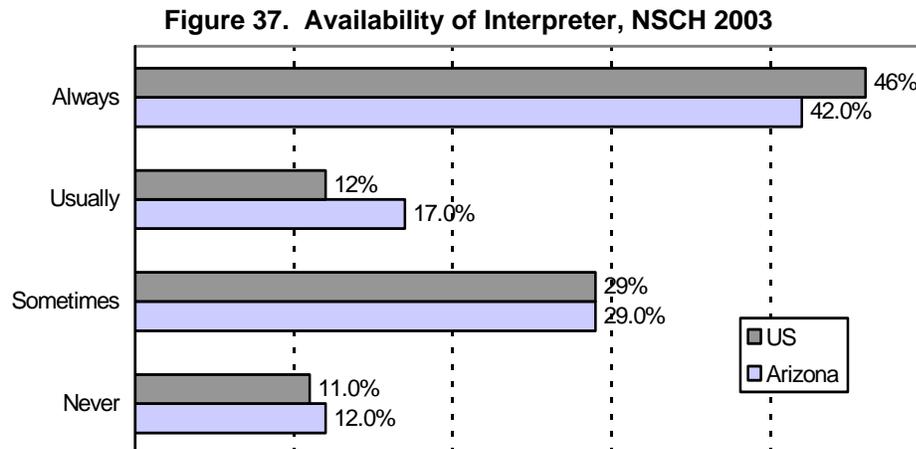


⁸⁴ United States. Centers for Disease Control and Prevention. *Pink Book* (Provider reference). Internet. <http://www.cdc.gov/nip/publications/pink/pert.pdf> June 19, 2005.

LANGUAGE BARRIER IN HEALTH CARE SETTING

According to United States Census data, 26 percent of residents age five and older spoke a language other than English at home, compared to 18 percent nationally, and 11 percent said they spoke English less than very well, compared to 8 percent nationally. Eighty-five percent of those who spoke English less than very well spoke Spanish.⁸⁵

Twenty-four percent of NSCH respondents in Arizona speak a language other than English as their primary language, and 7 percent said that they needed an interpreter to communicate with the medical staff (compared to 3 percent nationally). Among those who needed an interpreter, 59 percent said that one was either always available (42 percent) or usually available (17 percent) if they did not have someone with them that could translate. Twelve percent said that one is never available. Figure 37 shows how often interpreters are available in Arizona and nationally.



OBESITY, PHYSICAL ACTIVITY AND NUTRITION

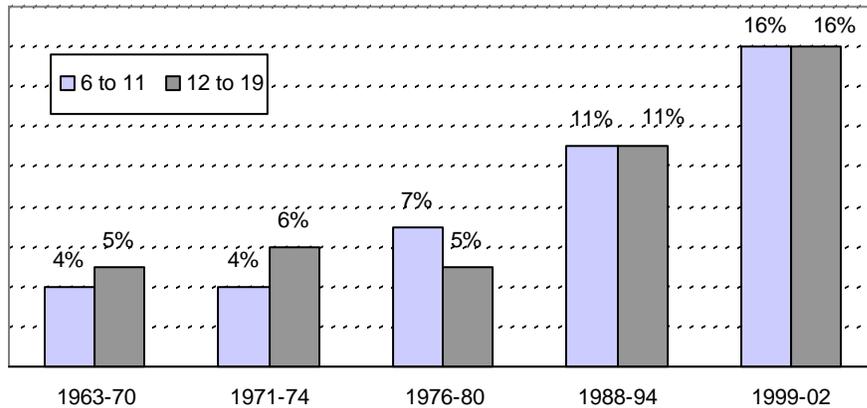
BODY MASS INDEX (BMI)

The percentage of children and adolescents that are overweight continues to rise nationally and in Arizona. Using measured heights and weights to calculate participants BMI, the National Health and Nutrition Examination Survey (NHANES) has been tracking body mass index (BMI) since the early 1960s. Figure 38 from NHANES data shows that, nationally, there has been a four-fold

⁸⁵ United States. Census Bureau. Selected Social Characteristics: 2003. (2003): Internet. http://factfinder.census.gov/servlet/ADPTable?_bm=y&-geo_id=04000US04&-qr_name=ACS_2003_EST_G00_DP2&-s_name=ACS_2003_EST_G00_-lang=en&-sse=on April 19, 2005.

increase in the proportion of six through eleven year-olds who are overweight (from 4 percent to 16 percent) and a three-fold increase for twelve through nineteen year-olds (from 5 percent to 16 percent) over the last forty years.⁸⁶

**Figure 38. Prevalence of Overweight
Among Children and Adolescents ages 6-19
National Health and Nutrition Examination Survey**



The prevalence of overweight among adolescents varies by race and ethnicity. In 1999–2002, 14 percent of non-Hispanic White adolescents, 21 percent of non-Hispanic African American adolescents, and 23 percent of Mexican-origin adolescents were overweight.⁸⁷

While maintaining a healthy weight is important for people of all ages, being overweight during childhood can carry life-long health consequences. In the Surgeon General’s Call to Action to Prevent and Decrease Overweight and Obesity, Richard Carmona states:

“Risk factors for heart disease, such as high cholesterol and high blood pressure, occur with increased frequency in overweight children and adolescents compared to children with a healthy weight. Type 2 diabetes, previously considered an adult disease, has increased dramatically in children and adolescents. Overweight and obesity are closely linked to type 2 diabetes. Overweight adolescents have a 70 percent chance of becoming overweight or obese adults. This increases to 80 percent if one or more parent is overweight or obese. The burden of obesity on the adult and the younger population is great, with consequences of multiple chronic disease and reduced quality of life.”⁸⁸

⁸⁶ United States. Centers for Disease Control and Prevention. Health, United States, 2004; with Chartbook on Trends in the Health of Americans. (2004): Internet. <http://www.cdc.gov/nchs/data/hus/04trend.pdf#070> June 8, 2005.

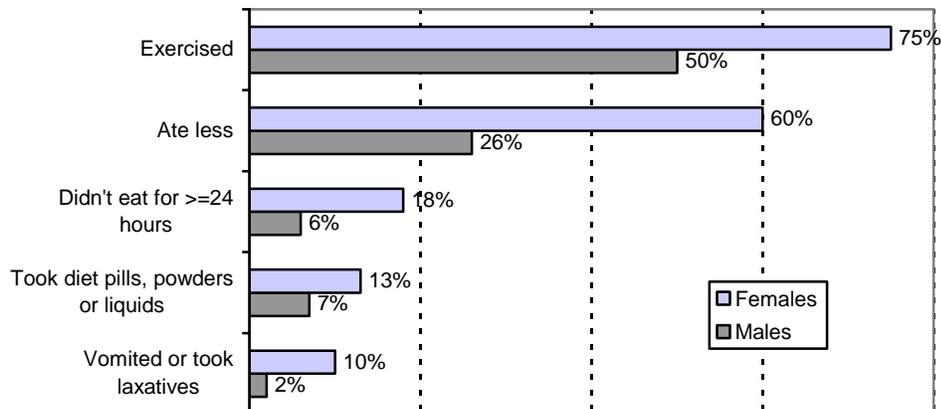
⁸⁷ *Ibid.*

⁸⁸ United States. Department of Health and Human Services, Office of the Surgeon General. The Surgeon General's Call to Action To Prevent and Decrease Overweight and Obesity. Overweight Children and Adolescents. (2001): Internet. http://www.surgeongeneral.gov/topics/obesity/calltoaction/fact_adolescents.htm June 2, 2005.

In 2003, two national surveys were conducted that used height and weight to calculate state and national BMI estimates. The NSCH provides estimates for all children under the age of 18 while the YRBS provides estimates for just high school students. The NSCH data indicated that about 40 percent of children in the US and Arizona are either at risk for being overweight, or are overweight.

In addition to asking questions on height and weight, the 2003 YRBS asked a series of questions regarding weight control behaviors and respondent's perception of their weight. Although only 24 percent of students in Arizona had BMIs at or above the 85th percentile (considered at risk for overweight or overweight), 32 percent thought they were overweight and nearly half (48 percent) were trying to lose weight. Females were more than twice as likely to be trying to lose weight (65 percent of females compared to 29 percent of males). Females were also more likely to report engaging in weight control behaviors – both healthy and unhealthy. Figure 39 shows that 75 percent of female high school students reported exercising for weight management (compared to 50 percent of males), 60 percent said they ate less (compared to 26 percent of males). Other weight management behaviors included not eating for at least twenty-four hours, taking diet pills, powders or liquids, and vomiting or taking laxatives.

Figure 39. Prevalence of Overweight Among Children and Adolescents ages 6-19 National Health and Nutrition Examination Survey



PHYSICAL ACTIVITY

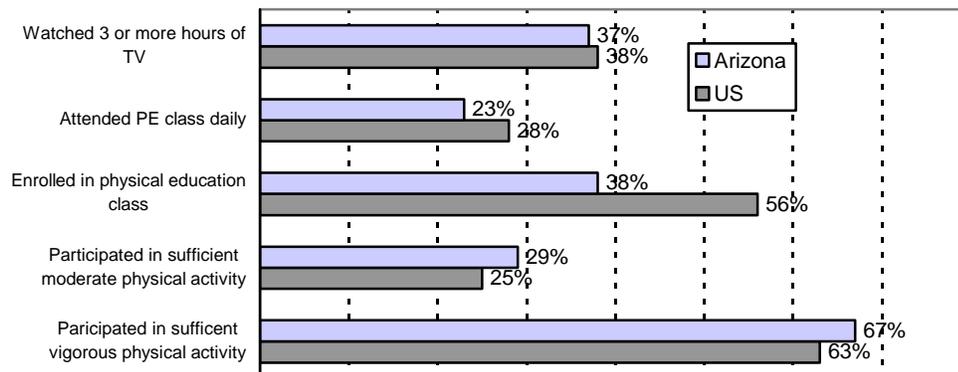
Physical activity is an important component of chronic disease prevention and is often touted as a tool for weight management. Children can obtain beneficial physical activity in a number of settings and situations, including physical education classes, recess at school, participating in after-school sports activities and teams, and just plain playing.

Since 1991, the CDC has been monitoring trends in adolescent physical activity levels through the YRBS. Nationally, the percent of students who did

strengthening exercises increased from 48 percent in 1991 to 52 percent in 2003 and the percent of students who watched television for at least three hours on an average school day decreased (from 43 percent in 1999 to 38 percent in 2003). However, daily attendance in physical education classes decreased from 42 percent in 1991 to only 28 percent in 2003. There has been no change in the percentage of students who participated in sufficient amounts of either vigorous or moderate physical activity, nor has there been a change in the percentage of children enrolled in physical education classes.⁸⁹

Thirty-eight percent of high school students in Arizona are enrolled in a physical education class, and 23 percent of students attend one daily. Sixty-seven percent of students had participated in vigorous physical activity that made them sweat and breathe hard for 20 minutes or more on three or more of the seven days preceding the survey. Twenty-nine percent of students had participated in moderate physical activity that did not make them sweat or breathe hard for 30 minutes or more on five or more of the seven days preceding the survey. Thirty-seven percent of students watched an average of three or more hours of television on school days. Although Arizona students are less likely to be enrolled in physical education classes, they are actually more likely than their students nationally to participate in sufficient moderate physical activity. On all other measures, Arizona students were very similar to the rest of the nation, with differences falling within overlapping confidence levels (see figure 40). Male high school students in Arizona are more likely than females to participate in vigorous physical activity (75 percent of males, compared to 59 percent of females).

Figure 40. Self-Reported Physical Activity Levels YRBS, 2003



Physical activity measures for children are also available through the National Survey of Children’s Health. Caregivers were asked about the amount of exercise their children had over the last seven days. Less than one out of three children ages 6 through 17 (nationally and in Arizona) were reported to get at

⁸⁹ United States. Centers for Disease Control and Prevention. YRBSS: National Youth Risk Behavior Survey: 1991-2003; Trends in the Prevalence of Physical Activity. Internet. <http://www.cdc.gov/HealthyYouth/yrbs/pdfs/trends-pa.pdf> June 7, 2005.

least 20 minutes of vigorous physical activity every day (28 and 26 percent respectively) and one in 10 (11 percent) did not get vigorous activity on any of the last seven days.

According to the 2003 Safe and Drug Free Schools Report, nine out of ten elementary schools have regularly scheduled recesses. Thirty-seven percent of schools reported that physical education is offered daily, and another 37 percent reported that it is offered between two and four days a week. Eighty-one percent of schools offering physical education classes reported that the class is between 30 minutes and 1 hour. Eight percent of schools reported that physical education classes are not offered at their school.

NUTRITION

Healthy eating patterns should be established early in life to minimize the risk of developing chronic disease such as cancer, coronary heart disease, obesity, diabetes, and osteoporosis. An important component of healthy eating patterns is eating five or more servings of fruits and vegetables daily. A diet high in calcium is also essential for the development of strong bones and to reduce the risk for developing osteoporosis later in life.

The YRBS has been tracking high school student's dietary habits in the United States since 1999. There has been no substantial change in these behaviors over the six years that they have been monitored, and there is much room to improve. In 2003, 20 percent of high school students in Arizona ate the recommended five fruits and vegetables, and 15 percent drank at least three glasses of milk per day. Forty-four percent had eaten less food, fewer calories, or foods low in fat to lose weight or to keep from gaining weight. These figures are very similar to national levels. Males in Arizona were more likely to drink the recommended amount of milk (22 percent of males compared to 8 percent of females).⁹⁰

CHRONIC CONDITIONS

As part of the NSCH, caregivers were asked whether a doctor had ever told them that their child had certain chronic conditions. The prevalence of chronic conditions in Arizona mirrored those of the nation. Fourteen percent of children had respiratory allergies, 12 had been diagnosed with asthma during their lives and 7 percent had been affected by asthma during the last year. Four percent of children had food allergies and three out of every thousand children had diabetes.

⁹⁰ Centers for Disease Control and Prevention. "Youth Risk Behavior Surveillance-United States, 2003." Morbidity and Mortality Weekly Report 53 SS-2 (May 21, 2004).

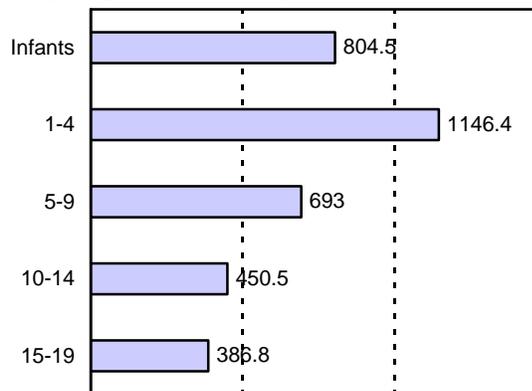
ASTHMA

Several recent reports have provided evidence that the burden of asthma may have levelled off, after increasing for decades. Implementation of prevention and management guidelines have led to earlier detection and improved treatment of asthmatics⁹¹. However, asthma is still a major public health concern. The characteristic episodes of the narrowing of the small airways in response to asthma triggers leads to coughing, chest tightness, shortness of breath, and wheezing. Although most cases of childhood asthma are mild or moderate, asthma can cause serious and sometimes life-threatening health risks when it is not controlled.

In 2003, asthma accounted for an estimated 12.8 million lost school days nationally.⁹² The National Survey of Children's Health showed that twelve percent of children age 0-17 in Arizona have been diagnosed with asthma at some point in their lives. Of those, nine percent still have the condition. Sixty-eight percent of children in Arizona who currently had asthma were reported to have minor difficulties, 27 percent reported to have moderate difficulties, and five percent reported to have severe difficulties. Four percent of children with asthma were hospitalized in the last year due to this condition.

There were 11,240 emergency room visits for children under the age of 20 in 2004; 701 of which were for infants under the age of 1. There were 3,937 visits for children age 1-4, 3,059 for children 5-9, 1,930 for children 10-14, and 1,613 for adolescents age 15-19. Children age 1-4 have the highest rates of emergency room visits for asthma, with 1,146.4 emergency room visits per 100,000 children age 1-4 (see figure 41).

Figure 41. Emergency Room visits per 100,000 children, Arizona 2004



⁹¹ Herten, L. and T. Haahtela. "Signs of Reversing Trends in Prevalence of Asthma." *Allergy*. 60.3 (March 2005) 283-292.

⁹² American Lung Association, Epidemiology and Statistics Unit. "Trends in Asthma Morbidity and Mortality." (May 2005): Internet. <http://www.lungusa.org/atf/cf/%7B7A8D42C2-FCCA-4604-8ADE-7F5D5E762256%7D/ASTHMA1.PDF> July 13, 2005.

ORAL HEALTH

The National Survey of Children's Health asked a series of questions regarding the oral health of children older than 12 months. While 62 percent of children in Arizona had teeth in excellent or good condition, according to their caregivers, 14 percent had teeth judged to be in fair or poor condition (compared to 10 percent of children nationally).

Those who indicated that their child's teeth were in fair or poor condition were asked to indicate the specific problems that the children had with their teeth. Caregivers were asked about each problem individually and were able to indicate multiple problems if applicable. Among the 14 percent of children in Arizona with teeth in fair or poor condition, 55 percent had cavities, 34 percent had crooked teeth or teeth that needed braces, and ten percent had broken teeth or teeth in need of repair.

ELEMENTARY SCHOOL

The Arizona Department of Health Services, Office of Oral Health conducted a school dental survey of kindergarten through third graders attending publicly funded schools. The survey included a paper survey that was mailed to parents, which assessed dental care utilization, and an examination of children by oral health professionals to determine oral health status. The survey found that from 1999 through 2003, more than 39 percent of Arizona third graders had untreated tooth decay—one of the highest proportions in 22 states with comparable oral health data. Almost 9 percent of children in kindergarten through third grade urgently needed dental care and another 31 percent also had non-urgent dental needs. Substantial disparities were found in oral health status, with low-income and minority children having more tooth decay and more urgent dental needs. Although 75 percent of children in kindergarten through 3rd grade had some type of insurance for dental care, only 57 percent visited a dentist in the last year.

Healthy People 2010 and Healthy Arizona 2010 objectives call for increasing the proportion of eight year-old children with dental sealants to 50 percent by 2010. Dental sealants are a plastic coating applied to the chewing surfaces of the molars and have been proven to be safe and effective, in reducing the risk of untreated decay.⁹³ Comparing recent survey data to data from 1987-1993, the Office of Oral Health found substantial improvement in the percent of eight year-old children in Arizona who have dental sealants. While 8 percent of eight year-olds had sealants in the 1987-1993 survey, almost 31 percent of eight year-olds had sealants in the more recent 1999-2003 survey. This increase in sealant prevalence can be at least partially explained by the expansion of school-based sealant programs in Arizona. In 2004, 7,040 children in five counties received sealants through the Arizona Dental Sealant Program.

⁹³ Simonsen RJ. "Pit and Fissure Sealant: Review of the Literature." *Pediatric Dentistry* 24.5 (Sept.-Oct. 2002): 393-414.

MIDDLE AND HIGH SCHOOL

The 2003 Arizona Youth Tobacco Survey (YTS) collected self-reported information from 6,620 middle and high school students in randomly selected public schools (including charter schools) across the state. In addition to tobacco-related questions, the YTS asked students a series of questions about their oral health and dental health care utilization. More than 20 percent of middle school students (grade 6 through 8) and almost 24 percent of high school students (grades 9 through 12) had not seen a dentist in the last year. Three percent had never been to a dentist.

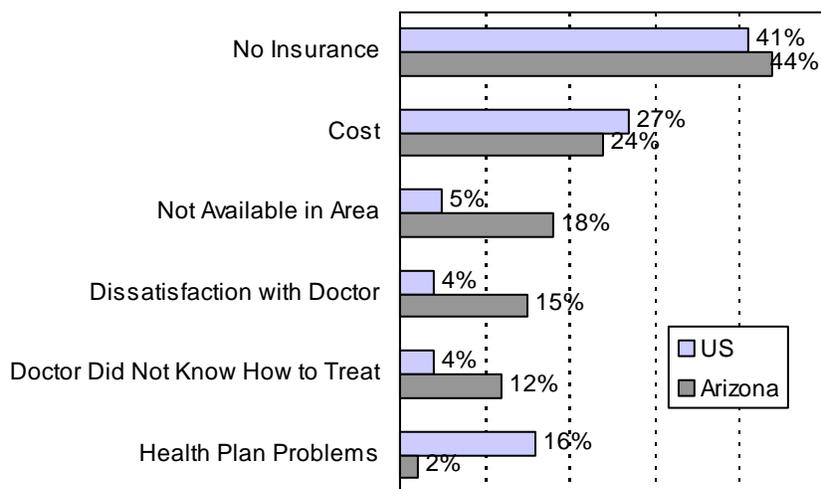
Students were asked if they believed that they currently had cavities in any of their teeth, and whether they had any sealants (plastic coatings to prevent cavities) on their back teeth (molars). Twenty-two percent of middle school students and 26 percent of high school students thought that they had a cavity at the time they were asked, and almost 40 percent of middle school students and 51 percent of high school students reported that they had sealants. It is unknown how well students are aware of or are able to recall the nature of any treatment (for example, the difference between white fillings and sealants).

BARRIERS TO ORAL HEALTH CARE

The Office of Oral Health evaluated emergency room visits in Arizona for the last six months of 2003, and found nearly 1,000 children age 1-14 presented at the emergency room for a dental problem caused not by trauma, but by dental disease. For 592 children a dental problem was the primary diagnosis, and for 324 children a dental problem was the secondary diagnosis.

Seven percent of NCHS respondents in 2003 indicated that their child had a need for dental services that was not met. The two most frequently cited reasons for not receiving all the dental care needed were no insurance and the cost of dental care. Forty-four percent of caregivers in Arizona said that no insurance was a barrier (compared to 41 percent nationally), and 24 percent said that cost was a barrier. Sixteen percent reported problems with their health plan, 8 percent reported that they had missed the appointment, and 5 percent reported that not being able to get an appointment kept them from obtaining the dental care needed (see figure 42).

Figure 42. Barriers to Obtaining Dental Care, NSCH 2003



Although health insurance is a barrier for many, even those with dental insurance often do not get regular dental care. AHCCCS provides comprehensive dental coverage to children under the age of 21. In its publication The Annual Medical Audit: Children’s Oral Health Visits Performance Improvement Project Baseline Measurement, AHCCCS presented findings on dental visits among 3-8 year old members who were continuously enrolled throughout federal fiscal year 2002. Fifty-one percent of three to eight year-old members had at least one dental visit during federal fiscal year 2002. Among children with a dental visit, 40 percent received preventive services only, 3 percent had treatment services only, and 57 percent had preventive and treatment services. Children in Maricopa County were more likely to have an annual dental visit than those living in Pima County or the combined rural counties. Children with special health care needs were also less likely to have received a dental visit.

AHCCCS also produces an annual Early Periodic Screening and Diagnosis and Treatment (EPSDT) Participation Report, which provides data for the entire Medicaid population regardless of continuous enrollment. For federal fiscal year 2002, 26 percent of eligible enrollees received some kind of dental services, 20 percent received a preventive service and 15 percent received a dental treatment service.⁹⁴ Only 4 percent of eligible enrollees age 1-2 years old received any kind of dental service, despite the recommendation of a child’s first dental visit at age one for this high-risk population. Both AHCCCS reports found decreased dental utilization among adolescents. Reversing this trend is important to efforts to apply protective dental sealants to molars that erupt at 12 years of age.

⁹⁴ United States. Centers for Medicare and Medicaid Services. Annual Epsdt Participation Report. (Jan. 20, 2005): Internet. <http://www.cms.hhs.gov/medicaid/epsdt/ep2002/pdf> June 14, 2005.

For thirty years, the Arizona Department of Health Services has had a mobile dental trailer program that serves as an interim step for communities to establish dental clinics for underserved populations. Four trailers, each with two fully equipped dental units, are available by application for a period of five years. Applicants must staff the trailers to provide treatment and demonstrate sustainability of the treatment services after the five-year loan period.

CHILDCARE, HOME, AND SCHOOL ENVIRONMENTS

Participants in public input sessions repeatedly emphasized that many of the factors in the community beyond health care services influence the health of children. Supporting parental involvement in children's lives and an emphasis on working through the childcare and school environment were often repeated themes. The National Children's Health Survey asked a series of questions about childcare, home, and school environments. Statistics presented in this section are drawn from this survey unless otherwise specified.

CAREGIVER MENTAL HEALTH AND SUPPORT SYSTEMS

Four percent of fathers and seven percent of mothers in Arizona had either fair or poor mental and emotional health, according to NSCH respondents. When asked whether they had adequate support systems, 20 percent of caregivers said that they did not have anyone to whom they could turn day-to-day for emotional help with raising children (compared to 14 percent nationally). Eleven percent of caregivers said that they always feel that they are giving up more of their life to meet their children's needs than they ever expected, and one out of every hundred caregivers said they did not cope very well with the day-to-day demands of parenting.

NEIGHBORHOOD ENVIRONMENT

The NSCH asked caregivers to rate their level of agreement with a number of statements regarding their neighborhoods. This series of questions was used by the NSCH Data Resource Center to create a measure of neighborhood support. Seventy-nine percent of children in Arizona were living in neighborhoods described as supportive, similar to the national proportion.⁹⁵ Caregivers were also asked how safe they felt their children were in their neighborhoods. Eighty percent of caregivers in Arizona felt their children were usually or always safe (compared to 84 percent nationally).

⁹⁵ United States. Census Bureau. Historical Health Insurance Tables, *loc. cit.*

CHILDCARE CENTERS

Childcare services include care at a childcare facility, being cared for by a nanny or other non-parent family member, or a family based childcare center outside of their home. According to the National Survey of Children's Health, 41 percent of caregivers of children under the age of four in Arizona use childcare services, compared to 54 percent nationally.

The Governor's School Readiness Action Plan recommends developing a health and safety consultation system for childcare providers. The Office of Women's and Children's Health, in conjunction with the Arizona Center for Community Pediatrics, sponsored a telephone survey to evaluate health and safety issues that childcare providers deal with on a regular basis. This survey, which was conducted in 2004, assessed the need for technical support and training in licensed childcare for children five years old and younger.

More than one-third of childcare workers said that they dealt with children with behavioral or emotional issues and children with learning or developmental delays on a daily basis. On a monthly basis, three-fourths said they cared for children with behavioral or emotional issues, and two-thirds said they dealt with infections. Respondents were generally satisfied with community resources for most health and safety issues, although they reported lower levels of satisfaction for resources dealing with signs of abuse or neglect, dental problems, and limited access to health care.

Ninety-five percent of the childcare providers reported that their centers provided parents with information about their child's health, and 85 percent said they provided parents with educational information. Sixty-seven percent said they provided parents of uninsured children with information about or help in applying for the Arizona Health Care Cost Containment System. When asked about certain safety practices, 95 percent said that they required infants to be placed on their backs to sleep, 62 percent said that they used booster seats to transport children age four through eight, and 71 percent administered breathing treatments.

Half of the centers reportedly used websites for health and safety information, and one-fourth of the centers used nurse consultants or public health nurses, school nurses or local doctors, phone lines, and on-site health screenings. In Pima County, where there is a full-time public health nurse dedicated to childcare consultation, 35 percent said they used this resource. For those that had actually used each resource, there was near unanimity that the resource was useful.

When asked who or what resources regularly help them with health and safety issues (such as outbreaks, compliance, or policy development) nearly half mentioned Arizona Department of Health Services, while one-third mentioned a county health department, and 12 percent mentioned an onsite resource.

SCHOOL ENVIRONMENT

According to the NSCH, 6 percent of Arizona students were enrolled in private schools (compared to ten percent nationally). Two percent, of children age 6 through 17 were home schooled, and fewer than one percent of children were not enrolled in school at the time of the survey. Caregivers in Arizona have similar perceptions to those nationally in regards to their children's safety at school. One in ten caregivers reported that they felt their child is sometimes not safe at school and one percent said their child was never safe at school.

The 2004 Arizona Youth Survey (AYS), which includes students in middle school and high school shows that there has been an increase in the percent of students who do not feel safe at their school. Twenty-two percent of AYS participants in 2004 reported that they did not feel safe at their school, up from 15 percent in 2002. A higher percentage of middle school students (26 percent) felt unsafe than high school students (22 percent of tenth graders, and 16 percent of twelfth graders). According to the YRBS, five percent of high school students (both nationally and in Arizona) did not go to school on at least one of the past 30 days because they felt unsafe at school or on their way to or from school (2003 YRBS).

A total of 77,810 incidents of violent and criminal behavior on school property were reported in the Safe and Drug Free Schools Report for the 2002-2003 school year. These reports includes all incidents, regardless of whether a student or non-student was involved, and include incidents happening during and after school hours. The largest proportion of incidents were physical attacks or fights without a weapon (33 percent), followed by intimidation and bullying (21 percent). Eleven percent of incidents were *threats* of a physical attack or fight without a weapon.

According to the Safe and Drug Free Schools Report, there were 105 incidents involving students bringing guns to campus in Arizona during the 2002-2003 school year. Among them, 45 were in high school, 43 in middle school, and 17 were in elementary schools. Five percent of YRBS participants reported carrying a weapon on campus in Arizona in the last year. Considering that there are close to 300,000 high school students in Arizona, this suggests that many more students bring guns and other weapons onto campus than are detected and reported.

There has been an overall decrease since the early 1990s in some of the behaviors that contribute to violence. National YRBS data show decreases in the percent of students reporting carrying a weapon in the last thirty days, whether on or off campus, from 26 percent in 1991 to 17 percent in 2003. Students were also less likely to have carried a gun in the last thirty days (8 percent in 1993 compared to 6 percent in 2003), or be in a physical fight in the last twelve months (43 percent in 1991 to 33 percent in 2003). There was no change in the percent

of high school students that reported being injured in a physical fight in the last twelve months (4 percent).

One in ten high school students in Arizona reported being threatened or injured with a weapon on school property. African American students were more likely than other students to be threatened or injured (18 percent of African Americans), and males were more likely to be threatened or injured with a weapon than females (13 percent of males compared to 6 percent of females).

DATING VIOLENCE AND RAPE

Eight percent of high school students in Arizona reported having been hit, slapped or physically hurt intentionally by their boyfriend or girlfriend in the past year, according to YRBS data. Seven percent of students said that they had been forced to have sexual intercourse when they did not want to, with females being twice as likely to report forced sexual intercourse as males (10 percent compared to four percent). Dating violence rates in Arizona were similar to national rates.

CHILD ABUSE

During the 2004 federal fiscal year (October 1, 2003 through September 30, 2004) the Arizona Department of Economic Security, Child Protective Services received 39,407 reports of child abuse, neglect or abandonment. Eight percent of the cases that were investigated were substantiated with findings of abuse or neglect. The majority of substantiated child abuse cases were for neglect (60 percent), followed by physical abuse (32 percent), sexual abuse (six percent), and emotional abuse (2 percent). According to the Child Fatality Review Report, 37 children died due to maltreatment in 2003.

In 2003, there were 149 inpatient hospitalizations in which a diagnosis code indicated that child abuse had occurred. The number of inpatient hospitalizations captures only those cases that were severe enough to be admitted into the hospital and those cases in which the cause of the admission was attributed to child abuse. A complete year of emergency room data became available in Arizona for the first time in 2004. There were 268 emergency room visits in 2004 with a diagnosis code indicating child abuse for which the child was not admitted into the hospital.

MENTAL/BEHAVIORAL HEALTH

Nine percent of children in Arizona over three years of age had moderate to severe difficulties in the areas of emotions, concentration, behavior, or getting

along with others.⁹⁶ Four percent of children age two and older were depressed or had anxiety, and 5 percent had ADD/ADHD. Seven percent of children received mental health care or counseling in the past year, according to the NSCH.

Among high school students, 30 percent of YRBS respondents reported feeling so sad or hopeless almost every day for two weeks or more in a row during the past twelve months that they stopped doing some usual activities. Female high school students were almost twice as likely to report these feelings as males (40 percent versus 21 percent).

According to a recent national survey, less than half of those in need of mental health services in the United States tend to get them.⁹⁷ Participants at each public input session raised the issue of mental health as a priority for their communities and reported that there is a large unmet need for mental health services.

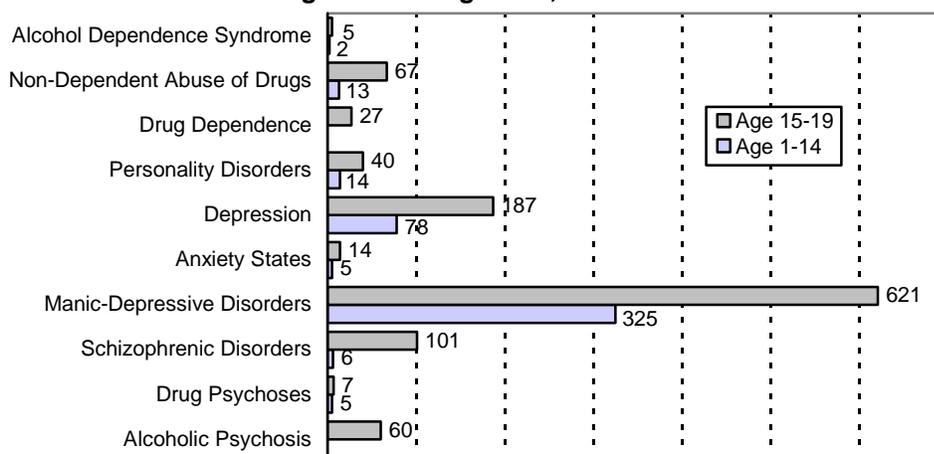
There were 2,166 inpatient hospital admissions for mental disorders among children age 1-19 in Arizona during 2003. These hospitalizations represent only those cases in which the principle reason for the hospital admission was a mental disorder. However, mental disorders also are present as complications and co-morbidities of other hospitalizations. There were 3,745 additional hospitalizations in which a mental disorder was identified as a complication or co-morbidity.

Manic-depressive disorders were the most common reason that children were hospitalized for a mental disorder in Arizona during 2003, followed by depression. Figure 43 shows the number of hospitalizations for mental disorders among children age 1-19 in 2003.

⁹⁶ United States. Census Bureau. *Historical Health Insurance Tables*, *loc. cit.*

⁹⁷ Kessler, Ronald C., et al. "Lifetime Prevalence and Age-of-Onset Distributions of DSM-IV Disorders in the National Comorbidity Survey Replication." *Archives for General Psychiatry*. 62 (2005): 593-602.

Figure 43. Hospitalizations for Mental Disorders Among Children Age 1-19, Arizona 2003



SUBSTANCE ABUSE

According to Dr. Sandra Brown, Associate Director of the National Institute of Mental Health, Child and Adolescent Services Research Center, the younger a person is when they begin using drugs and alcohol, the greater the lifetime risk for dependence. New research on patterns of substance abuse have shown that the most prevalent age of onset of tobacco dependence is 15 and for alcohol dependence the most common age of first diagnosis is 18. These statistics are troubling for two reasons. Such early onset of dependency may cause social, behavioral, health, and economic consequences for years to come. In addition, exposure to drugs during adolescence may produce more adverse effects because of important developmental changes occurring in the brain during adolescence.⁹⁸

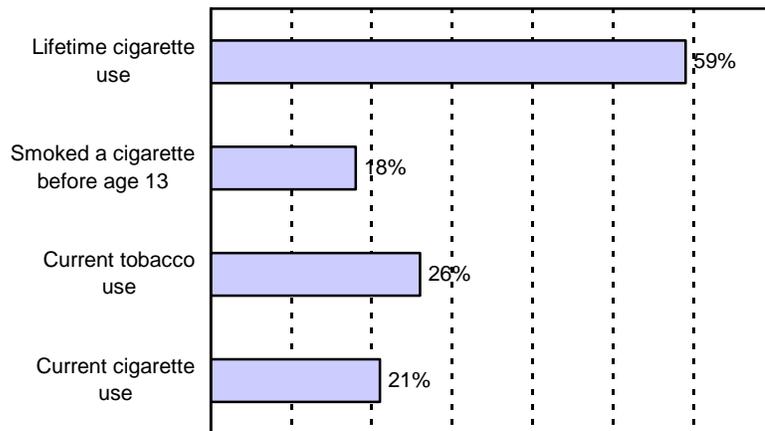
TOBACCO

Adolescent tobacco use appears to be decreasing in recent years, after some increases during the 1990s, according to YRBS data. The percent of students who had ever tried cigarette smoking, even one or two puffs, declined from 70 percent in 1991 to 58 percent in 2003. The percent of students who were current smokers (smoking cigarettes in the 30 days preceding the survey) decreased from 28 percent in 1991 to 22 percent in 2003, and the percent of students who smoked on school property declined from 13 percent in 1993 to 8 percent in 2003. The percent of students who were current frequent smokers (smoking cigarettes on 20 or more of the 30 days preceding the survey) increased between 1991 and 1999, and then decreased from 17 percent in 1999 to 10 percent of students in 2003.

⁹⁸ APA Congressional Testimony on Substance Abuse Prevention and Treatment Services to Adolescents, <http://www.apa.org/ppo/issues/browntest604.html>, accessed 6/13/2005

In Arizona, 59 percent of high school students had smoked at some time in their lives, and 18 percent had smoked a cigarette before age 13. One in five Arizona high school students said that they currently smoke cigarettes. While cigarette smoking was the most common form of tobacco use, there are also other forms of tobacco that students used, such as smoking cigars, or using smokeless tobacco. Considering all forms of tobacco use, 26 percent of high school students were current tobacco users in 2003 (see figure 44). Fourteen percent of high school students purchased cigarettes at a store or gas station, and 5 percent said that they had smoked at school. Arizona students do not substantially differ from students nationally on measures of tobacco utilization.

Figure 44. Tobacco Use Among Arizona High School Students, 2003 YRBS



ALCOHOL

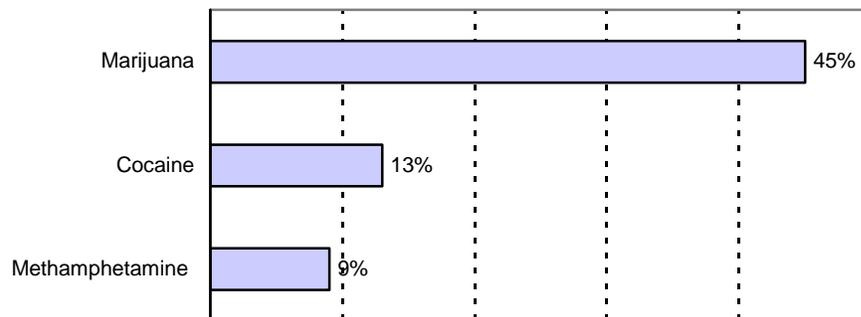
As with tobacco use, national YRBS data indicate that high school students are engaging in risky alcohol related behaviors less frequently than in the previous decade. Nationally, the percent of students who had ever had a drink in their lifetime decreased from 82 percent in 1991 to 75 percent in 2003. The percent of students who said that they had a drink of alcohol in the 30 days preceding the survey decreased from 51 percent in 1991 to 45 percent in 2003, and the percent of students who engaged in episodic heavy drinking (drinking five or more drinks of alcohol in a row on one or more of the 30 days preceding the survey) decreased from 28 percent in 1991 to 22 percent in 2003.

Students in Arizona are more likely to use alcohol than students nationally. In 2003, 51 percent of students in Arizona reported current alcohol use (compared to 45 percent nationally), and 34 percent reported episodic heavy drinking (compared to 28 percent nationally). Thirty percent of students reported drinking before the age of 13 (33 percent of males and 26 percent of females) and 7 percent said they drank on school property (9 percent of males and 4 percent of females).

OTHER SUBSTANCES

Although there have been some recent decreases, a review of YRBS data from the last decade do not show the same declines in illegal substance use as were seen for tobacco and alcohol. In 2003, more students reported ever trying marijuana (from 31 percent in 1991 to 41 percent in 2003), current marijuana use (from 15 percent in 1991 to 22 percent in 2003), and illegal steroid use (from 3 percent in 1991 to 6 percent in 2003). However, lifetime inhalant use has decreased from 20 percent in 1995 when the YRBS first began monitoring this behavior to 12 percent in 2003. Figure 45 shows reported lifetime drug use among Arizona high school students in 2003.

Figure 45. Lifetime Drug Use, Arizona 2003



TEEN SEXUAL BEHAVIORS AND OUTCOMES

A theme that was heard at each of the public input sessions in Arizona is that there is a need for enhanced teen pregnancy prevention, sexuality education, and family planning services to prevent unwanted pregnancies and sexually transmitted diseases. Teen pregnancy was seen as important as an outcome and as a cause. In addition to the consequences that pregnancy has for the teenager's health and life chances, babies born to teenagers are less likely to get a healthy start at life.

Many changes have occurred in the last decade, which have impacted teen sexual behavior and outcomes. During the late 1990s, the federal and state governments put substantial amounts of money in teen pregnancy prevention programs, mostly focusing on abstinence. Additionally, a wide variety of effective hormonal birth control methods became available that do not require the user to adhere to daily regimens, like birth control pills do (e.g., transdermal patches and the vaginal ring).

In 1998, the Food and Drug Administration approved the first emergency contraceptive for post-coital contraception available via prescription in the United States. Emergency contraception, which contains the same hormones that are used in birth control pills, is estimated to be 75 percent effective in preventing

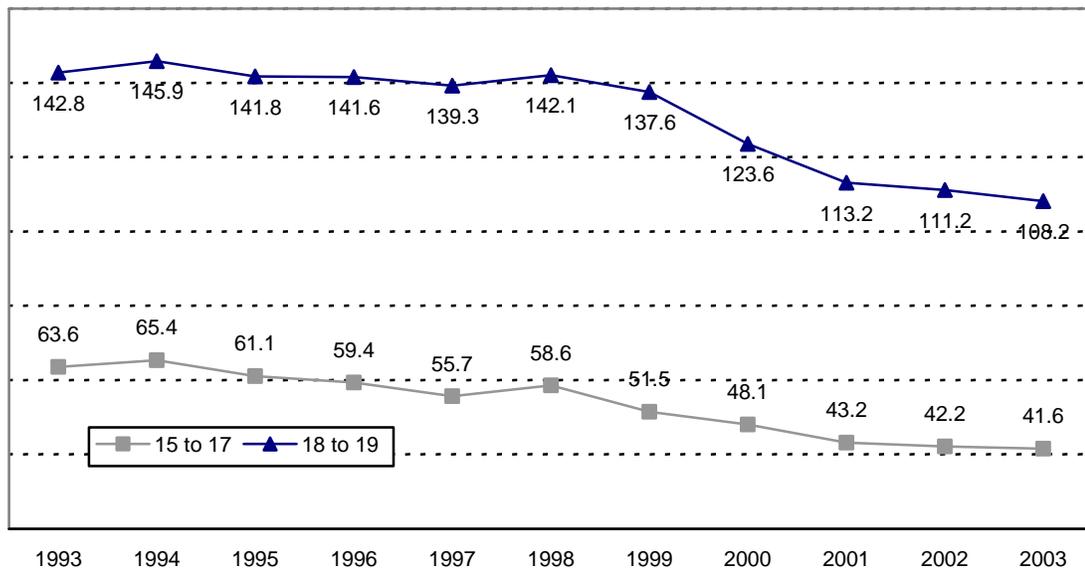
pregnancy if taken within 72 hours of unprotected sex. It is difficult to separate out the effect that abstinence programs and new birth control methods have had on pregnancy rates, but it is important to keep these historic events in mind when analyzing reproductive health data in the late 1990s and early part of this century.

TEEN PREGNANCY

In 2003, there were an estimated 26,691 mothers in Arizona who were younger than 20 years old, and 13,654 girls under the age of 20 got pregnant. Twenty-eight percent of them had been pregnant before. Twenty-one percent had one previous pregnancy, 5 percent had two, 1 percent had three, and there were 29 girls who had four or more previous pregnancies before being pregnant in 2003.

Of the 13,654 pregnancies, 87 (less than 1 percent) ended in spontaneous fetal losses, 1,867 (14 percent) were terminated through abortions, and 11,700 teenagers (86 percent) gave birth. The oldest teens had the highest birth rate, with 108.2 births per 1,000 girls age 18-19. Girls age 15-17 had the next highest birth rate, with 41.6 births per 1,000. Finally, 272 girls under age 15 gave birth in 2003, representing a birth rate of 1.4 per 1,000 girls age 10-14. Six of these young girls had given birth before. Figure 46 shows the pregnancy rates for teens age 15-17 and 18-19 from 1993 to 2003.

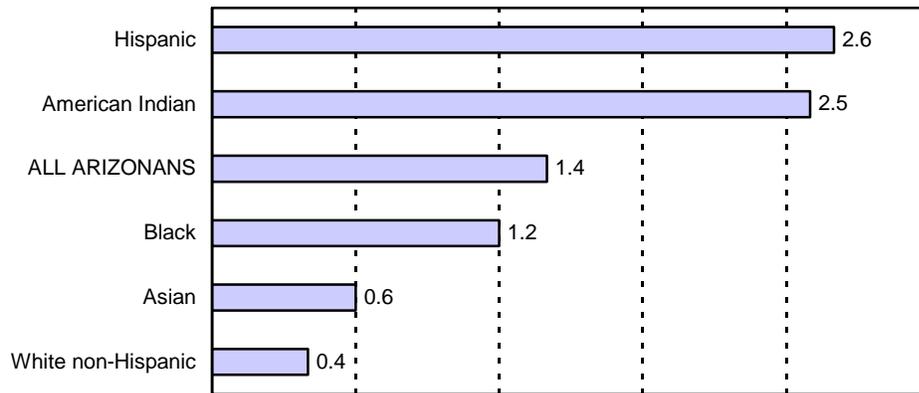
Figure 46. Pregnancy Rates per 1,000 Adolescents by Age Group



Source: Arizona Health Status and Vital Statistics, 2003, Figure 1A-3

Pregnancy rates for females age 10-14 over the same time period ranged from a high of 2.2 in 1995 to a low of 0.9 per 1,000 girls age 10-14 in 1999. Pregnancy rates among 10-14 year-old girls were higher among Hispanics (2.6 per 1,000) and American Indians (2.5 per 1,000) girls in this age group (see figure 47).

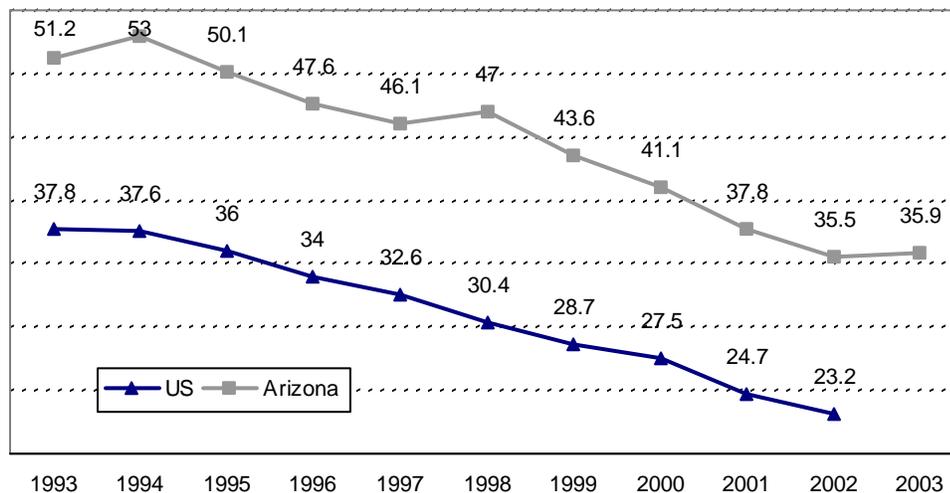
Figure 47. Pregnancies Among Females Age 10-14



TEEN BIRTHS AGE 15-17

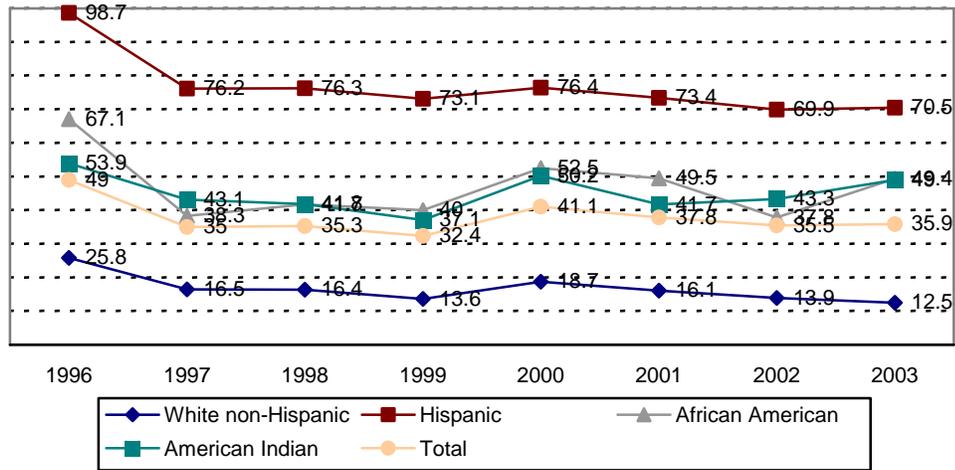
Births among teens age 15-17 has been tracked with particular interest over the last decade. After reaching a high of 53 births per 1,000 girls age 15-17 in 1994, the teen birth rate had been declining until it reached a low of 35.5 in 2002. The 2003 rate is slightly higher, at 35.9 per 1,000 girls age 15-17. Arizona's birth rate remains higher than the national average. Figure 48 shows teen birth rate trends (for 15 to 17 year-olds) for the nation and Arizona.

Figure 48. Teen Birth Rates Age 15-17



Teen birth rates have been consistently higher for Hispanic, American Indian, and African American teenagers (see figure 49).

**Figure 49. Birth Rates by Ethnicity per 1,000 Teens
Age 15-17 by Race/Ethnicity, Arizona 1996-2003**

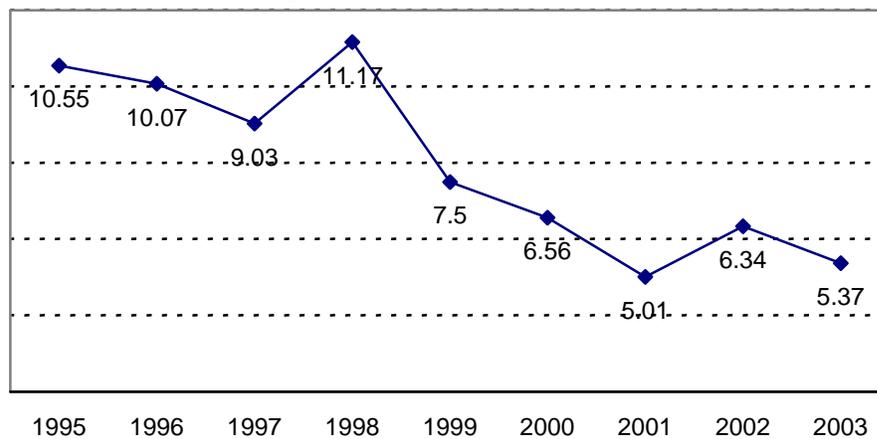


Source: Arizona health status and vital statistics table 1A-3

TEEN ABORTIONS

In 2000, the Arizona legislature passed a law requiring parental consent for a minor to obtain an abortion. Constitutional challenges delayed implementation until 2003. The most recent data available on abortion rates is for 2003. Because data is not yet available for any complete year after the law was implemented, it is not yet possible to determine if the law has affected abortion rates for minors. Figure 50 shows that abortion rates in Arizona were declining among 15-17 year-old girls before the consent law was implemented, and even before it was passed.

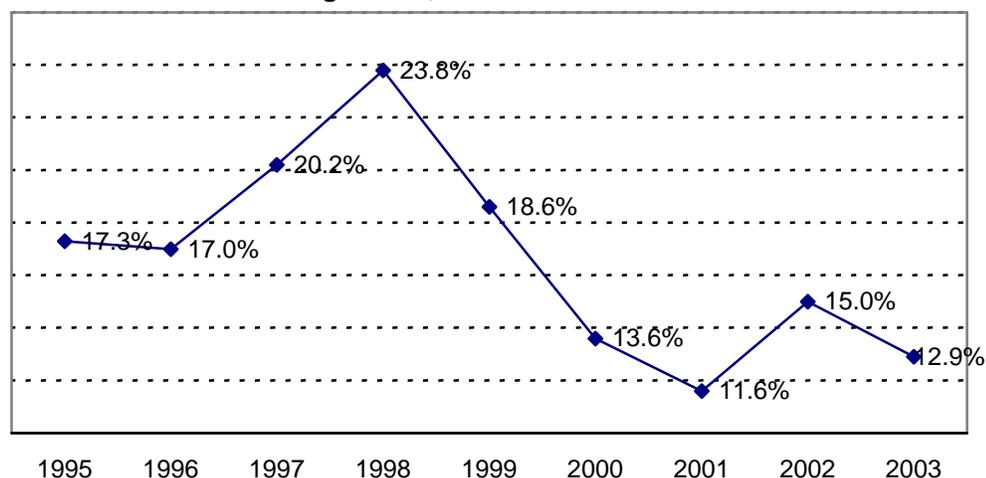
**Figure 50. Abortion Rates per 1,000 Teens
Age 15-17, Arizona 1995-2003**



Another way of looking at trends related to abortions is to examine the percent of pregnancies ending in abortion. Figure 51 shows that the trend for abortion ratios in the 15-17 year-old population has followed that of abortion rates with an

increase in 1998 followed by a general decline. Once data is available for 2004 onward, the abortion ratio may be a better measure than the abortion rate to analyze the impact of the consent law. On average, 17 percent of pregnancies over the last nine years have ended in abortion in the 15-17 year-old age group. Young females ages 10-14 had the highest abortion ratio of all age groups with 22 percent of all pregnancies ending in abortion.

**Figure 51. Percent of Teen Pregnancies Ending in Abortion
Age 15-17, Arizona 1995-2003**



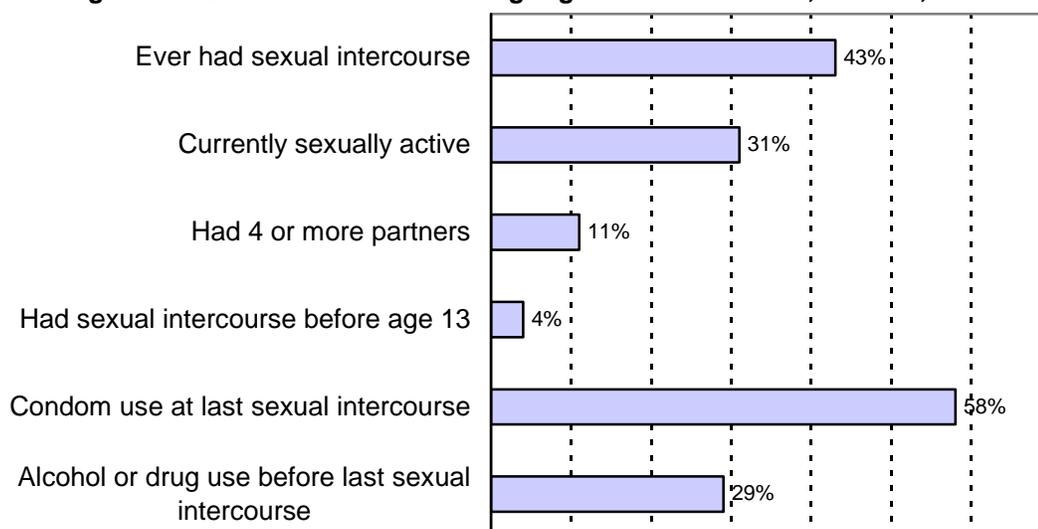
SEXUAL BEHAVIORS

The Youth Risk Behavior Survey has tracked the prevalence of sexual risk behaviors on a national level since the early 1990s. Over the last decade, there has been a trend towards healthier teen sexual behaviors. The percent of high school students reporting that they have ever had sexual intercourse has decreased, the percent reporting four or more sexual partners has decreased, and the percent reporting using a condom at last intercourse has increased. However, the percent that report being currently sexually active has remained the same and the percent reporting that they used drugs or alcohol before their last sexual intercourse has increased.⁹⁹

Forty-three percent of Arizona high school students said that they had ever had sexual intercourse, and 31 percent were currently sexually active. Eleven percent of students said they have had four or more partners, and four percent had sexual intercourse before the age of 13. Fifty-eight percent of students said they had used a condom the last time they had sexual intercourse, and 29 percent said they used alcohol or drugs before the last time they had sexual intercourse. (See figure 52.)

⁹⁹ United States. Centers for Disease Control and Prevention. YRBSS: National Youth Risk Behavior Survey: 1991-2003; Trends in the Prevalence of Sexual Behaviors. Internet. <http://www.cdc.gov/HealthyYouth/yrbs/pdfs/trends-sex.pdf> June 10, 2005.

Figure 52. Sexual Behaviors Among High School Students, Arizona, 2003



Arizona students were less likely than students nationally to have sex before the age of 13 (4 percent in Arizona compared to 7 percent nationally) and less likely to have four or more partners (11 percent in Arizona compared to 14 percent nationally). No other significant differences were reported in sexual activity of Arizona students compared to their national counterparts. Eighty-one percent of students said that they had been taught in school about HIV/AIDS.

SEXUALLY TRANSMITTED DISEASE AND HIV/AIDS (15-19)

CHLAMYDIA

Chlamydia, the most commonly reported disease in the United States, disproportionately affects adolescent females. In 2004, 4,396 cases of Chlamydia were reported among 15-19 year-old females in Arizona representing a rate of 2,193 cases per 100,000 (compared to only 449 per 100,000 15-19 year-old males and an overall rate of 451 per 100,000 in the general Arizona population). The Chlamydia rate in young women has fluctuated over the last decade with a high in 1993 of 2,648 cases per 100,000, to a low of 1,791 in 2003 and an average of 2,457 cases per 100,000. During this time, there have been changes in Chlamydia testing technologies used in Arizona and changes in clinician screening guidelines and practices making it difficult to interpret changes in Chlamydia rates. What is certain is that Chlamydia infection, which is asymptomatic in up to 70 percent of cases,¹⁰⁰ and which can have devastating consequences for those women with untreated infections, remains an epidemic in this population. Chlamydia can cause an array of health problems, such as

¹⁰⁰ United States. Centers for Disease Control and Prevention. Chlamydia Screening Among Sexually Active Young Female Enrollees of Health Plans --- United States, 1999—2001. (Oct. 29, 2004): Internet. <http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5342a1.htm> June 13, 2005.

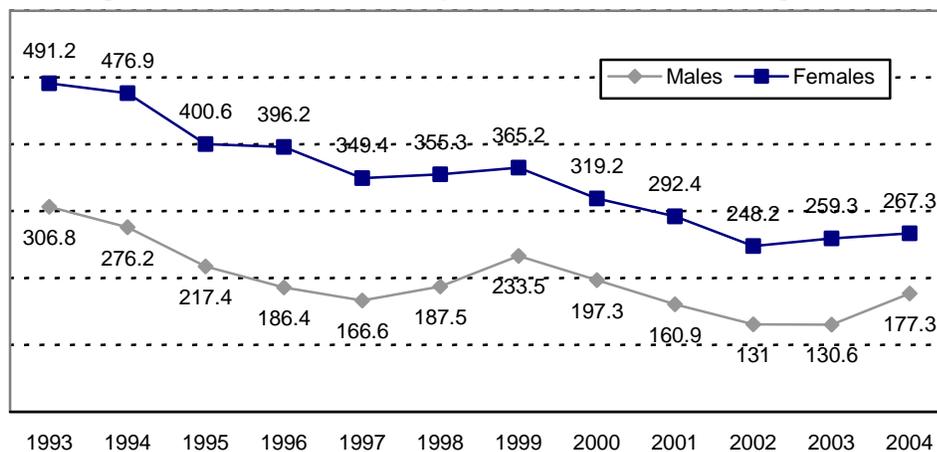
pelvic inflammatory disease, infertility, ectopic pregnancy, and chronic, long-term pelvic pain. In pregnant women, Chlamydia can cause premature delivery and other complications.

Since the early 1990s, the Centers for Disease Control and Prevention has recommended routine screening for sexually active females under the age of 26. However, compliance with these guidelines has remained low with only 26 percent of sexually active females 16 to 26 years of age being screened in commercial health plans and 38 percent being screened in Medicaid plans during 2001.¹⁰¹

GONORRHEA

In 2003, reported gonorrhea cases were at an all time national low.¹⁰² Gonorrhea rates have also declined in Arizona and are even lower than national rates. However, gonorrhea is still the second most commonly reported STD in Arizona. In 2003, there were 193 cases per 100,000 15-19 year-olds compared to 443 nationally. In 2004 there were 774 reported cases, representing a rate of 221 per 100,000 females age 15-19. Female adolescents continue to have higher rates of Gonorrhea than males (267.3 per 100,000 females compared to 177.3 per 100,000 males). (See figure 53).

Figure 53. Gonorrhea Rates per 100,000 Adolescents Age 15-19



SYPHILIS

Although syphilis is relatively rare, (34 cases among 15 to 19 year-olds in 2004 in Arizona), if it is left untreated, it can lead to serious complications including death. Congenital syphilis can cause stillbirth, death soon after birth, and neurological problems in children who survive.¹⁰³ The number of syphilis cases

¹⁰¹ *Ibid.*

¹⁰² United States. Centers for Disease Control and Prevention. *STD Surveillance 2003, Trends in Reported Sexually Transmitted Diseases 2003 – National Data on Chlamydia, Gonorrhea, and Syphilis*. Internet. <http://www.cdc.gov/std/stats/trends2003.htm> June 13, 2005.

¹⁰³ *Ibid.*

in adolescents has remained low over the last decade with a high of 36 cases reported in 2002 and a low of 10 cases in 1995. More females adolescents are diagnosed with syphilis than males. Over the last decade, 70 percent of adolescent syphilis cases were in females.

HIV AND AIDS

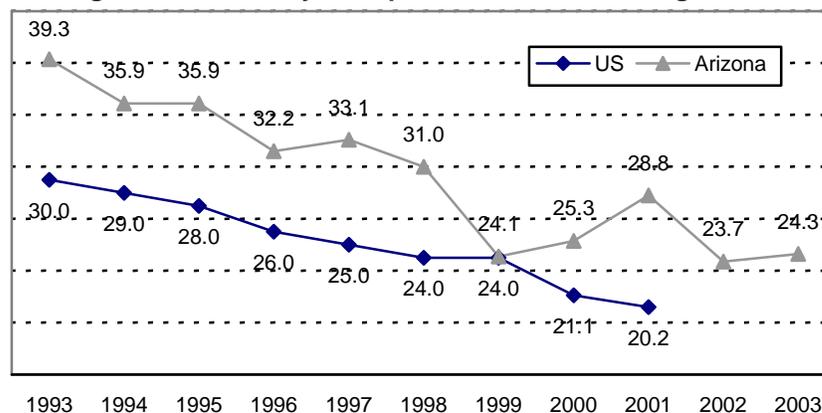
Beginning in 1981, HIV and AIDS cases have been accumulated by age at diagnosis within each of three categories: HIV, Ab+, Asymptomatic, Ab+ Symptomatic, and AIDS. When a person's condition changes from one category to another, the case is removed from the previous categorization and counted in the new category according to the person's age at the time of the new diagnosis. By 2003 there were 298 reported HIV and AIDS cases for the 0-19 age group. Eighty-nine cases were in the under 5-age group, 32 were age 5-12, and 177 were age 13-19.

MORTALITY RATES AND MAJOR CAUSES OF DEATH

CHILD MORTALITY AGE 1-14

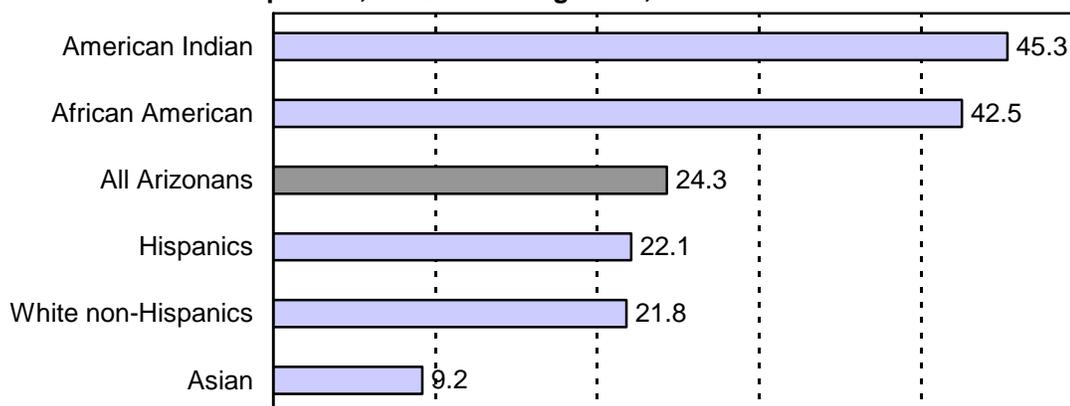
In 2003 there were 286 deaths among children age 1-14 in Arizona, representing a rate of 24.3 deaths per 100,000 children. Child mortality in Arizona and in the nation has declined over the past decade. In Arizona child mortality has declined by 38 percent, from 39.3 in 1993 to 24.3 in 2003.

Figure 54. Mortality Rate per 100,000 Children Aged 1-14



Mortality rates tend to be higher in the rural counties than in urban counties (22.4 per 100,000 urban children, compared to 33.5 per 100,000 rural children in 2003) and for males (27.5 per 100,000 males, compared to 20.9 per 100,000 females). American Indians and African American children have considerably higher mortality rates than the statewide rates. (See figure 55.)

Figure 55. Mortality Rates by Race and Ethnicity per 100,000 Children Age 1-14, Arizona 2003



Motor vehicle accidents are the leading cause of child deaths in Arizona, accounting for 22 percent of all child deaths in 2003, followed by cancer, drowning, congenital malformations, accidents other than those caused by motor vehicles, and homicide. Table 6 shows death rates from the leading causes of child deaths from 1993 through 2003. Of the five leading causes of death of children age 1-14, only two were medical causes. Unintentional injury, homicide, and suicide together account for 79 percent of all deaths among children age 1-14 in 2003.

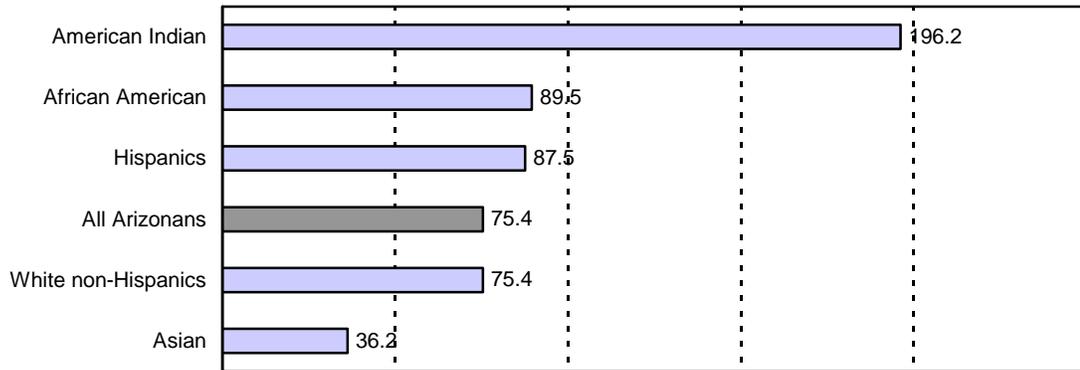
Table 6. Mortality Rates for the Leading Causes of Death per 100,000 Children Age 1 through 14 1993 through 2003

Cause	1993	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003
Unintentional Injuries	16.8	14.4	18.2	14.9	15.0	12.7	9.7	10.8	11.6	8.5	9.1
<i>Motor Vehicle Accidents</i>	7.8	6.5	9.1	8.7	8.4	6.5	5.8	5.8	5.3	4.8	5.4
<i>Drowning</i>	3.6	3.2	4.4	3.0	3.3	3.4	2.2	2.8	3.1	1.9	2.0
<i>Other Accidents</i>	5.4	4.8	4.6	3.2	3.3	2.8	1.8	2.2	3.2	1.8	1.7
Cancer	3.6	3.6	2.1	2.3	3.0	2.2	2.7	2.7	2.3	1.9	2.6
Congenital Malformations	3.3	1.8	1.6	1.8	1.8	1.5	1.7	1.0	1.9	1.5	1.8
Homicide	2.7	2.5	2.9	2.8	1.3	2.5	1.1	0.8	2.2	1.6	0.8
Suicide	1.3	1.0	1.2	0.8	0.7	1.1	0.7	0.6	0.8	1.0	0.7
All Causes Arizona	39.3	35.9	35.9	32.3	33.1	31.0	24.1	25.3	28.1	23.7	24.3
All Causes Urban	33.3	31.9	31.0	27.3	29.0	29.2	21.4	24.4	27.3	21.8	22.4
All Causes Rural	60.3	53.1	38.4	42.1	34.6	27.4	30.3	29.6	35.3	32.7	33.5

ADOLESCENT MORTALITY

There were 304 deaths among adolescents age 15-19 in Arizona in 2003, representing a rate of 75.4 deaths per 100,000 adolescents. Adolescent death rates are three times higher than the death rates of children age 1-14. In 2003, there were 101.5 deaths per 100,000 rural adolescents, compared to 69.8 per 100,000 urban adolescents. American Indian adolescents died at two and a half times higher rate than adolescents statewide (see figure 56).

Figure 56. Mortality Rates per 100,000 Adolescents Age 15-19 by Race and Ethnicity, Arizona 2003



Motor vehicle accidents were the leading cause of death among adolescents, followed by homicide, suicide, other accidents, cancer and heart disease. Table 7 shows the death rates from leading causes of death from 1993 through 2003. Unintentional injury, homicide, and suicide together account for 75 percent of all deaths among adolescents age 15-19 in 2003.

Table 7. Mortality Rates for the Leading Causes of Death per 100,000 Adolescents Age 15 through 19 1993 through 2003											
Cause	1993	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003
Unintentional Injuries	48.9	43.9	52.8	46.1	35.7	39.9	35.8	35.9	37.6	36.7	34.7
<i>Motor Vehicle Accidents</i>	38.4	35.9	40.9	37.0	27.2	32.3	29.4	27.5	26.3	28.1	26.0
<i>Other Accidents</i>	10.6	8.0	11.9	9.1	8.5	7.6	6.5	8.4	11.3	8.6	8.7
Homicide	23.9	27.9	33.4	24.4	19.0	16.8	16.2	14.4	12.9	14.8	11.9
Suicide	22.7	23.7	18.7	18.2	23.7	15.2	10.6	11.1	10.5	9.9	9.7
Cancer	3.9	5.7	4.3	3.3	4.4	3.7	3.5	3.8	5.3	4.3	2.5
Heart Disease	2.7	2.3	1.4	1.6	2.2	2.4	2.1	1.6	2.6	1.8	1.2
All Causes Arizona	117.0	115.6	130.4	114.6	103.1	90.9	81.4	78.9	86.6	82.7	75.4
All Causes Urban	103.7	108.1	114.2	93.3	84.5	81.4	72.4	75.4	77.6	82.4	69.8
All Causes Rural	159.6	145.2	128.2	145.1	117.0	91.1	96.1	92.8	123.2	83.9	101.5

Source: Arizona Health Status and Vital Statistics, 2003 Table 2C-12

Motor vehicle accidents accounted for 105 of the deaths, representing 35 percent of all adolescent deaths. Males had a higher mortality rate related to motor vehicle accidents compared to females, with a rate of 35.9 compared to 15.5. Rural adolescents had a higher rate than urban adolescents, with a rate of 44.5 compared to 22 per 100,000.

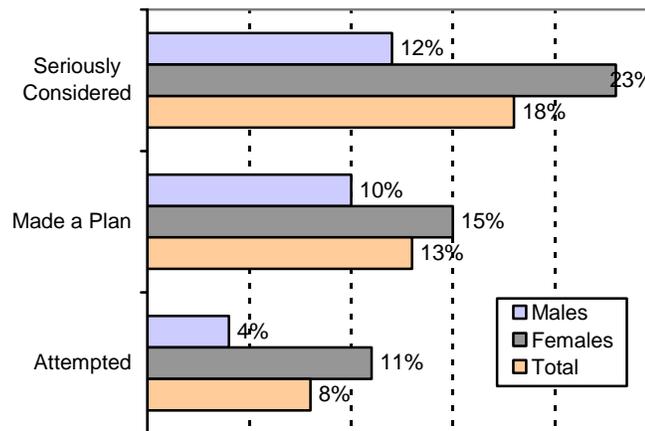
The YRBS asked questions about some risk behaviors related to motor vehicle mortality. Thirteen percent of students in Arizona said that they never or rarely wore a seatbelt when riding in a vehicle driven by someone else. Thirty-five percent of high school students reported that they had ridden in a vehicle being driven by someone who had been consuming alcohol, and 14 percent of students reported that they had driven a vehicle at least once in the past thirty days after consuming alcohol.

SUICIDE

Thirty-nine adolescents committed suicide in 2003, representing a rate of 9.7 per 100,000 adolescents age 15-19. Males committed suicide at a rate three times higher than females (14.8 compared to 4.1 per 100,000), and rural adolescents committed suicide at a higher rate than urban adolescents (12.5 compared to 9.1 per 100,000).

While males commit suicide at a higher rate than females, females appear to be a higher risk in terms of suicide ideation. Eighteen percent of students said that they had seriously considered suicide, 13 percent said they had made a plan, and 8 percent said they had actually attempted suicide. Among females, 23 percent had seriously considered suicide, 15 percent had made a plan, and 11 percent said they had actually attempted suicide (see figure 57).

Figure 57. Suicide Risk Grades 9-12 in Last 12 Months, Arizona 2003



Only 39 percent of schools offered a suicide prevention education program or service at their school, according to the 2003 Safe and Drug Free Schools report.

CHILD FATALITY REVIEW

The Child Fatality Review teams from across the state review deaths of children under the age of 18 to determine which deaths could reasonably have been prevented and make recommendations for elected officials, policy makers, and the Arizona public. They reviewed 937 of the 1,053 deaths of children under age 18 in 2003, and concluded that the deaths of 240 children, representing 26 percent of all child deaths, could have been prevented last year through the use of safety belts and infant restraints, secured pool fences, locked storage of guns, and other preventive practices.

Motor vehicles crashes have consistently been the most common cause of preventable death for Arizona children. In 2003, the Child Fatality Review Teams determined that 9 out of 10 of them could have been prevented. Driving under the influence of alcohol or drugs and the driver's youth were factors in many of the motor vehicle deaths. The team recommends supporting legislation that will increase seat belt use by children and adults, supporting legislation to increase restrictions on teen driving, and messages to parents to model safe behaviors for children through their use of seat belts, always buckling up their children, and placing them in the back seat of the car, in the center, whenever possible.

Drowning deaths continue to be a major cause of preventable deaths in young children, especially those under five-years old. Twenty-eight children drowned in 2003, 14 were children under age five who died in backyard pools. The vast majority of these deaths could have been prevented by better supervision of the child and secured pool fencing. The Child Fatality Review Team recommends uniform, statewide pool-fencing ordinance that restricts young children's access to pools, and education of parents that they should never leave children unsupervised around water.

Homicide, suicide and child maltreatment accounted for 79 of the deaths in 2003. Violent deaths are major public health concerns in Arizona and are significant categories of preventable deaths.

NONFATAL INJURY AND POISONING

Nine percent of children age 0-5 were injured and required medical care in the past 12 months, according to NCHS data for 2003. Of those 70 percent stated that the injury occurred at home, 5 percent reported that it occurred at a childcare facility, and 25 percent reported that the injury occurred at some other place. Each question was asked individually, and the respondent had the opportunity to mark more than one location.

Less than one percent of children age five and younger had been accidentally poisoned and required medical care in the past 12 months. Of those 73 percent

stated that the poisoning occurred at home, none reported that the poisoning occurred at a childcare facility, and 60 percent reported that the injury occurred at some other place.

HOSPITAL INJURY DATA -- CHILDREN UNDER AGE 15

There were 4,345 inpatient hospitalizations for non-fatal injuries and poisonings among children under age 15 in 2003. Many more children who are injured are cared for on an outpatient basis in the emergency room. In 2004, there were 84,255 such emergency room visits among children age 1-14.

Most of the injuries (97 percent) were unintentional, 5 per 1,000 injuries were self-inflicted, and assaults represented 1 percent of injuries. For 1 percent of the emergency room visits, the manner was either undetermined, or some other classification. There were 1,382 injuries that were intentional. Eighty-one percent of unintentional injuries occurred in the 10-14 age group, and 376 (or 34 percent) were self-inflicted. Table 8 shows the number of nonfatal emergency room visits for injury and poisoning by cause and manner among children age 1-14 in 2004.

Table 8. Emergency Room Visits for Nonfatal Injuries and Poisonings By Mechanism and Manner Children Age 1-14, Arizona 2004						
	Unintentional	Self-Inflicted	Assault	Undetermined /Other	Total	Percent
Cut/Pierce	6,907	95	19	11	7,032	8.3%
Drowning/Submersion	81				81	0.1%
Fall	21,491		1	18	21,510	25.5%
Fire/Hot Object	1,684			7	1,691	2.0%
Firearm	25		5		30	0.0%
Machinery	54				54	0.1%
Motor-vehicle Traffic	4,655			3	4,658	5.5%
Pedacyclist	3,366				3,366	4.0%
Pedestrian	83				83	0.1%
Transport	1,593				1,593	1.9%
Natural/Environment	5,977				5,977	7.1%
Overexertion	4,885				4,885	5.8%
Poisoning	1,477	267	9	149	1,902	2.3%
Struck by, Against	18,676		552	8	19,236	22.8%
Suffocation	87	8			95	0.1%
Other and Unspecified	10,873	19	407	763	12,062	14.3%
Total	81,914	389	993	959	84,255	
Percent	97.2%	0.5%	1.2%	1.1%		

The leading cause of nonfatal injury among children under age 15 was falls, which accounted for 26 percent of nonfatal injuries, followed by being struck, which accounted for 23 percent of nonfatal injuries.

HOSPITAL INJURY DATA -- ADOLESCENTS AGE 15-19

There were 2,529 inpatient hospitalizations for non-fatal injuries and poisonings among adolescents age 15-19 in 2003. Many more adolescents are seen on an outpatient basis in the emergency room. In 2004, there were 37,084 non-fatal outpatient injury-related emergency room visits among adolescents age 15-19.

Most of the injuries (87 percent) were unintentional, 3 percent were self-inflicted, and 7 percent were the result of assaults. For 2 percent of the emergency room visits, the manner was either undetermined, or some other classification. There were 3,983 injuries that were intentional. Of the intentional injuries, 31 percent were self-inflicted, however females were more likely than males to have inflicted their injuries on themselves. Fifty-three percent of intentional injuries among females were self-inflicted, compared to 16 percent among males. Table 9 shows the number of nonfatal emergency room visits for injury and poisoning by cause and manner among adolescents age 15-19 in 2004.

Table 9. Emergency Room Visits for Nonfatal Injuries and Poisonings By Mechanism and Manner Adolescents Age 15-19, Arizona 2004						
	Unintentional	Self-Inflicted	Assault	Undetermined /Other	Total	Percent
Cut/Pierce	3,686	338	174	25	4,223	11.4%
Drowning/Submersion	16				16	0.0%
Fall	3,565	4		24	3,593	9.7%
Fire/Hot Object	558	2	3	1	564	1.5%
Firearm	106	2	69	17	194	0.5%
Machinery	162				162	0.4%
Motor-vehicle Traffic	7,354	1	2		7,357	19.8%
Pedacyclist	793				793	2.1%
Pedestrian	34				34	0.1%
Transport	1,197				1,197	3.2%
Natural/Environment	1,357				1,357	3.7%
Overexertion	3,520				3,520	9.5%
Poisoning	430	813	3	286	1,532	4.1%
Struck by, Against	6,475		1,648	67	8,190	22.1%
Suffocation	3	11	2		16	0.0%
Other and Unspecified	3,002	72	839	423	4,336	11.7%
Total	32,258	1,243	2,740	843	37,084	
Percent	87.0%	3.4%	7.4%	2.3%		

The leading cause of nonfatal unintentional injuries among adolescents was motor-vehicle accidents, accounting for 23 percent of unintentional injuries, followed by being struck, which accounted for 20 percent of unintentional injuries. Eleven percent of unintentional injuries were caused by cutting and piercing, and another 11 percent were caused by falls, and yet another 11 percent were caused by overexertion. There were 1,243 emergency room visits for nonfatal self-inflicted injuries. Sixty-five percent of them were due to poisoning, and 27 percent were due to cutting and piercing.

CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS

The Arizona Department of Health Services, Office for Children with Special Health Care Needs (ADHS/OCSHCN) has adopted the federal Maternal and Child Health definition of children and youth with special needs which focuses more on the need for services rather than specific conditions:

“Those children and youth who are 0-22 years old and who have, or at increased risk for, chronic physical, developmental, behavioral, or emotional conditions that require health and related services beyond those typically needed by children in the state.”¹⁰⁴

Children and youth with special health care needs (C/YSHCN) can have conditions that range from asthma to developmental delays such as autism or cerebral palsy or chronic mental health or behavioral conditions such as Attention Deficit Hyperactivity Disorder (ADHD), schizophrenic or bipolar disorder. Children and youth with genetic conditions such as Sickle Cell Disease and metabolic disorders are also included.

C/YSHCN METHODOLOGY

OCSHCN attempted to integrate a variety of different data sources to evaluate the needs of children and youth with special health care needs throughout the state. Several reports issued by other agencies or community groups were utilized to enhance the picture of C/YSHCN throughout Arizona. The overall methodology of this Needs Assessment was to provide convergent data on those factors that impeded achievement of the six National Performance Measures, to identify any specific unmet service needs, and as much as was feasible, to identify the reasons for the unmet needs.

There is a heavy reliance on the use of data from the National Survey of Children with Special Health Care Needs (NSCSHCN) to give an overview of the prevalence of C/YSHCN and the ability of families to achieve the six National Performance Measures.¹⁰⁵ However, the NSCSHCN only provides data on children age birth to 17 years of age and the criteria for inclusion as a C/YSHCN was very broad, with most of the children meeting the criteria through the use of medications. To supplement the prevalence data, additional information was utilized from Vital Records (birth and death of children with congenital

¹⁰⁴ McPherson M., Arango P., Fox H., Lauver C., McManus M., Newacheck P., Perrin J., Shonkoff J., and Strickland B. “A New Definition of Children with Special Health Care Needs.” *Pediatrics* 102.1 (1998):137-140.

¹⁰⁵ Blumberg S.J., L. Olsen, and M. Frankel, et al. National Center for Health Statistics. “Design and Operation of the National Survey of Children with Special Health Care Needs, 2001.” *Vital Health Statistics* 1.41 (2003).

abnormalities and/or birth defects, children receiving services through the Children's Rehabilitative Services (CRS) network of providers, children receiving services through Arizona Early Intervention (IDEA, Part C), the Arizona Department of Education database reporting the children by type of disability enrolled in Special Education throughout Arizona, and the Arizona Head and Spinal Cord Injury Registry.

Despite the diversity of data sources, not all C/YSHCN are included. For example, children not enrolled in CRS, but receiving medical treatment privately or through some other governmentally sponsored program, such as Indian Health Services, are not included; in fact, there was a paucity of data on Native American children with special health care needs in Arizona. Whenever appropriate, national studies of C/YSHCN were used to supplement these deficits, but it remains an empirical question as to whether these national data are reflective of the needs and experiences of Arizona C/YSHCN. If a child is not enrolled in special education, but still has special health care needs in the school system, they are not captured in the data provided by the Department of Education. To some degree, data from the Arizona Survey of School Nurses, the School-Based Health Centers, and the Asthma Coalition supplemented the deficiencies of the Department of Education data.

More inferential analyses of the NSCHSCN allowed definition of some of the risk factors for children not achieving the National Performance measures. Extensive analyses were performed on the service needs identified in the NSCSHCN and the association between unmet needs and demographic variables.

To supplement this picture of C/YSHCN, Arizona fielded a survey modeled after the NSCSHCN. The Arizona survey asked only questions related to the performance measures, any unmet needs the family was experiencing, and the reasons for the unmet needs. The Arizona survey focused on population of pre-defined special needs children [i.e., family members of C/YSHCN in the Community Development Teams, family members of developmentally delayed children (this survey was distributed by the Developmental Disability Council's annual public forums), Down's Syndrome Support Groups, families from Raising Special Kids, and families participating in Pilot Parents of Southern Arizona's Partners in Policy Making]. To ascertain if the perceptions of need expressed by the families of C/YSHCN matched those of the specialty providers, a survey was distributed to the Children's Rehabilitative Services providers that provided input on priority needs and barriers to having those needs met.

INTEGRATED SERVICES PARTNERS FORUM

In November 2004, OCSHCN convened a group to provide input on the response to a Request for Proposal for an Integrated Services Grant from the Division of Maternal and Child Health Bureau. This group consisted of 45 individuals representing local and state agencies, community organizations, providers,

consumers, family members of C/YSHCN, and YSHCN. The purpose of the meeting was to review the results of the National Survey of Children with Special Health Care Needs and the six National Performance Measures that relate to C/YSHCN. The group was asked to identify current and planned activities throughout the state that addressed the six National Performance Measures and who was working on them. Additionally, they were asked to identify any missing service elements and missing participants. As a final task they were asked to list the top three or four activities that related to each of the National Performance Measures. This information was summarized and delivered to the participants. This group will continue to review the activities throughout the state as they relate to the six National Performance Measures, evaluating them for effectiveness.

OCSHCN NEEDS ASSESSMENT PLANNING GROUP

In March 2005, OCSHCN convened a small group of individuals (some of whom had participated in the Integrated Services Partners Forum) from throughout Arizona to provide public input on the Needs Assessment. There were three meetings. The first was to review the results from the National Survey for Children with Special Health Care Needs, the results of focus groups conducted throughout the state, and to identify any activities that could address improving performance on the National Measures. The second meeting addressed the specific unmet needs of C/YSHCN in Arizona as shown by the National Survey of Special Health Care Needs Children, as well as the surveys and focus groups conducted by OCSHCN, and to evaluate the capacity of the health care system to meet these needs. The third meeting was conducted to achieve a group consensus in identify the priority needs for Arizona to address in the next five years. This group reviewed and provided comment on the Needs Assessment and Block Grant document submitted to MCHB July 15, 2005.

PUBLIC INPUT MEETINGS

Four formal public input sessions were held around the state. One session was scheduled to coincide with the Arizona chapter of the American Public Health Association meeting held in Tucson in the southern part of the state. Another session was held in more centrally located Phoenix. A third session coincided with the Arizona Local Health Officers Association conferences, and was held in Prescott in the northern part of the state. Finally, a session was held in Phoenix, which focused specifically on Native Americans. Each of these sessions were structured to present information on health trends and issues, and to gather input on community concerns, priorities, and preferred strategies. All of the sessions were well attended.

During the public input sessions, information was presented on health issues and trends in Arizona. Attendees then participated in facilitated group discussion about concerns in their communities, as well as priorities and strategies. In identifying priorities, public-input participants were asked to consider the size and

seriousness of problems, as well as the availability and effectiveness of interventions and resources to carry them out. In addition to the facilitated group discussion, comment sheets were made available for later review.

FOCUS GROUPS

OCSHCN conducted three focus groups in preparation for this Needs Assessment, two with family members of the Community Development Teams (one was conducted completely in Spanish) and one with providers contracted with OCSHCN to provide service coordination throughout the state. The locations of the focus groups conducted with the families were chosen to represent traditionally under-served locations, rural and monolingual Spanish and the availability and willingness of the families to participate. The focus groups with the family members consisted of administering the Arizona Survey of Children with Special Health Care Needs and then asking the participants to identify any obstacles in achieving the six National Performance Measures in their communities. Additionally, family members were asked to address any specific unmet need in their family or in the community. The provider focus group occurred during a regularly scheduled Service Coordinator Training offered by OCSHCN. The contracted providers were asked to describe any barriers to meeting the six National Performance Measures and to provide suggestions on how they might be overcome.

Each focus group took approximately three hours. Information was collected through the use of the initial survey and flip charts to record the participants' remarks. A recorder was present in all sessions.

SUSTAINABILITY PLAN

It is anticipated that future planning and review meetings will consist of a combination of the participants in the original Integrated Services Forum and the Needs Assessment Planning Group. This new group, supported by U.S. Department of Health and Human Services, Maternal and Child Health Bureau, State Implementation Grant for Integrated Community Systems for Children with Special Health Care Needs, will provide statewide leadership to the identification of activities to promote integration of services and achieve the six National Performance Measures. Over the three-year period of the grant, this group will meet at least quarterly, culminating in the publication of a white paper to be submitted to the Governor's Office with recommendations on enhancing/ changing services for C/YSHCN to maximize the breadth of services and to reduce duplication and improve access. One of the first activities of the Integrated Services Task Force will be to conduct a needs assessment looking at specific services, the population served, potential duplication and/or underserved populations, and to evaluate the funding mechanisms for these services. Additional surveys and focus groups will be conducted to complement the more quantitative data collection techniques. OCSHCN will continue to meet with the Integrated Services Partner's Forum and the Needs Assessment Planning Group as they evolve into the Integrated Services Task Force.

HEALTH CARE SYSTEM CAPACITY

PROVIDER CAPACITY

ADHS/OCSHCN has developed specific goals to provide expertise and educational outreach, and to develop and expand programs that serve as resources for Arizona providers serving C/YSHCN. As part of these activities, specific training and education is provided to the practicing physicians, residents, and other health care professionals which increases the capacity of these providers to assess, evaluate, and improve the provision of care for C/YSHCN.

One of these mechanisms to provide training and education involves a web-based educational delivery, tracking, and feedback system—the ADHS Learning Management System. As part of OCSHCN participation in the Learning Environment Assessment Project (LEAP), OCSHCN assessed the learner and technical readiness of physicians within the State of Arizona to participate in internet-based training. Based on OCSHCN Learner and Technical Readiness Assessment Surveys, 97 percent of the physicians rated their web-browsing skills as ok to excellent; 86 percent have access to the Internet; 80 percent would like to learn new things via the Internet; and more than one-fourth have already participated in Internet-based training. These positive results have led to the development of web-based training for physicians that will allow for teaching related to best practices, information and resources regarding C/YSHCN. OCSHCN is in the process of obtaining continuing education units for providers participating in these trainings.

DENTAL CAPACITY

The Office of Oral Health has a Robert Wood Johnson grant that provides hands on training for practicing dentists in working with special needs patients. OCSHCN has partnered with the community teams to identify interested dentists and has worked with them to identify potential issues and concerns raised by families who have children with special health care needs. This includes the lack of public funding for dental care for youth beyond age 18 in Arizona. OCSHCN partially funds a dentist in the Office of Oral Health who works to increase the number of children with special health care needs that receive sealants as well as expanding the provider pool of dentists who will treat C/YSHCN.

SPECIALTY CAPACITY

A recent study by the Health and Disability Research Group from Arizona State University reported that of the 12,013 physicians reporting a primary specialty on their Arizona license renewal, only 110 (approximately 1 percent) reported a pediatric specialty.¹⁰⁶

¹⁰⁶ Johnson, W. G., Rimza, M. E., Garcy, T., & Grossman, M. Arizona Physician Workforce Study, Part I, The Numbers of Practicing Physicians 1992-2004. Arizona State University William

CHILDREN'S REHABILITATIVE SERVICES (CRS)

The Arizona Department of Health Service (ADHS), Office for Children with Special Health Care Needs (OCSHCN) transitioned from direct service delivery to administrative oversight to the Children's Rehabilitative Services network of contracted providers in 1985. CRS provides interdisciplinary medical treatment, rehabilitation, and related support services to Arizona children birth to 21 years of age who have certain medical, handicapping, or potentially handicapping conditions and who meet financial eligibility requirements. The objective of CRS is to assure the highest quality comprehensive care through a family-centered, multi-specialty, interdisciplinary team approach in a cost-effective managed care setting. CRS provides these services through four regional Centers of Excellence; each with its own hospital and physician support. There are four primary CRS sites located throughout the state: Phoenix, Tucson, Flagstaff, and Yuma. Each of these primary sites provides outreach clinics in various specialties in other areas of the state. The outreach clinics occur in the rural communities of Casa Grande, Globe, Hilldale, Prescott, Safford, Sierra Vista, Springerville, Showlow, and Wilcox; the Colorado River communities of Bullhead City, Lake Havasu City, and Kingman; the border communities of Nogales and Douglas; and in the Native American communities of Chinle, Fort Defiance, Ganado, Kayenta, Keams Canyon, Page, Peach Springs, Sacaton, San Carlos, Tuba City, Whiteriver, and Winslow. These outreach clinics are designed to provide a limited specific set of services including evaluation, monitoring, and treatments in settings closer to a family's home. OCSHCN monitors the service delivery system, ensures contractual compliance, initiates quality improvement activities, and provides education, support, and technical consultation.

Table 10 shows the number of eligible members at each of the four Regional CRS sites for the past five years as well as the number of outreach clinic visits and inpatient days by site. The overall number of eligible members increased from 16,108 to 18,830 between FY 1999 and FY 2003 (17 percent). The largest percentage increases were seen at the Flagstaff site (27 percent), followed by Tucson (25 percent) and Phoenix (23 percent). The smallest increase was seen in Yuma (9 percent). Overall, the number of regional outreach clinic visits increased (13 percent), although the pattern varied depending on the regional site. Three of the sites showed a percentage increase in the number of outreach clinic visits: Phoenix (19 percent), Tucson (12 percent), and Yuma (3 percent). Flagstaff had a 7 percent decline in the number of outreach clinic visits. The number of eligible members receiving inpatient services declined slightly over the five-year period (13 percent) with the largest proportional decline seen at the Yuma clinic (54 percent). With advances in medical technology becoming more costly, it would be expected that there would be more of a decline in acute

C. Carey School of Business and the University of Arizona Health Sciences Center. June 12, 2005.

inpatient services at the more rural locations [e.g., Flagstaff (21 percent) and Yuma (54 percent)] compared to the tertiary hospitals in the metropolitan areas [e.g., Phoenix (18 percent) and Tucson (10 percent)].

Table 10. CRS Membership and Service Utilization ¹⁰⁷					
	FY 1999	FY 2000	FY 2001	FY 2002	FY 2003
Total Eligible Members	16,108	17,137	17,002	18,342	18,830
Phoenix	9,572	10,201	9,879	10,721	11,787
Tucson	3,712	3,827	3,959	4,209	4,646
Flagstaff	1,896	2,143	2,158	2,413	2,416
Yuma	928	966	1,006	999	1,007
Regional Outreach Clinic Visits*					
Total	9,851	9,846	10,864	10,211	11,158
Phoenix	5,845	5,746	6,662	5,613	6,981
Tucson	2,372	2,424	2,534	2,712	2,649
Flagstaff	1,178	1,209	1,174	1,383	1,101
Yuma	592	621	651	674	611
Number of eligible members with inpatient services					
Total	979	1,037	937	935	857
Phoenix	686	753	631	654	558
Tucson	240	238	256	226	263
Flagstaff	44	35	45	36	35
Yuma	13	14	13	20	6

* Excludes physician office visits and home visits.

SICKLE CELL ANEMIA PROGRAM

OCSHCN provides statewide screening, referral, and genetic education to infants, children, and adults with ancestry from the “world-wide malaria belt,” (i.e., Africa, Italy, Greece, Spain, India, Pakistan, Mexico, South America, and countries of the Middle East, Asia, Southeast Asia, and the Caribbean) that have the sickle cell gene. The program’s goals are to provide referrals for early diagnosis and treatment, educate individuals with the sickle cell disease or trait to make informed decisions regarding child bearing, provide guidelines and protocols to health care providers, and provide public education about the economic and social impact of sickle cell disease.

SERVICE COORDINATION

¹⁰⁷ Arizona Department of Health Services, Office for Children with Special Health Care Needs. Children’s Rehabilitative Services Utilization Report, FY 2003.

OCSHCN provides service coordination for Arizona families with children birth to three years of age who are eligible for the Arizona Early Intervention Program (AzEIP) and for children/youth with chronic medical problems, developmental delays, or traumatic brain injuries. Service coordination is an enabling function that assists families in accessing needed services and work toward independence. Through the program, families and community-based providers develop and implement an Individualized Family Service Plan, a Family Service Plan, or an Individualized Service Plan. Program objectives include having families acquire knowledge and skills to support the development of their child with special needs; communicate and coordinate all services among providers, emphasizing the team approach; and identify their concerns, priorities, and resources.

The AzEIP is a collaborative program of the Arizona Department of Economic Security (DES), Arizona Health Care Cost Containment System (AHCCCS), Arizona Department of Health Services (ADHS), Office for Children with Special Health Care Needs (OCSHCN); the Arizona Department of Education; and the Arizona Schools for the Deaf and Blind (ASDB) to provide individualized treatment plans for children eligible for early intervention under the Department of Education I.D.E.A, Part C. OCSHCN provides developmental screening and referral services through contracted providers to Arizona's infants and toddlers age birth to three years who are exhibiting developmental delays and may benefit from early intervention.

Table 11 shows the utilization of early interventions services for Arizona from 1997 through 2002, as reported to the U.S. Department of Education. There has been a 121 percent increase in the number of children served through AzEIP between the years 1997 and 2002, with the largest increase seen in children 24 to 36 months of age (150 percent). While the overall highest number of children served were non-Hispanic White, the largest proportional increase between 1998 and 2002 was seen in the Asian population (85 percent increase), followed by Hispanic children (62 percent increase).

	1997	1998	1999	2000	2001	2002	2003
Total Served by IDEA, Part C	1,575	2,281	2,520	2,924	2,924	3,487	3,725
Number Served by Age							
0-12 months	238	436	375	560	417	453	453
12-24 months	582	840	950	1,002	1,035	1,147	1,266
24-36 months	755	1,005	1,195	1,379	1,472	1,887	1,968
Number Served by Race/Ethnicity							
White not Hispanic	NA *	1,150	1,214	1,351	1,399	1,740	1,852
Black not Hispanic	NA	121	111	116	123	145	164
American Indian/Alaskan Native	NA	200	240	302	279	284	312
Asian/Pacific Islander	NA	27	32	33	47	50	52
Hispanic	NA	783	923	1,139	1,076	1,268	1,345

* Data were first reported by race/ethnicity in 1998. If all children were not reported by race/ethnicity, the number of children reported by age may not equal the number reported by race/ethnicity.

Children and teenagers with traumatic brain injuries (TBI), their families, and the providers involved in their care are provided an array of coordination services to assist in: the determination of priorities and the creation of the Individualized Service Plan; the assessment of needs and resources; the navigation of multiple service delivery systems; the completion of forms and applications for services; locating service providers; coordination of services; and supporting the child/youth and their family in the development and implementation of the Individual Educational Plan (IEP). As needed, TBI service coordinators advocate for children/youth and their families with providers, services, schools, and insurance companies; provide continuity as the child/youth moves through the stages of recovery; and assist in transitions from hospital to rehabilitation to home to school. In addition, the program provides community education and awareness of TBI and its effects.

The TBI Service Coordination Program is a jointly funded program between ADH/OCSHCN, the Governor's Council on Head and Spinal Injuries, and the BHHS Legacy Foundation, an Arizona charitable organization whose philanthropic mission is to enhance the life and health of Arizona.

¹⁰⁸ United States. Department of Education, Office of Special Education Programs, Data Analysis Systems (DANS). Individuals with Disabilities Education Act (IDEA) Data. Internet. <http://www.ideadata.org/> July 30, 2003.

COMMUNITY HOME NURSING

Community home nursing services are available to assist families who have children who are medically fragile or are at risk for developmental delays. OCSHCN partners with ADHS Office of Women and Children's Health (OWCH) to contract with specially trained community health nurses who provide in-home follow-up services to infants, children, and youth with special health care needs. OWCH funds services to infants 0-3 years of age who are enrolled in the Newborn Intensive Care Program, and OCSHCN funds services to children 0-21 who do not meet eligibility for other early intervention programs, but have a chronic medical condition or developmental concern that could benefit from short-term in-home intervention. Community home nurses support the family during transition from the hospital to home; conduct developmental, physical, and environmental assessments; and make referrals to appropriate community resources. The community health nurse provides support, education, and guidance to the family as they develop plans for the child's ongoing care.

COMMUNITY-BASED SERVICE SYSTEMS

OCSHCN works with local communities to develop parent-led, self-reliant, self-sustaining community organizations that can mobilize local, state, and federal resources to improve the quality of life for C/YSHCN and their families. Currently there are 11 teams serving 23 communities. Each community identifies its unique resources and issues impacting C/YSHCN and their families, and purposefully works to improve the system of care within their community. The community is strengthened by recognizing and building upon local community capacities to care for children. OCSHCN provides financial and technical resources to the team and to the parent leaders. In addition to monthly conference calls with the parent leaders, OCSHCN sponsors a biennial conference.

In 2005, OCSHCN staff partnered with parent community development leaders to develop or refine guidelines for parent involvement that include Community Parent Leadership/Roles and Responsibilities, Family Involvement Continuum, Organizational Steps to Create a Community Action Team, Protocol for Community Development, Service versus Development, Levels of Parent-Professional Partnership, Billing Guidelines, and Guidelines for Sustainability.

Building on the success of OCSHCN community development teams, parent leaders recommended a process of bringing families and constituents of Arizona's child-serving agencies together to expand the Community Development model to all agencies serving children and youth in Arizona to the Governor and the Governor's Children's Cabinet. The cabinet endorsed the participation of all state agencies in a summit, "Circles of Success, Communities of Strength," which was held in April 2005. Participants developed a strategic plan to implement this initiative within their own agencies. The statewide

partnership includes representation from the Office of the Governor, Arizona Department of Economic Security, Arizona Department of Education, Arizona Department of Health Services (OC SHCN and Behavioral Health Services), Arizona Department of Juvenile Corrections, AHCCCS, as well as families working with or being served by these agencies. The goal of this unique partnership is for families and agencies to work hand in hand to develop and enhance self-reliant, self-sustaining community organizations that mobilize local, state, and federal resources to improve the systems of care for C/YSHCN and their families.

INFRASTRUCTURE SYSTEM CAPACITY

LEARNING MANAGEMENT SYSTEM

ADHS has created the infrastructure to develop a learning management system by combining the resources of four offices: the Office of Nutrition and Chronic Disease Prevention, Public Health Preparedness and Response, Office for Children with Special Health Care Needs, and Emergency Medical Services. This system will allow the electronic tracking and evaluation of all web-based educational modules. These modules are always available, and can be utilized in real time or can be stored and reviewed at a later time. In addition to the tracking and educational modules, there will be a listserv available to participants to discuss the information with other e-learners. This system will be available to the four offices to provide training opportunities to their staff, their community partners, and family members. OC SHCN plans to utilize this technology to implement many of its training curriculums.

TELEMEDICINE NETWORK

Beginning in 2001, ADHS/OC SHCN/CRS Regional Contractors and the University of Arizona joined to expand the availability of CRS services through the use of telemedicine. The overall goal of this emerging delivery technology was to expand CRS services by allowing CRS members access to specialists without traveling to one of the metropolitan areas. It will also allow specialists the capability of providing CRS services to members in Flagstaff, Yuma, Tucson, and Phoenix without leaving their primary clinic.

QUALITY IMPROVEMENT ACTIVITIES

OC SHCN has instituted the use of the logic model as a tool to examine the strategic planning process, the evaluation methodology, and the service delivery processes utilized within the office. This information is formally shared in the OC SHCN Quality Improvement Committee that oversees the data collection and analysis of various quality improvement projects in the office.

CRS conducts its own Quality Improvement Committee that reviews a variety of quality issues in the delivery of services to CRS members (including utilization reports, grievances and appeals, denials, and complaints) and establishes clinical practice guidelines. As part of the contractual relationship with AHCCCS, OCSHCN/CRS Quality Improvement Committee must have two active Quality Improvement Projects. Currently, the committee is studying the delivery of transition-related services to CRS members 14 years of age and older.

Each of the parent-led community development teams conducts a needs assessment of their community, defines strategies to address those needs in a strategic plan, and monitors achievement of those goals through a report card. OCSHCN provides technical assistance in all of these activities.

OCSHCN conducts annual site visits of all contracted providers: CRS Regional Clinics, service coordinators, and community nursing providers. During these site visits, there is a comprehensive review of the medical records of selected cases to evaluate the appropriateness and effectiveness of the treatment plans, clinical interventions, and follow-up, as well as a financial audit to ensure compliance with appropriate billing procedures.

Additionally, OCSHCN conducts public forums in local communities to identify any unmet needs and to strategize with the local community on methods to address these needs. Numerous surveys are fielded to both professional communities and to families with C/YSHCN asking about unmet needs, service capacity, and the quality of the services in the communities. This information is integrated in the OCSHCN strategic planning process.

PREVALENCE AND DISTRIBUTION

Several information sources were used to develop a reasonably complete picture of children and youth with special health care needs and their families. This was necessary because no single data set contained the full complement of information needed. For example, some data sets only provided information of children ages 0-3 or 0-17, rather than ages 0-22, while others included only statewide data, rather than regional- or county-level data. Data on the specific types of special needs was similarly difficult to obtain from a single source.

BIRTH DEFECT PREVALENCE

The total number of birth defects is declining, dropping from 1,007 in 1999 to 940 in 2003, despite the fact that the population has substantially increased during that time (see table 12). While the highest number of birth defects for the past five years has been Other Respiratory or Circulatory Problems, except for 1999 when this classification was not used, there has been an overall decline in the number. Overall, most of the conditions showed a decline or a level effect over

the five years. The notable exceptions were anencephalus, other urogenital conditions, and cleft lip/palate. The prevalence of Spina bifida and Polydactyly increased between 2002 and 2003.

Congenital Anomalies	1999	2000	2001	2002	2003
Total Live Births	80,505	84,985	85,213	87,379	90,783
Total Congenital Anomalies	1007	1071	1107	1,125	940
Anencephalus	8	3	6	8	14
Spina Bifida	12	11	13	6	12
Hydrocephalus	14	17	16	13	5
Microcephalus	2	0	1	0	2
Other CNS Anomaly	4	5	9	5	0
Heart Malformations	25	24	41	51	34
Other Respiratory/Circulatory	0	222	206	237	139
Rectal Atresia	2	4	3	4	2
Fistula/Esophageal Atresia	4	7	8	6	4
Omphalocele	14	25	23	32	22
Other Gastrointestinal	7	7	12	0	0
Malformed Genitalia	19	19	16	13	12
Renal Agenesis	4	2	5	7	4
Other Urogenital	20	22	32	30	36
Cleft Lip/Palate	40	35	54	50	66
Polydactyly	16	11	21	11	15
Club Foot	22	25	37	31	31
Diaphragmatic Hernia	2	14	13	9	10
Other Musculoskeletal	28	23	29	24	15
Down's Syndrome	31	43	42	43	45
Other Chromosomal	15	17	14	15	18
Other	774	627	635	648	541
Overall Birth Defect Rate	1.3%	1.3%	1.3%	1.3%	1.0%

Source: Arizona Department of Health Services, Bureau of Public Health Statistics.

COMPLICATIONS AT BIRTH

In addition to the identified anomalies at birth, newborns can be at risk for future special health care needs by birth-related complications. Table 13 shows the incidence of complications at birth for children born in Arizona between the years 1999 and 2003. While the overall number of complications has gone down, there are two exceptions to this trend: an increase in the number of children who received ventilator assistance for more than 30 minutes and the number of children having a seizure at birth.

Table 13. Complications at Birth					
Condition of the Newborn	1999	2000	2001	2002	2003
Anemia	53	55	42	34	45
Birth Injury	108	137	110	99	59
Fetal Alcohol Syndrome	8	4	4	3	0
Membrane Disease	378	278	283	441	297
Meconium Aspiration	154	108	84	89	78
Assisted vent <30 min	1,820	1,316	1,575	1,643	1,731
Assisted vent >30 min	470	438	472	743	633
Seizures	120	124	140	146	199
Other	5,716	5,631	6,912	6,549	5,789
Total	8,153	7,333	7,939	7,767	6,788

Source: Arizona Department of Health Services, Bureau of Public Health Statistics, 2003.

NATIVE AMERICAN BIRTH DEFECTS

While the overall birth defect rate has decreased in Arizona newborns and the state has achieved the 2010 Healthy People Goal of 1.0 birth defects per 1,000 live births, a similar achievement has not been seen among Native Americans (see table 14). In 2003 the overall birth defect rate for Native Americans was 1.3 per 10,000 live births, down from 2.9 in 1999, but not at the 2010 goal. Much of this difference is due to the rate of Fetal Alcohol Syndrome (FAS) among children born to Native Americans in Arizona. In 1999, the rate of FAS among all Arizona live births was 0.1, decreasing to 0.03 in 2002. On the other hand, the rate of FAS among Native American live births was 0.6 in 1999, decreasing to only 0.36 in 2002.

Table 14. Rate of Fetal Alcohol Syndrome and Birth Defects per 1,000 Live Births					
	1999	2000	2001	2002	2003
Native American FAS Rate	0.60	0.36	0.19	0.36	NA
All AZ FAS Rate	0.10	0.05	0.05	0.03	NA
Native American Birth Defect Rate	2.9	1.9	1.9	2.2	1.3
All AZ Birth Defect Rate	1.3	1.3	1.3	1.3	1.0

Source: Arizona Department of Health Services, Bureau of Public Health Statistics.

NATIONAL SURVEY OF CHILDREN WITH SPECIAL HEALTH CARE NEEDS

The U.S. Centers for Disease Control and Prevention (CDC) collected data for the National Survey of Children with Special Health Care Needs (NSCSHCN) on a statewide level.¹⁰⁹ Using a screening tool to identify a child with special health care needs in households, the survey estimated the population of children and youth with special health care needs in Arizona at 11 percent (153,410) of the total child and youth population aged 0-17 years. In comparison, 13 percent of the United State's children and youth were estimated to have special health care needs. Given the rapid growth in the general population in Arizona, this number has no doubt grown since 2001. Based on the 2001 NSCHSCN, the proportion of all households with at least one child with a special health care need in Arizona was 18 percent, suggesting many families have more than one special needs child (see table 15). The prevalence of special needs was greater among males (13 percent) compared to females (8 percent) and both estimates were significantly lower than the national estimates for males and females. The prevalence of C/YSHCN increased with the age of the child, both nationally and in Arizona, which may reflect increasing identification and/or development of special health needs with age. Arizona had the highest prevalence of C/YSHCN (13 percent) in families with the income range of 200 percent to 300 percent above the Federal Poverty Level (FPL), but had significantly lower prevalence of C/YSHCN (9 percent) of families with the income level of less than 200 percent of the FPL compared to the national prevalence of 14 percent. In 2001, the FPL for a family of four was \$17,650. The prevalence of C/YSHCN was highest among Arizona families that identified themselves as multi-racial (18 percent), followed by non-Hispanic Black families (16.0 percent) and non-Hispanic White families (14 percent). Arizona had a significantly lower prevalence of C/YSHCN in Hispanic families (7 percent) compared to the national prevalence of 9 percent. There were insufficient cases to give a reliable estimate of the prevalence of C/YSHCN in Native American families.

¹⁰⁹ United States. Department of Health and Human Services. The National Survey of Children with Special Health Care Needs Chartbook 2001. Internet. <http://mchb.hrsa.gov/chscn/pages/toc.htm>.

Table 15. Prevalence of Children and Youth with Special Health Care Needs in Arizona, 0-17 years old ¹¹⁰		
	State %	Nation %
Child-Level Prevalence		
Percentage of C/YSHCN, 0 - 17 yrs old	10.8	12.8
Household-Level Prevalence		
Percentage of households with children that have one or more SHCN, 0 - 17 yrs old	17.8	20.0
Prevalence by Age		
Children 0-5 years of age*	5.5	7.8
Children 6-11 years of age*	12.0	14.6
Children 12-17 years of age	15.0	15.8
Prevalence by Sex:		
Female*	8.4	10.5
Male*	13.1	15.0
Prevalence by Poverty Level:		
< 200% FPL*	9.1	13.6
200% – 300% FPL	13.0	12.8
> 300% FPL	12.3	13.6
Prevalence by Race/Ethnicity:		
Hispanic*	6.8	8.5
White (non-Hispanic)	13.8	14.2
Black (non-Hispanic)	16.0	13.0
Multi-racial (non-Hispanic)	17.8	15.1
Asian (non-Hispanic)	4.4
Native American/Alaskan Native (non-Hispanic)	5.7	16.6
Native Hawaiian/Pacific Islander (non-Hispanic)	9.6

* Weighted Estimates

.... Prevalence data only available for States where this minority group makes up at least 5% of total population of children in the State.

■ Estimates based on sample sizes too small to meet standards for reliability or precision. The relative standard error is greater than 30 percent.

* Statistically significant from national data based on 95 percent Confidence Intervals.

IMPACT OF SPECIAL NEEDS ON THE CHILD AND FAMILY

The population meeting the broad definition of children with special health care needs is diverse, including children with a wide range of conditions with varying levels of impact.¹¹¹ This section describes the types of special needs these children have and the impact of their conditions on both children and their families in Arizona.

¹¹⁰ *Ibid.*

¹¹¹ *Ibid.*

Types of special health care needs are defined here not by the types of conditions or diagnoses that children have, but by the *consequences* of their conditions—that is, the types of services or treatments that children require or the effect of the condition on the child’s functional abilities.¹¹²

The NSCSHCN asked families about the impact of children’s conditions on their ability to do the things most children of the same age do. This question provides a general measure of the magnitude of the challenges that C/YSHCN experience in their daily lives. Families were also asked to rate the severity of their child’s condition on a 0 to 10 scale. Finally, the survey measured one specific aspect of impact that is important to all children of school age: the number of days of school missed due to both chronic and acute conditions during the year.

As shown in table 16, 23 percent of C/YSHCN had conditions that affected their activities usually, always, or a great deal. While looking at school absence due to illness, 15 percent of C/YSHCN had 11 or more days of school absences due to illness. For most children, the average is about three school absences due to illness in a given school year.

Financial problems had a substantial impact on the family; 18 percent of Arizona families faced financial problems due to their child’s condition and 9 percent of Arizona families with C/YSHCN paid \$1,000 or more out-of-pocket for medical care in the past year. Twelve percent of Arizona families with C/YSHCN spent 11 or more hours/week providing and/or coordinating health care for their child and 30 percent of C/YSHCN had families whose employment was affected by the child’s condition (e.g. reduced work hours or stopped working).

Table 16. Impact of Special Health Care Needs on the Child’s Health and on Their Families		
Impact on Child Health:	State %	Nation %
Health conditions often greatly affect their daily activities.	22.8	23.2
More than 11 days of school absences due to illness.	15.2	15.8
Currently uninsured.	5.1	5.2
Currently insured with coverage that is not adequate.	30.4	33.8
Impact on Family:		
Families pay \$1,000 or more in medical expenses per year.	8.6	11.2
Families experienced financial problems due to child’s health needs.	18.3	20.9
Families spend 11 or more hours per week providing and/or coordinating health care for child.	11.7	13.5
Family members had to cut back or stop working because of child’s health needs.	30.3	29.8

+ Weighted Estimates

Source: National Survey of Children with Special Health Care Needs (2001)

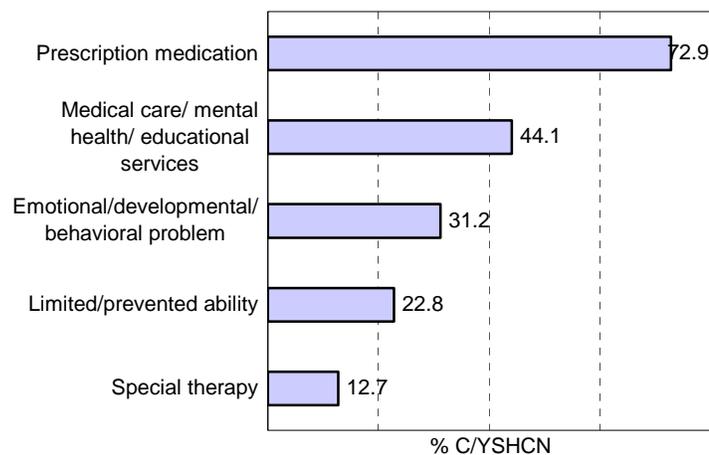
¹¹² *Ibid.*

TYPES OF SPECIAL HEALTH CARE NEEDS

No single database exists that provides comprehensive information on the types of conditions experienced by Arizona's children and youth with special health care needs. To address this, several data sources were utilized. Data from the NSCSHCN is the most inclusive of children with special healthcare needs, but is less specific about the types of special health care needs. Data from Arizona birth records indicates the prevalence of birth defects and congenital abnormalities identified at birth; the Arizona Department of Education data provides information on children enrolled in special education by their primary disability category; the data from Individuals with Disabilities Education Act (IDEA) provides information on the number of children access early intervention services; and the data from the Children's Rehabilitative Services shows the diagnostic categories of children receiving services.

The NSCSHCN has a C/YSHCN screener that includes five questions on general health care needs that could be the consequence of chronic health conditions (e.g., need for special therapies or need for prescription medication). If the parent reported that the child experienced one of these consequences, follow-up questions determined whether this health care need was the result of a medical, behavioral, or other health condition, and whether the condition had lasted or was expected to last for 12 months or longer. Those with affirmative answers to the item and both follow up questions were considered children with a special health care need. Figure 58 shows the most common reason for being classified as a C/YSHCN in the NSCSHCN was the use of prescription medication (73 percent).

Figure 58. Percentage of Children with Different Special Health Care Needs



ARIZONA DEPARTMENT OF EDUCATION DATA

Table 17 shows the number of children enrolled in special education in Arizona for 2002 and 2003 by the type of special health care needs. The most frequent special needs found in the educational system were related to learning disabilities, followed by speech and language impairments, and some type of developmental delays. These data only reflect the special need that required special education services in the academic setting.

Table 17. Number of Students Enrolled in Special Education in Arizona ¹¹³				
	2003		2002	
	N	%	N	%
Specific Learning Disabilities	56,890	50	54,165	52
Speech/Language Impairments	20,219	18	18,165	17
Mental Retardation	8,419	8	7,940	8
Emotional Disturbance	7,590	7	6,977	7
Multiple Disabilities	2,150	2	1,698	2
Auditory Disabilities	1,782	2	1,764	2
Orthopedic Disabilities	697	<1	681	<1
Other Health Impairments	3,566	3	2,922	3
Visual Disabilities	636	<1	667	<1
Autism	2,296	2	1,880	2
Visual and Auditory Disabilities	82	<1	80	<1
Traumatic Brain Injury	374	<1	319	<1
Developmental Delay	8,185	7	7,287	7
All Disabilities	112,886		105,121	

Source: <http://www.ade.az.gov/ess/DataManagement/2002-2003/default.asp>

Table 18 shows the number of children with specific types of disability or impairment by the age that they were enrolled in special education during the 2002 school year (other comparative data were not available). It is of some note that the number of children diagnosed with specific learning disabilities, multiple disabilities, emotional disturbances, and TBI increased between the ages of 6-11 and 12-17 years of age. On the other hand, the number of children diagnosed with autism and speech/language impairment decreased dramatically with increasing age.

¹¹³ State of Arizona. Department of Education. Arizona Department of Education Home Page. (June 24, 2005): Internet. www.ade.az.gov June 08, 2005.

Table 18. Number of Students by Age Enrolled in Special Education in Arizona (2002) ¹¹⁴				
	Ages 3 - 5	Ages 6 - 11	Ages 12 - 17	Ages 18 - 21
Specific Learning Disabilities	163	19,679	31,241	2,427
Speech/Language Impairments	2,522	14,548	1,372	33
Mental Retardation	246	3,037	3,476	900
Emotional Disturbance	47	1,988	3,658	246
Multiple Disabilities	62	869	1,354	339
Auditory Disabilities	139	822	709	94
Orthopedic Disabilities	45	369	228	42
Other Health Impairments	67	1,375	1,351	89
Visual Disabilities	114	290	248	36
Autism	152	1,073	519	97
Visual and Auditory Disabilities	4	27	31	7
Traumatic Brain Injury	1	97	187	24
Developmental Delay	7,044	-	-	
All Disabilities	10,606	44,174	44,374	4,334

Source: <http://www.ade.az.gov/ess/DataManagement/2002-2003/default.asp>

TRAUMATIC BRAIN INJURY

It is well documented that brain injury, and traumatic brain injury (TBI) in particular, is a leading cause of acquired disability in childhood.¹¹⁵ A traumatic brain injury is an injury to the head from a blunt or penetrating trauma or from acceleration-deceleration forces. This injury is associated with any of the following symptoms or signs: decreased level of consciousness, amnesia, neurologic or neuropsychologic abnormalities, skull fracture, diagnosed intracranial lesions, or death. The prevalence of TBI in children has been estimated to be 1 million injuries per year,¹¹⁶ with an incidence of 150 to 200 per 100,000 children annually.¹¹⁷ Other data indicate that there are as many as 5 million pediatric TBIs per year, with only 200,000 children hospitalized annually.¹¹⁸ Each year in the United States, among children ages 0 to 14 years, TBI results in an estimated 3,000 deaths, 29,000 hospitalizations, and 400,000 emergency room visits.¹¹⁹ Youth between the ages of 15 and 19 are the most

¹¹⁴ Ibid.

¹¹⁵ Lazar, M. F. & Menaldino, S. "Cognitive Outcome and Behavioral Adjustment in Children Following Traumatic Brain Injury: A Developmental Perspective." *Journal of Head Trauma and Rehabilitation* 5 1995: 55-63.

¹¹⁶ Savage, R. C. "Identification, Classification, and Placement Issues for Students with Traumatic Brain Injuries." *Journal of Head Trauma and Rehabilitation* 1 1991: 1-9.

¹¹⁷ Kraus, J. F. & McArthur, D. L. "Epidemiological Aspects of Brain Injury." *Neuroepidemiology*. 53 1996: 519-531.

¹¹⁸ DiScala, C., Osberg, J., & Savage, R. "Children Hospitalized for Traumatic Brain Injury: Transition to Acute Care". *Journal of Head Trauma and Rehabilitation*. 2 1997: 1-10.

¹¹⁹ National Association of State Head Injury Administrators. *Home Page of NASHIA*. Internet. www.nashia.org May 23, 2005.

likely to sustain a TBI, and by the age of 16, four out of every 100 boys and 2.5 out of every 100 girls will have sustained a TBI.¹²⁰

The consequences of a TBI may include problems with: cognition (concentration, memory, judgment, and mood), movement abilities (strength, coordination, and balance), sensation (tactile sensation and special senses such as vision), and emotion (instability and impulsivity).¹²¹ A TBI may present with numerous learning difficulties including the ability to learn and retain new and old information, attention deficits, and difficulty planning and following through with tasks.

Arizona is one of 12 states receiving CDC funding for ongoing, systematic collection and analysis of TBI data as part of the Traumatic Brain Injury Surveillance Program. Through this program, each participating state characterizes TBI risk factors, incidence, external causes, severity, and short-term outcomes via population-based surveillance of TBI-related hospitalizations and deaths. The most recent data from Arizona's Traumatic Brain Injury Surveillance Program show an incidence rate of 112.9 TBIs per 100,000 persons compared to a national estimate of 95 per 100,000 persons.¹²² Spinal cord injury (SCI) rates are difficult to determine nationally due to smaller numbers and fewer studies of incidence. The incidence rate in Arizona for the four-year period 1995-1998 was 5.9 SCI's per 100,000 persons. From 1995 to 1998, 20,221 Arizona residents sustained traumatic brain-related injuries, which resulted in pre-admission death or hospitalization. More than 4,000 (21 percent) died. Nearly 75 percent of those deaths occurred before admission to a hospital.

- Males outnumbered females in TBI incidence by 2:1 and were three times more likely to die from a TBI than females.
- The highest incidence rate of TBI was seen in those 85 years and older (242.1 TBIs per 100,000) followed by 15-19 year olds (174.7 TBIs per 100,000) and 20-24 year olds (169.9 TBI per 100,000). The annualized age-adjusted rate was (112.9 TBIs per 100,000).
- By race/ethnicity in 1998 alone, the age-adjusted rate of TBI was highest among Native American males (263.3 per 100,000), with Hispanic males second highest (162.0 TBIs per 100,000). For females, Native Americans had the highest rate (101.4 per 100,000), and White, non-Hispanic females second highest (64.8 TBIs per 100,000).

¹²⁰ Christensen, J. R. "What is traumatic brain injury?" Children with Traumatic Brain Injury: A Parent's Guide. Schoenbrodt, I. (ed). New York: Woodbine House, 2001.

¹²¹ Thurman, D. J., Sniezek, J. E., Johnson, D., Greenspan, A., & Smith, S. M. Guidelines for Surveillance of Central Nervous System Injury. Atlanta: Centers for Disease Control and Prevention, 1994.

¹²² Arizona Department of Health Services. Arizona Injury Surveillance and Prevention Plan 2002 – 2005. Internet. <http://www.azdhs.gov/bems/trauma-pdf/injuryprevplan.doc>.

The Arizona Governor's Council on Spinal and Head Injuries, founded in 1992, is funded through the State Trust Fund that receives funds from a surcharge on civil and criminal penalties, including motor vehicle violations. The Arizona Department of Health Service, Office for Children with Special Health Care Needs collaborates with the Arizona's Governor's Council on Spinal and Head Injuries to provide service coordination for children and youth up to age 22 who have experienced a TBI. To be eligible to TBI Service Coordination, the head injury must have occurred between the ages of 2 and 17 and one or more of the following conditions must be present: 1) observed or decreased level of consciousness, 2) amnesia, 3) skull fracture, 4) objective neurological or neuropsychological abnormality linked to traumatic event, 5) intra-cranial injury, including lesion, concussion, contusion, laceration, or hemorrhage, 6) mild, moderate, or severe brain injury. Referrals may be made within two years post-injury.

CHILDREN'S REHABILITATIVE SERVICES (CRS)

CRS has restrictions on the type of child that can be served in this system and therefore the data does not provide a statewide prevalence of certain diagnostic conditions. However, an examination of the prevalence of conditions served by this system does give some measure of need in the system. As seen in table 19, the number of children served by CRS has increased from 15,372 in 1999 to 18,830 in 2003, a 23 percent increase in the number of children served. The largest increases were seen among children with genitourinary diseases (80 percent), diseases of the respiratory systems (56 percent), nervous system (52 percent), and endocrine systems (52 percent). There was a decline in the proportion of children with cystic fibrosis (1 percent), congenital anomalies (3 percent), and other conditions (65 percent).

Table 19. Primary Diagnosis/Disease Classification of Children and Youth in CRS						
Primary Diagnosis/Disease Classification	1999	2000	2001	2002	2003	Percent Change from 1999 to 2003
Cerebral Palsy	1,858	2,004	2,009	2,204	2,306	24.1%
Cleft Lip/Cleft Palate	972	995	1,017	1,034	1,090	12.1%
Cystic Fibrosis	147	151	145	148	145	-1.4%
Spina Bifida	478	493	486	485	491	2.7%
Neurofibromatosis	170	188	192	209	246	44.7%
Metabolic	167	184	192	222	249	49.1%
Scoliosis	370	39	349	364	386	4.3%
Sickle Cell	71	67	66	69	81	14.1%
Neoplasm	131	115	123	163	195	48.9%
Endocrine	235	266	281	320	358	52.3%
Blood and Blood Forming Organs	21	19	19	19	21	0.0%
Nervous System	1,356	1,528	1,598	1,894	2,062	52.1%
Sense Organs	1,993	2,051	2,000	2,164	2,383	19.6%
Circulatory System	2,675	2,675	3,003	3,359	3,708	38.6%
Respiratory System	50	66	73	67	78	56.0%
Digestive System	212	222	229	267	305	43.9%
Genitourinary System	556	612	626	817	999	79.7%
Skin and Subcutaneous	53	56	47	56	67	26.4%
Musculoskeletal and Congenital Deformities	2,432	2,497	2,399	2,655	2,989	22.9%
Congenital Anomalies	268	275	240	235	260	-3.0%
Other	1,157	1,150	1,043	689	411	-64.5%
Total	15,372	16,206	16,137	17,440	18,830	22.5%

Source: Children's Rehabilitative Services Utilization Report FY 2003

ASSESSMENT OF THE NEEDS

ASTHMA PREVALENCE

Asthma is the most common chronic disease in children. The CDC reports that 9 million U.S. children have been diagnosed with asthma at some point in their lives, and more than 4 million have had an asthma attack in the past 12 months.¹²³ This report, based on 2002 data from the CDC's National Health Interview Survey, shows that 12 percent of children under the age of 18 have been diagnosed with asthma. Boys (14 percent) were more likely than girls (10 percent) to have been diagnosed with asthma. Children from poorer families (16 percent) were more likely to be diagnosed with asthma than children in families that were not poor (11 percent).

¹²³ United States. Centers for Disease Control and Prevention. National Center for Health Statistics. (July 1, 2005): Internet. www.cdc.gov/nchs May 2, 2005.

The Arizona Hospital Discharge Data (2003) showed that for children under the age of 21 years of age, there were a total of 2,952 hospitalizations where asthma was the principal diagnosis. Approximately 39 percent were between birth and 4 years of age, 46 percent were between 5 and 14 years of age, and 9 percent were between 15 and 21 years of age. The average stay was 2.5 days with a total of 7,250 days for all hospitalizations. An average of \$8,153 was spent per hospitalization with a total health care expenditure of \$24 million.

IMPACT OF ASTHMA IN THE SCHOOL SYSTEM

To determine the impact of asthma prevalence in the school system, OCSHCN sent a modified version of the “Survey of Delaware School Nurses Regarding Students with Asthma Survey” to a random sample of 671 elementary schools and 452 high schools in the spring of 2001. There was a response rate of 68 percent (n=454) in schools with pre-kindergarten through 8th grades and a 56 percent (n=255) response rate for high schools. Forty-nine percent of the schools require parents to notify school personnel if their child has asthma. Schools reported that they were notified of the existence of asthma by the parents 89 percent of the time, by the student 18 percent of the time, and by an acute asthma episode 14 percent of the time. Approximately 80 percent of both public and charter schools reported having at least one child with asthma attending classes. The overall asthma prevalence was 7 percent, 7 percent in elementary schools, 9 percent in high schools, 8 percent for public schools, and 4 percent for charter schools.

Nearly 60 percent of the schools did not maintain a readily accessible care plan for children with asthma, although 63 percent of the schools documented the care provided at school in the child’s health record. Less than 30 percent of schools obtained a baseline peak flow reading for students with asthma. Twenty-four percent of the schools did not allow students to carry their asthma medications; 80 percent obtained their medications from the school nurse, and 14 percent obtained their medications from the principal’s office. Elementary schools were nine times more likely than high schools to not allow students to carry their asthma medications. Schools that did allow students to carry their medications generally required either a physician’s request or a special release from the parents. More than 25 percent of the schools reported student compliance with their treatment plans was problematic. The primary reasons for noncompliance were improper inhaler technique (64 percent), missed scheduled doses (61 percent), and lack of information/education (59 percent). Seventy-nine percent of schools used non-pharmacological interventions for children; 92 percent used a calming environment, 87 percent used emotional support, and 74 percent administered hot liquids.

Recent legislative changes in Arizona now allow students to carry asthma medications. It will be interesting to watch how these new regulations impact the effective utilization and management of these medications and control of the negative symptoms of asthma.

Most schools took some action to eliminate environmental triggers. Eighty-five percent performed cleaning during non-class hours; 73 percent performed painting during non-school hours; and 65 percent routinely changed air filters. However 5 percent of the schools took no action to improve the air quality and reduce environmental triggers. Only 1 percent of the schools never allowed students with asthma to participate in physical activity, and 97 percent of the schools permitted participation in physical activity when the asthmatic students were asymptomatic.

This survey revealed that asthma is a significant problem for Arizona children attending public and charter schools and there is a significant variability in the policies and services for school children with asthma. The specific recommendations resulting from this study were:

- All children with asthma have baseline peak flow readings and a care plan on file with their school.
- Schools adopt procedures to give students ready access to their asthma medications.
- Schools use EPA “Tools for Schools” to reduce asthma triggers.
- School personnel, students and their families, and providers receive education on treatment compliance.

The Arizona Asthma Coalition—a non-profit partnership of state and local public health departments, the Indian Health Service, health plans, academic faculty, school nurses, environmental health experts, members of the legislature, community non-profit organizations, and health care providers—was formed in 1996 because public health and managed care providers were concerned that asthma is more prevalent and serious in Arizona than in other states.

ASTHMA MORTALITY RATE

As seen in table 20, the rate of death from asthma in Arizona increased between 2000 and 2003 and the death rate among very young children (0-4 years old) was above the Healthy People 2010 goal of 0.1 per 100,000.¹²⁴ The asthma mortality rate among children aged 5 to 14 years (1.2 per 100,000) was less than that of younger children, but still did not meet the 2010 goals of 0.1 for this age group.

¹²⁴ Arizona Department of Health Services. Public Health Services, Bureau of Public Health Statistics. Arizona Health Status and Vital Statistics, 2003.

Table 20. Mortality Rates for Asthma in Arizona Compared to 2010 Target ^a						
	Baseline for the U.S.	2000	2001	2002	2003	2010 Target
Asthma deaths among children under age 5 years	2.1	0	0	0	4.8	1.0
Asthma deaths among children age 5 to 14 years	3.3	1.3 ^b	0	2.4 ^b	1.2 ^b	1.0

^a Mortality rates are per 1,000,000 population

^b These rates are based on fewer than 10 deaths and are not statistically reliable

INFANT MORTALITY RATE BY BIRTH DEFECTS

As seen in table 21, while the infant mortality rate due to birth defects has been decreasing, the rate of 1.4 per 1,000 live births in 2003 is still above the 2010 target of 1.1 deaths per 1,000 live births.¹²⁵

Table 21. Mortality Rates by Birth Defects in Arizona Compared to 2010 Target ^a						
	Baseline for the U.S.	2000	2001	2002	2003	2010 Target
Infant death due to birth defects	1.6	1.6	1.7	1.1	1.4	1.1

^a Mortality rates are per 1,000 live births

Table 22 presents the mortality of children enrolled in CRS for the year 1999 through 2003. The number of deaths to children served by this system has gone down over the five-year period.

Table 22. Inpatient Deaths of CRS Members					
	1999	2000	2001	2002	2003
Percent of Death to Eligible Members	0.1	0	0.1	0.1	0
Number of Deaths	12	6	11	10	8
Mean Age	3.8	8.0	4.3	4.0	6.6
Total Eligible Members	15,321	16,206	16,137	17,440	18,830

Source: Arizona Department of Health Services, Office for Children with Special Health Care Needs, Children's Rehabilitative Services, Utilization Report FY 2003, Summary for Fiscal Years 1999-2003.

NATIONAL PERFORMANCE MEASURES

The Maternal and Child Health Bureau, Health Resources and Service Administration, has identified six performance measures to assess the progress in implementing community-based systems of services for C/YSHCN. Four of the six performance measures are presented here utilizing the data from the NSCSHCN. Performance Measure 1 (early and continuous screening) was not measured by the NSCSHCN and the data relating to Performance Measure 6 (transitions) did not meet acceptable reliability standards.

¹²⁵ *Ibid.*

Each of the four performance measures from the NSCSHCN were disaggregated into its essential elements or underlying concepts, and these essential elements were then translated into measurable criteria using items contained in the survey. A performance measure was achieved when participants responded “yes” to all essential elements or underlying concepts (key indicators). The percentage shown in each individual table reflects the weighted frequencies of each of the overall performance measures and each of the underlying concepts.

- National Performance Measure 1. The percent of newborns who are screened and confirmed with condition(s) mandated by their state-sponsored newborn screening programs (i.e., phenylketonuria and hemoglobinopathies) who receive appropriate follow up as defined by their state.

Newborn Screening Program screens Arizona newborns twice for 27 inherited disorders—once prior to hospital discharge, and again at the two-week well baby doctor visit. Follow-up is provided to ensure that medical treatment can be promptly initiated to avert metabolic crisis and prevent irreversible neurological and developmental outcomes. Arizona achieved 100 percent compliance with this performance measure in 2004. Newborns in Arizona also receive a mandated hearing screening.

ADHS/OCSHCN provides consultation and educational services for children with Sickle Cell Disease, as well as those with the trait. OCSHCN staff contact parents immediately upon notification by the newborn screening unit of a diagnosis of Sickle Cell Disease. OCSHCN maintains contact with the parents up to three times a week during the first three months following the diagnosis. Additionally, OCSHCN provides education to parents, medical providers, and schools on Sickle Cell Disease.

In 2003 the Sedona Group (a world-renowned group of hematologists, the state Sickle Cell Program, and consumers from several states) developed and administered the Sickle Cell Patient and Family Needs Assessment Survey. There were 42 parent/caregiver respondents in Arizona of children ranging in age from 9 months to 20.9 years. The results indicated that 74 percent of the respondents had no trouble getting good health care; 76 percent felt comfortable treating and controlling their child’s pain; 7 percent were having no problems with health insurance; 88 percent were comfortable with the clinic staff’s knowledge of Sickle Cell Disease; 90 percent stated that the clinic understood and was sensitive to the family’s cultural background and needs; 95 percent felt they were part of the decision-making process; and 60 percent of those with children over the age of 12 felt their children were being prepared for an independent life. In open-ended questions, parents reported that they had difficulty dealing with their children’s pain and needed more information on support groups, transition to adulthood, and research/transplants.

ADHS/OCSHCN also monitors children identified through the rapid-response system of the Arizona Birth Defects Registry to ensure that families have information about the services provided through Children's Rehabilitative Services.

The members of the two planning committees and the focus groups approached this national performance measure as it related to screening in general. They felt that, other than newborn screening, there was no standard for screening for developmental delays. They felt there needed to be standardized assessment tools, standardized timeframes defining when assessments were done, standardized definitions of what was screened, and a standardization of who was qualified to conduct screenings. Additionally, they felt there was a general need to identify best practices for screening, including a statewide set of core competencies that would determine training and certification needs. Family members and professionals all agreed on the need to expand what is being screened for (e.g., to add screening for TBI, depression/anxiety, domestic violence) and a need to educate providers and consumers about screening.

- National Performance Measure 2. The percent of children with special health care needs age 0 to 18 years whose families partner in decision making at all levels and are satisfied with the services they receive.

The Omnibus Budget Reconciliation Act of 1989 mandated that states promote and provide family-centered, community-based, coordinated care for children and youth. Family satisfaction is also a crucial measure of the system's effectiveness. When children, youth, and families are fully informed and understand their health care options, better decisions can be made regarding individual treatment and services, which results in a more effective use of systems of care.

Table 23 shows the percentage of respondents and the standard error (SE) from the NSCSHCN that agreed with the performance measure and the component parts of the measure. The responses represent input from the NSCSHCN (state and national), as well as input from the individuals that participated in the focus groups throughout Arizona. Respondents to the NSCSHCN reported that 51 percent of Arizonans partnered in decision-making and were satisfied with the services they received compared to 58 percent nationally, which ranked Arizona 46 among the 50 states and Washington, D.C. In contrast, only 25 percent of the members of the focus group agreed that they were treated as a partner in the decision-making process and only 32 percent were satisfied with the services they received.

Table 23. National Survey of Children with Special Health Care Needs			
<i>Outcome Measures</i>	Arizona % (S.E.)	Focus Groups % (S.E.)	National % (S.E.)
Outcome #2: Families of C/YSHCN will partner in decision-making and will be satisfied with the services they receive.	51.4 (4.6)	24.5 (4.4)	57.5 (0.8)
a. Doctors usually or always make the family feel like a partner	82.2 (3.7)	59.8 (5.0)	84.3 (0.7)
b. Family is very satisfied with services received	54.4 (4.6)	32.3 (4.8)	60.1 (0.8)

OCSHCN conducts a biannual family satisfaction survey of a random sample of families enrolled in the Children's Rehabilitative Services (CRS) program. The CRS program believes that the family is the most important participant in the system of care for children with special health care needs. The survey evaluates the family's satisfaction with the clinic operations and how well each of the disciplines involved in the multidisciplinary team achieves the national performance measures. Table 24 shows the percentage of families that reported satisfaction with various clinic operations. While there was non-response bias favoring input by the more satisfied families, the specific areas causing dissatisfaction were the wait time in the clinic and the size of the waiting rooms.

Overall, 90 percent CRS members were satisfied with appointment scheduling and coordination with other providers. The CRS members at the Yuma clinic were the most satisfied with appointment scheduling and time with doctors; the Flagstaff members were the most satisfied with wait time at clinic and coordination with other providers, and the Tucson clinic members were the most satisfied with information on treatment/surgery and size of the waiting room. This result may be biased due to disproportionate response rates.

Table 24. Percent of Families Satisfied with Services Received at Regional CRS Clinics					
SATISFACTION WITH CLINIC	All	Phoenix	Tucson	Flagstaff	Yuma
Appointment scheduling	90	87	89	97	100
Wait time at clinic	75	66	76	97	83
Time with physician	88	83	93	97	100
Information on treatments/surgeries	92	90	96	94	92
Coordination with other providers	91	86	94	97	92
Size of waiting rooms	89	87	93	88	92
Care received at CRS Regional Clinics	92	87	94	97	100

Source: Arizona Department of Health Services, Office for Children with Special Health Care Needs, Children's Rehabilitative Services, Family Centered Survey, 2004.

The CRS Family-Centered Survey evaluated three of the national performance measures. The first measure evaluated the presence of usual source of care. Sixty-three percent of the respondents reported that their child had a usual source of care. Almost 80 percent of the families reported that they received most of their medical services in one location (79 percent); 80 percent reported that there was one person that they thought of as their child's personal doctor or nurse, and 64 percent believed that the personal doctor or nurse provided most of the child's care.

The family was asked to rate each of the multi-disciplinary providers within the CRS clinic on aspects of family-centered care and care coordination. The results are shown in table 25. There was a very high level of satisfaction with all the staff, and there was no statistically significant difference between the different CRS staff members).

	Physicians	Nurses	Social Workers	Therapist
Child Receives Family-Centered Care:				
▪ Uses words that we understand	91.2	93.3	94.7	93.3
▪ Encourages us to ask questions during visits	84.6	79.8	87.8	88.3
▪ Makes decisions with us about our child	86.1	79.0	83.3	85.7
▪ Supports the decisions made by the family	90.7	89.2	90.4	90.7
▪ Respects our family's beliefs and customs	93.9	93.7	93.8	96.7
Child Receives Effective Care Coordination:				
▪ Helps us get the information we need	81.6	82.5	88.0	88.0
▪ Schedules visits that are good for our family	84.3	86.5	90.0	90.8
▪ Helps us get support from friends or community	67.0	68.3	76.8	75.5
▪ Helps us coordinate with other programs	71.2	71.7	81.8	82.6

The Needs Assessment Planning Group focused on the need for training of professionals and families related to involving the family as a partner in the decision-making process. They felt that there was a need to develop a definition of core competencies and specific training to each competency, as well as an intra-agency repository of training materials. They also felt there needed to be better integration of other service delivery systems, such as behavioral health. The family members were more specific in what they reported as deficits in the current system, potentially defining the topics to be included in an educational module. Families thought consistent policies and procedures focused on communication and ensuring that the family was involved in all communication, with or without a formal release of information, were needed. The families reported more specific instances of physician-to-physician communication not occurring; for example, when there were many physicians involved with the care of the child. Poor communication between professionals occurred when the physicians did not know one another, when there was an urban specialist physician and a local physician involved in the care (the specialist did not always

concur with the local physician's recommendations), and when physicians had different prescribing preferences. In none of these cases did the families consider themselves pivotal in the decision making process, although they did report that they were required to obtain all of the information and make sure each participating provider had all of the information.

- National Performance Measure 3. The percent of children with special health care needs age 0 to 18 who receive coordinated, ongoing, comprehensive care within a medical home.

Children with a stable and continuous source of health care are more likely to receive appropriate preventative care and immunizations, are less likely to be hospitalized for preventable conditions, and are more likely to be diagnosed early for chronic or disabling conditions. ADHS/OCSHCN uses the American Academy of Pediatrics (AAP) definition of a medical home, which states that a medical home is the provision of accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally competent healthcare services in a high-quality and cost-effective manner.

Table 26 shows the percentage of respondents from the NSCHSCN for Arizona and nationally, as well as results from the Arizona focus groups. Fifty-one percent of Arizonans agreed with the overall achievement of a medical home compared to 53 percent nationally, ranking Arizona 39th out of 50 states and the District of Columbia. On the other hand, only 18 percent of the members of the focus groups throughout Arizona agreed that their children received coordinated, ongoing, comprehensive care in a medical home. In general, Arizona respondents to the NSCSHCN were not significantly different from the overall national figures. The only exception was that Arizona had a significantly higher rating than the national data for the receipt of professional care coordination. Consistently, more members of the Arizona NSCSHCN and the Arizona focus groups reported that their child had a usual source of care than was seen in the national data. However, Arizonans (both NSCSHCN and focus group respondents) were less likely to endorse the statements that their child had a personal doctor or nurse, their child had no problems obtaining referrals, their child received effective care coordination, or their child received family-centered care than was noted in the national figures. The focus group members were significantly less likely than NSCSHCN national respondents to report that their child received effective care coordination, and they were significantly lower in their rating of physicians communicating with other programs than were the national respondents.

In general, the focus group respondents were less likely to endorse the performance measure than the NSCSHCN respondents. This may have been due to the fact that many of the focus group respondents were from rural communities and did not feel that the multiple long-distance providers identified one place where comprehensive care was delivered.

Table 26. National Survey of Children with Special Health Care Needs			
<i>Outcome Measures</i>	Arizona % (S.E.)	Focus Groups % (S.E.)	National % (S.E.)
Outcome #3: C/YSHCN will receive coordinated ongoing comprehensive care within a medical home.	50.5 (2.6)	17.7 (3.9)	52.6 (0.5)
a. The child has a usual source of care	91.2 (1.3)	91.6 (2.8)	90.5 (0.3)
I The child has a usual source for sick care	91.7 (1.2)	92.6 (2.7)	90.6 (0.3)
II The child has a usual source for preventive care	98.4 (0.5)	97.9 (1.5)	98.8 (0.1)
b. The child has a personal doctor or nurse	88.2 (1.5)	75.8 (4.4)	89.0 (0.3)
c. The child has no problems obtaining referrals when needed	74.4 (2.7)	48.1 (5.6)	78.1 (0.6)
d. Effective care coordination is received when needed	30.5 (6.2)	9.1 (6.7)	39.8 (1.5)
I The child has professional care coordination when needed	84.0 (4.9)	52.7 (3.9)	81.9 (1.1)
II Doctors communicate well with each other	53.7 (8.8)	22.6 (5.7)	54.4 (1.5)
III Doctors communicate well with other program	25.3 (6.7)	12.0 (4.6)	37.1 (1.6)
e. The child receives family-centered care	63.7 (2.6)	38.9 (5.0)	66.8 (0.5)
I Doctors usually or always spend enough time	82.3 (2.2)	54.2 (5.1)	83.6 (0.4)
II Doctors usually or always listen carefully	87.3 (1.7)	67.4 (4.8)	88.1 (0.3)
III Doctors are usually or always sensitive to values and customs	83.9 (1.9)	66.3 (4.8)	87.0 (0.4)
IV Doctors usually or always provide needed information	79.0 (2.1)	46.9 (5.1)	81.0 (0.4)
V Doctors usually or always make the family feel like a partner	84.9 (1.9)	62.1 (5.0)	85.9 (0.4)

The strong common theme between the various audiences that provided qualitative data on the medical home performance measure was the need for training on the concept for C/YSHCN, families of C/YSHCN, and medical providers. This training should outline a realistic standardized set of policies and procedures. Both parents and professionals felt there was a need to disseminate information about medical home and dental home to the community as a whole. They felt that the data that existed in Arizona regarding Medical Home did not have a wide enough distribution to change the system.

The Integrated Services Forum and the Needs Assessment Planning Group took more of an infrastructure examination of why medical home was not being achieved. They focused on: the need for new/different/additional reimbursement for those components of a medical home that add time to the provision of care and services (e.g., care coordination and longer medical visits); the need to expand the provider network by attracting new pediatricians to Arizona as well as the need to develop and mentor adult providers to accept C/YSHCN who are aging out of the pediatric system; and the need for data on medical homes including data related to the cost-effectiveness of a medical home and what are the necessary and sufficient elements that constitute a medical home. One member of the Needs Assessment Planning Committee expressed a concern that the concept of a medical home may be too closely aligned with an acute care medical model and does not incorporate enough habilitation and quality of life issues to appeal to all different types of C/YSHCN.

The family members in the focus groups seemed to intuitively know and understand the concept of a medical home and were better able to point to specific changes in physician's practices that would facilitate a medical home.

They emphasized the need for coordination in two areas: 1) coordination of care plans between multiple providers, particularly the coordination of test results and treatment recommendations with one central repository of information, and 2) coordination with the schools, with the medical practitioner reaching out to the school system and participating in the development and review of the Individualized Education Plan (IEP), and conversely the school providing a medical person to sit in on the development and review of the IEP. The families of C/YSHCN emphasized the importance of communication, stressing the needs for language-specific translators in physician's offices and the need to always keep the family in the loop—sometimes professionals communicated and made plans without the parent's involvement. However, the parents were realistic about the barriers to medical information transmission and felt that there was a need for clearly articulated policies and procedures about the sharing of information in a HIPAA (Health Insurance Portability and Accountability Act) environment.

- National Performance Measure 4. The percent of children with special health care needs age 0 to 18 whose families have adequate private and/or public insurance to pay for services they need.

Children with special health care needs often require an amount and type of care beyond that required by typically developing children and are more likely to incur catastrophic expenses. These populations of children, youth, and their families often have disproportionately lower incomes and therefore are at higher risk of being uninsured. Since children are more likely to obtain health care if they are insured, insurance coverage and the content of that coverage is an important indicator of access to care. Because C/YSHCN often require more and different services than typically developing children, under-insurance is a major factor in determining the adequacy of coverage. Adequacy of insurance facilitates comprehensive care, which in turn reduces emergency room visits, hospitalizations, and time lost from work or school.

Table 27 shows the percentage of respondents from the NSCHSCN for Arizona and nationally, as well as results from the Arizona focus groups. Sixty-one percent of Arizona NSCSHCN respondents reported their families have adequate insurance, compared to 60 percent of national respondents, ranking Arizona 23rd among the 50 states and the District of Columbia. Only 27 percent of the respondents in the Arizona focus groups had a similar endorsement. While a similar proportion of focus group respondents and Arizona NSCSHCN respondents reported their child was covered by insurance at the time of the interview and that there were no gaps in coverage during the preceeding year, the focus group respondents were less likely to report that insurance met the child's needs, that the costs were reasonable, or that they were permitted to see needed providers than were Arizona respondents to the NSCSHCN.

Data from the NSCSHCN indicated that the majority of C/YSHCN in Arizona are covered through some form of private insurance (67percent)¹²⁶. Additional analysis of the insurance questions in the NSCSHCN showed that 10 percent of Arizona’s C/YSHCN had no health insurance and their family income was less than 200 percent FPL, which ranked Arizona 48th, ahead of Louisiana (10 percent) and Montana (10 percent). However, these analyses also showed that Arizona C/YSHCN were less likely to be uninsured than non-C/YSHCN (5 and 14 percent, respectively). C/YSHCN were as likely to be insured through private insurance than non-C/YSHCN (67 and 66 percent, respectively) and more likely to be covered by a public insurance program than non-C/YSHCN (21 and 16 percent, respectively).

Table 27. National Survey of Children with Special Health Care Needs			
<i>Outcome Measures</i>	Arizona % (S.E.)	Focus Groups % (S.E.)	National % (S.E.)
Outcome #4: Families of C/YSHCN will have adequate private and/or public insurance to pay for the services they need.	60.8 (2.5)	26.9 (4.6)	59.6 (0.5)
a. The child has public or private insurance at time of interview	94.9 (1.1)	95.7 (2.1)	94.8 (0.2)
b. The child has no gaps in coverage during the year prior to the interview	86.4 (1.9)	91.1 (3.0)	88.4 (0.3)
c. Insurance usually or always meets the child’s needs	86.7 (1.7)	56.0 (5.2)	85.5 (0.4)
d. Costs not covered by insurance are usually or always reasonable	75.4 (2.1)	37.1 (5.1)	71.6 (0.5)
e. Insurance usually or always permits child to see needed providers	86.0 (1.7)	66.7 (5.0)	87.8 (0.4)

Both the Needs Assessment Planning Group and the youth and families involved in the focus groups felt there was a significant need for education about the various insurance options and/or requirements among families, providers, and utilization review personnel. There was a deficit in knowledge about coordination of benefits issues among the family members, and the use of appropriate contracted providers. Several family members expressed the need for consistent rules on coverage of specific services. Examples were provided where private insurance denials lead to public insurance denials, particularly with Capstone and Indian Health Services around newer medications. Family members cited many examples of referrals to non-contracted providers (particularly to providers who did not accept AHCCCS) that resulted in excessive out-of-pocket costs for the family. There was also considerable discussion about the pending changes in Medicare coverage for individuals who are or will soon be classified as Dual Eligible for Medicare and Medicaid.

The issue of “churning” in the system was of concern to the professionals and to the families. Families of C/YSHCN described many instances of losing coverage, particularly public health insurance because of changes in eligibility status. There are several isolated studies occurring throughout the state to identify the barriers to maintaining insurance coverage, but this information is not

¹²⁶ National Survey for Children with Special Health Care Needs (2001).

consistently available to decision makers or families of C/YSHCN. There was an overwhelming consensus among the participants to increase the enrollment of eligible children in AHCCCS or KidsCare.

The family members in the focus groups reported that there was a lack of health care coverage for specific services. There was a need for dental and vision coverage for C/YSHCN over age 21—AHCCCS covers only emergency dental care for beneficiaries over age 21. There was a need for more behavioral health options—in small towns confidentiality was an issue due to small number of providers. There was a need to make the coverage options consistent with the family’s wishes—for example, long-term care may require out-of-home placement, which the family did not always want. Families reported a need to advocate for changes to insurance coverage that matched the needs of C/YSHCN. Similarly, family members also wanted more recognition of non-traditional health care services such as increased access to school-based health centers and the need to increase funding for non-traditional treatments/lifestyle accommodations.

- National Performance Measure 5. Percent of children with special health care needs age 0 to 18 whose families report the community-based service systems are organized so they can use them easily.

Families, service agencies, and the Federal Interagency Coordinating Council have identified major challenges in accessing coordinated health and related services that families need for their C/YSHCN. Differing eligibility criteria, duplication and gaps in services, inflexible funding streams, and poor coordination among service agencies are concerns in most states.

Table 28 shows the percentage of respondents from the NSCSHCN for Arizona and nationally, as well as results from the Arizona focus groups. Arizona respondents to the NSCSHCN were somewhat lower than the national figure, but not significantly. Respondents to the focus groups were substantially lower, a difference that was also not significant. Arizona ranked 41st among the 50 states and the District of Columbia on this performance measure.

Table 28. National Survey of Children with Special Health Care Needs			
<i>Outcome Measures</i>	Arizona % (S.E.)	Focus Groups % (S.E.)	National % (S.E.)
Outcome #5: Community-based service systems will be organized so families can use them easily.	70.9 (4.2)	41.1 (5.0)	74.3 (0.7)
a. Services are usually or always organized for easy use	70.9 (4.2)	41.1 (5.0)	74.3 (0.7)

The Needs Assessment Planning Group and the focus groups identified three primary needs under access to community-based systems: The need to complete the Universal Application to facilitate accessing service systems, the need to increase the capacity of the system, and the need to expand the Community Development Initiative.

The Universal Application is an attempt to combine multiple agency applications into one document, which would reduce the time required for families to apply individually, and sometimes sequentially, to multiple agencies for services. This project has yet to come to fruition.

Both groups expressed the need to increase the number, type, and geographic dispersion of medical providers throughout the State of Arizona, including dentists serving C/YSHCN. Families in Somerton reported that the knowledge level, as well as the comfort level, of dentists dealing with children with special health care needs needed to be improved. The dentists they were referred to believed that general anesthesia was always necessary when providing dental care to a C/YSHCN, and they do not perform dental procedures under general anesthesia. As a result, the families were always referred to Phoenix dentists. This was the case for all types of dental services, even preventive dental services.

Families in the rural communities expressed the need for more home health nurses for nursing care in the home; they were not satisfied with one agency's attempt to utilize non-nursing staff. On the other hand, these families also supported the use of health care extenders, and reported that there was a need to increase the number of allied health professionals assisting the medical and dental communities in rural Arizona. Families also reported a need to identify and increase the number of alternative health care delivery sites (e.g., school-based health centers, telehealth, and mobile vans).

The communities where the focus groups were conducted have Community Development Teams. Parents thought that this model improved communication, marshaled resources, and provided community-based integration. They wanted to see this model expanded to other communities and to other agencies.

Families in Page reported specific examples of systems of care not being organized for ease of use. Families looked to CRS to coordinate services and to ensure appropriate insurance is billed, but there were reports of referrals made to non-CRS physicians resulting in significant costs to the family. Additionally, parents reported that Phoenix Children's Hospital does not ask if the patient is enrolled in CRS nor do they provide any information about CRS as a alternative provider/payor.

Another Page mother reported that maintaining a ventilator-dependent child in a rural community was difficult. The local hospitals have policies that interfere with family wishes; the mother wanted to stay in her home town, but the hospital would not admit her child due to the lack of ventilator-trained nursing staff, and consequently her child was air evacuated to Phoenix for every health care need. Similarly, a mother reported that if her child, who is covered by Arizona Long Term Care (ALTC) is hospitalized in Phoenix, the child must be in an intensive care unit, and the parents object.

- National Performance Measure 6. The percentage of youth with special health care needs who received the services necessary to make transitions to adult life, including health care, work, and independence.

More than half a million children with special health care needs will turn 18 this year, the first generation to reach adulthood since sweeping medical advances ensured an unprecedented number would survive congenital conditions that until recently would have killed them.¹²⁷ More than 90 percent of children with special health care needs now live to adulthood, but are less likely than their non-disabled peers to complete high school, attend college, or to be employed.

Table 29 shows the percentage of respondents from the NSCSHCN for Arizona and nationally, as well as results from the Arizona focus groups. Data for this measure for 2001 may not be accurate due to the small sample sizes in many states. Despite the small numbers, it is interesting to note that the respondents from the focus groups reverse a trend. Rather than having lower compliance with the national performance measure, in most cases the focus group respondents reported a significantly higher compliance with the standard than was seen in the NSCSHCN.

Table 29. National Survey of Children with Special Health Care Needs			
<i>Outcome Measures</i>	Arizona % (S.E.)	Focus Groups % (S.E.)	National % (S.E.)
Outcome #6. Youth with special health care needs will receive the services necessary to make transitions to adult life, including health care, work, and independence.	2.5 (1.5)	9.1 (6.1)	5.8 (0.6)
a. The child receives guidance and support in the Transition to adulthood.	3.9 (1.9)	9.5 (6.4)	15.3 (1.0)
i) Doctors have talked about changing needs	35.0 (6.5)	22.7 (8.9)	50.0 (1.3)
ii) The child has a plan for addressing changing needs	40.9 (10.5)	42.9 (18.7)	59.3 (1.7)
iii) Doctors discussed shift to adult provider	28.9 (8.2)	50.0 (17.7)	41.8 (1.7)
b. Child has received vocational or career training	28.0 (7.1)	28.6 (9.9)	25.5 (1.2)

Note: Shaded estimates do not meet the National Center for Health Statistics requirements for reliability and validity. The relative standard error is greater than or equal to 30 percent.

¹²⁷ University of Florida Health Sciences Center, 2005.

Both the Needs Assessment Planning Group and the families of C/YSHCN reported there was a need for standardization of transition terminology, data collection, and the development and implementation of transition planning. While they felt that there was a need to expand the concept of transition beyond pediatric to adult transition (e.g., transition from early intervention to school-based services), they also reported a need to develop post-secondary education transition options.

Families reported that there was a need for education and training around transition. They reported there was a need to train pediatric residents on transition issues, but there was also a need to educate teens about health prevention and wellness programs for youth with special health care needs (YSHCN). YSHCN also need information on disability, diagnosis, and options; the teens need to feel empowered to make their own decisions. An emerging issue among teens is the increased incidence of traumatic brain injury in this age group. Families felt that providers needed to know the risk for this type of injury and the potential needs of a TBI child.

The issue of provider capacity has a major impact on youth transitioning to adult providers. There are insufficient adult providers in the system with the knowledge to treat many of the teens. Parents were not always pleased with this transition process. One reported that their pediatric physician knew their history the best, but Arizona Long-Term Care would not allow the teen to stay with pediatric provider.

RISK FACTOR ANALYSIS OF THE NATIONAL PERFORMANCE MEASURES

To determine if there were certain demographic groups who were less likely to achieve the National Performance Measures, bivariate and logical regression analyses were conducted utilizing data from the NSCSHCN. Bivariate analyses of National Performance Measures by socio-demographic characteristics showed that Hispanics were significantly less likely to agree that parents were involved in all aspects of decision-making compared to non-Hispanics. Non-White families of C/YSHCN with incomes more than 200 percent FPL, and C/YSHCN with moderate or severe health condition were less likely to meet the National Performance Measure of having a medical home. For the performance measure of having adequate insurance coverage, Hispanics and families of C/YSHCN with incomes of more than 200 percent FPL were less likely to meet this outcome compared to non-Hispanics and families of C/YSHCN with incomes less than 200 percent FPL. C/YSHCN with moderate to severe health conditions did not find community based service systems easy to use. The complete results of the bivariate analysis are in Appendix A, table 1.

To explore the associations between achieving the National Performance Measures and socio-demographic characteristics and health factors, a predictive model was generated that included the child's race (White and non-Whites),

ethnicity (Hispanic, non-Hispanic), gender, household poverty level (<200 percent, and >= 200 percent FPL), age groups (0-5, 6-11, 12-17 years), Metropolitan Statistical Area (MSA) status, and the severity of health condition (mild, moderate, and severe). Adjusted odds ratio (ORs) and 95 percent confidence intervals (CIs) were computed for each performance measure. Chi-square analyses were used to test for differences in the proportion of the performance measures in different socio-demographic groups. To account for the complex sample design involving stratification, clustering, and multistage sampling of the National Survey of Children with Special Health Care Needs, SPSS¹²⁸ was used to perform descriptive and logistic analyses using appropriate population weights.

No significant age or gender differences were found in achieving the performance measures after adjusting for other covariates. Hispanics are less likely to achieve the performance measure of being involved as a key decision maker (OR 0.31, 95 percent CI: 0.1-0.8) and the performance measure of having adequate insurance coverage (OR 0.58, 95 percent CI: 0.3-0.9) as compared to non-Hispanics. After controlling for other factors, poverty was associated only with the performance measure of adequate insurance coverage. Severity of the child's health condition was associated with all the performance measures except for having adequate insurance coverage. As the severity of health condition of C/YSHCN increased, they were less likely to meet the National Performance Measures. The complete results of the bivariate and logistic regression analyses are in Appendix A.

IDENTIFIED NEEDS

UNMET NEED FOR SPECIFIC HEALTH CARE SERVICES

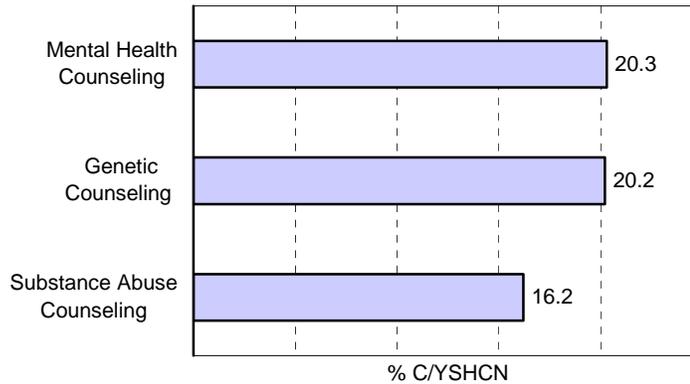
The National Survey of Children with Special Health Care Needs was used to estimate the prevalence of unmet needs. This survey assesses the need for a variety of medical care services such as routine preventive care, dental care, mental health care, etc. Respondents first were asked whether the sampled child needed the service. For those who responded that the service was needed, respondents then were asked whether the child received the needed service. Specific health care services were divided into three major categories: counseling, service delivery and coordination, and ancillary services.

UNMET NEED: COUNSELING

The greatest unmet counseling need was for mental health care counseling and genetic counseling (20 percent in both cases, see figure 59).

¹²⁸ SPSS Inc., Chicago; version 13.0.

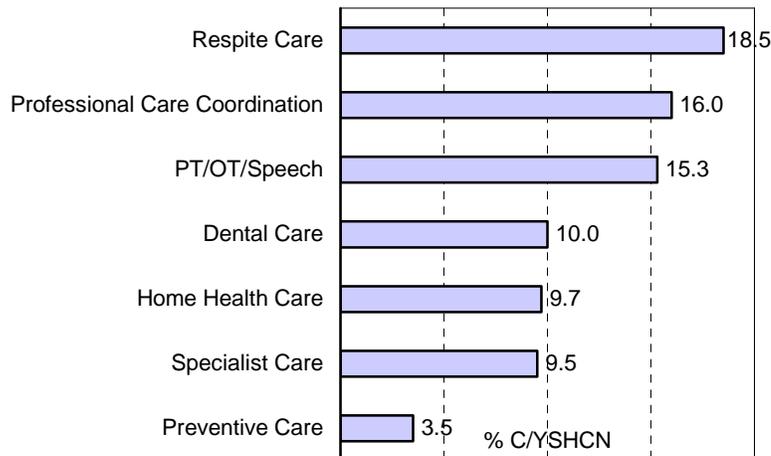
Figure 59. Percent of C/YSHCN Not Receiving Needed Counseling Services



UNMET NEED: SERVICE DELIVERY AND COORDINATION

The greatest unmet service delivery and coordination need was respite care. Nineteen percent of Arizona families with C/YSHCN reported they did not receive respite care when needed. However, professional care coordination and many services that would be needed to support a child with special health care needs were also unmet (e.g., professional care coordination and PT, OT, and speech therapy, see figure 60).

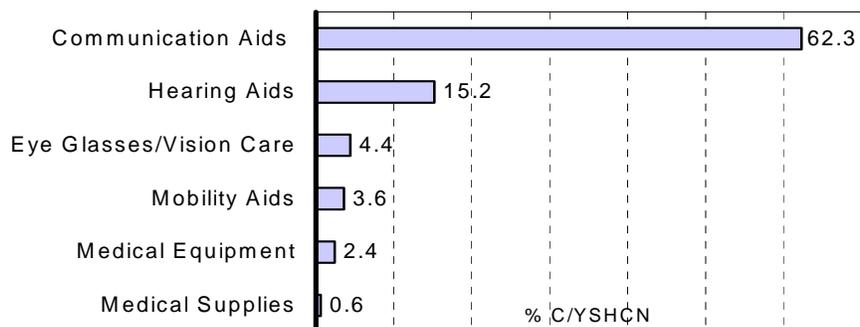
Figure 60. Percent of C/YSHCN Not Receiving Needed Service Delivery and Care Coordination



UNMET NEED: ANCILLARY SERVICES

The greatest unmet ancillary service need was communication aids. Almost two-thirds (62 percent) of Arizona families with C/YSHCN reported they did not receive communication aids or devices when needed (see figure 61).

Figure 61. Percent of C/YSHCN Not Receiving Needed Ancillary Services



To determine if there were demographic factors that might contribute to C/YSHCN not having their health care needs met, bivariate and logistic analyses were performed. Logistic regression analyses were conducted to determine the extent to which the risk of unmet need in C/YSHCN was associated with demographic characteristics. To explore the associations of unmet need with demographic characteristics, the child's race (White and non-Whites), ethnicity (Hispanic, non-Hispanic), gender, household poverty level (<200 percent, and >= 200 percent Federal Poverty Guidelines), age groups (0-5, 6-11, 12-17 years) and MSA status was included into the base model.

Routine preventive care, dental care, specialist care, mental health care, physical/occupational/speech (PT/OT/Speech) therapy, and eyeglass/vision care were included in bivariate analyses (see Appendix A, table 3). The remaining unmet needs were not included because of insufficient sample size. Hispanics were more likely to have unmet needs for dental care and mental health care counseling compared to non-Hispanics. Families with less than 200 percent FPL were more likely to have unmet needs for specialist care, mental health care counseling and dental care compared to people with incomes equal to or more than 200 percent FPL. Families of C/YSHCN living in a MSA were more likely to have an unmet need for specialist and dental care.

Logistic analyses were conducted to assess the effects of demographic characteristics on the likelihood of having an unmet need for routine preventive care, dental care, specialist care, mental health care, physical, occupational, speech (PT/OT/Speech) therapy, and eyeglass/vision care. The odds of having an unmet need for routine preventive, dental, mental health, PT/OT/Speech, and eyeglass/vision care were higher among Hispanics compared to non-Hispanics though not significant (see Appendix A, table 4). Age and gender did not relate significantly to any of the unmet needs. Families with incomes less than 200 percent FPL had significantly high odds of unmet needs for specialist and dental care compared to families with incomes equal to or more than 200 percent FPL. Likewise, the odds of having an unmet need for specialist and dental care were significantly higher among families living in MSA compared to families not living in MSA.

COMPARISON OF NEEDS USING POPULATION-BASED DATA AND LOCAL SURVEY DATA

Table 30 presents the proportion of individuals reporting their child/family had a need for a specific service and whether that need was currently being met. A comparison is provided between the population-based data from the NSCSHCN and the data from the Arizona Survey of Special Needs Children. While the population-based responses did differ significantly from the focus group responses (bolded cells), the ability of the current service system to meet the needs did not differ between the two groups.

The need for services among the focus group respondents was significantly higher in all but two needs (substance abuse counseling and disposable medical equipment). This inflation seen among the focus group respondents may be due to the fact that the severity of their children’s needs far exceeded a more general population figure. Another hypothesis for the inflation may be that the respondents anticipated some secondary aim by inflating their responses in direct response to a request from the health department.

Table 30. A Comparison of the Identified Needs from the National Survey of Children with Special Health Care Needs and Arizona Focus Group Responses				
Specific Health Care Services	Arizona NSCSHCN % (95% C.I.)		Arizona Focus Groups % (95% C.I.)	
	Services Needed	Services Not Received	Services Needed	Services Not Received
Routine Preventive Care	69.5 (64.6-74.4)	3.5 (1.4-5.5)	95.7 (91.7-99.8)	0
Specialist Care	48.0 (43.0-53.0)	9.5 (5.3-13.6)	91.3 (85.5-89.7)	6.1 (0.9-11.3)
Dental	73.9 (69.2-78.5)	10.0 (7.0-12.0)	81.9 (74.1-89.7)	13.7 (5.8-21.6)
Mental Health	27.2 (22.6-31.8)	20.3 (13.2-27.4)	46.1 (35.7-56.4)	26.3 (12.3-40.3)
Substance Abuse	4.3 (1.2-7.3)	16.2 (0.0-36.8)	3.4 (-0.4-7.1)	50.0 (1.0-99.0)
Genetic Counseling	5.1 (3.5-7.4)	20.2 (9.7-27.5)	24.2 (15.6-33.3)	45.5 (24.6-66.3)
Prescription Medications	88.0 (84.7-91.4)	1.1 (0.3-1.8)	91.3 (85.5-97.1)	3.7 (-0.4-7.8)
PT/OT/Speech	22.5 (18.2-26.9)	15.3 (8.4-22.1)	85.7 (78.5-92.9)	26.7 (16.7-36.7)
Home Healthcare	6.7 (3.9-9.5)	9.7 (0.0-19.9)	14.3 (7.1-21.5)	42.9 (16.9-68.8)
Respite Care	8.0 (5.6-11.1)	18.5 (10.0-31.8)	65.9 (56.2-75.7)	41.0 (28.6-53.3)
Professional Care Coordination	12.0 (9.0-15.9)	16.0 (8.5-28.1)	69.0 (59.2-78.7)	38.6 (26.0-51.2)
Vision Care	33.6 (28.9-38.3)	4.4 (1.4-7.4)	63.0 (53.2-72.9)	11.9 (3.6-20.1)
Hearing Aides	8.4 (5.1-11.7)	15.2 (0.0-36.5)	31.5 (21.8-41.1)	17.2 (3.5-31.0)
Mobility Aids	4.9 (2.8-6.0)	3.6 (0.0-9.5)	15.4 (8.0-22.8)	28.6 (4.9-52.2)
Communication Aids	2.6 (0.4-4.7)	62.3 (22.5-100.0)	21.6 (13.0-30.2)	42.1 (19.9-64.3)
Disposable Medical Supplies	25.4 (21.1-29.6)	0.6 (0.0-1.5)	16.7 (9.0-24.4)	20.0 (-0.2-40.2)
Durable Medical Equipment	10.3 (7.8-12.)	2.4 (9.7-37.5)	22.2 (13.6-30.8)	19.0 (2.3-35.8)

Bold indicates significant differences between the NSCSHCN and the focus group

Respondents to the NSCHSCN reported the highest unmet need was for communication devices (62 percent), followed by mental health care and genetic counseling (both at 20 percent). The extraordinarily high proportion reporting an unmet need for communication devices was somewhat explained by a member of one of the focus groups; C/YSHCN may obtain communication devices as part of their Individualized Educational Plan (IEP). However, the use of the device is limited to the school setting and is not necessarily available at home. That interpretation may in fact be the reason for the high unmet need is confirmed by the high response rate among the focus group respondents. The parent felt the device was needed at all times.

While there were no significant differences between the proportions that reported that the need had not been met in the two groups, there was a significant trend for more members of the focus group respondents to report a need not being met. Unlike the respondents in the NSCHSCN, the focus group respondents had a wider range of unmet needs. The largest unmet need among the focus group respondents was the need for substance abuse counseling (50 percent), followed by genetic counseling (46 percent), home health care (43 percent), communication aids (42 percent), and respite care (41 percent).

PROVIDER INPUT ON UNMET NEEDS

CRS providers were asked to rate various issues that have been shown to be important for children with special health care needs. They were asked to indicate if the issue had been adequately addressed in the planning of services, adequately implemented, and finally to indicate an overall priority of the issue. The results are shown in table 31. More than two-thirds of the providers rated the concept of medical home, care coordination, involvement of parents in medical decisions, developing transition plans, and having adequate insurance coverage as being adequately addressed. However, only involvement of the family in decision-making (73 percent), care coordination (53 percent), and adequate insurance coverage (40 percent) were considered somewhat implemented. The providers rated coordination with educational and medical systems (33 percent) and reducing racial and ethnic disparities (53 percent) as the lowest priorities. They rated coordination with other medical providers (87 percent), developing transition plans with youth (80 percent) and adequate insurance coverage (80 percent) as the highest priority.

Table 31. Priority of General Themes in the Treatment of C/YSHCN						
Issue	Adequately Addressed		Adequately Implemented		High Priority	
	N	%	N	%	N	%
Developing the medical home concept	10	66.7	3	20.0	10	66.7
Implementation of the medical home concept	4	26.7	1	6.7	10	66.7
Integrating PCPs with specialty clinics	7	46.7	3	20.0	10	66.7
Coordination with other medical providers	12	80.0	8	53.3	13	86.7
Coordination of educational and medical systems	9	60.0	4	26.7	5	33.3
Involvement of the parents/caregivers in all medical decisions	14	93.3	11	73.3	11	73.3
Developing transition plans for SHCN youth	11	73.3	4	26.7	12	80.0
Involvement of the SHCN youth in transition plans	5	33.3	1	6.7	9	60.0
Adequate number of trained adult providers to provide services to children transitioning to adult systems	1	6.7	1	6.7	11	73.3
Adequate insurance coverage for SHCN children and youth	12	80.0	6	40.0	12	80.0
Reduce racial/ethnic disparities in health care	7	46.7	4	26.7	8	53.3

REASONS FOR UNMET NEED

Table 5 (Appendix A) shows the weighted percentage of respondents from the NSCSHCN that reported that care was delayed or not received in the past 12 months. Respondents in Arizona did not differ significantly from the national reports and the pattern of responses was similar between the local reports and the national data. Thirteen percent of the Arizona respondents reported that their child had forgone or delayed care in the past 12 months compared to 10 percent nationally. The most frequently cited reason, both locally and nationally, was financial; 10 percent of Arizona respondents and 8 percent nationally reported that financial concerns delayed or eliminated access to care and the specific financial reason was that they had no money to pay the provider. The second most frequently reported reason for delayed or forgone care was time constraints (5 percent in Arizona and 4 percent nationally), and the Arizona respondents reported they had a time conflict with responsibilities at home or work.

To determine if there were certain demographic groups that were more likely to delay or forgo care, bivariate and logical regression analyses were conducted utilizing data from the NSCSHCN. Table 6 (Appendix A) shows the results of stratifying the global reasons for delayed care by demographic variables for the Arizona respondents. Bivariate analyses of the reasons reported for delaying forgoing care showed families that reported their child's impairment was mild were less likely to delay or forgo care than parents that reported their child's impairment as moderate or severe, suggesting that a mildly impaired child might benefit more from medical intervention. On the other hand, parents that reported incomes of less than 200 percent FPL were significantly more likely than parents with incomes of more than 200 percent FPL to report they had delayed or forgone care in the past 12 months. There was no significant difference between the racial groups in the reason for delaying or forgoing care; however, Hispanics were significantly more likely than non-Hispanics to delay or forgo care due to

lack of accessibility of the provider, financial reasons, and language problems. Families were significantly less likely to delay or forgo care for a male child than for a female child. Families reporting incomes of less than 200 percent of FPL were significantly more likely than families with incomes greater than 200 percent FPL to report language barriers as a reason for delaying or forgoing care.

To explore the associations between the reasons for families reporting an unmet need and the socio-demographic characteristics and health factors of the families and C/YSHCN, a predictive model was generated that included the child's race (White and non-Whites), ethnicity (Hispanic, non-Hispanic), gender, household poverty level (<200 percent, and \geq 200 percent FPL), age groups (0-5, 6-11, 12-17 years), MSA status, and the severity of health condition (mild, moderate, and severe). Adjusted odds ratio (ORs) and 95 percent confidence intervals (CIs) were computed for each performance measure. Chi-square analyses were used to test for differences in the proportion of the performance measures in different socio-demographic groups. To account for the complex sample design involving stratification, clustering, and multistage sampling of the NSCSHCN, SPSS¹²⁹ was used to perform descriptive and logistic analyses using appropriate population weights (see Appendix A, table 7).

There were no significant associations between race, age of the child, or living in a MSA and families reporting that they had delayed or forgone care for their child in the past 12 months. Only having a child rated as severe was significantly associated with delayed or forgone care (OR = 3.87, CI = 1.1 – 16.2). While the association between delayed or forgone care was not significantly associated with any other variables, the trend was for non-Whites, Hispanics, having a child between the ages of 8 and 11 years of age, having a male child, living in a MSA, and the mother having less than a high school education to be predictive of not delaying or forgoing care.

An analysis of the specific reasons for delaying care showed no significant association between race, age of the child, and living in a MSA and a specific reason for delaying or forgoing care. Being Hispanic (OR=18.46, CI=21–155.4) and the mother having less than a high school education (OR=8.36, CI=1.2–55.1) were significant predictors of the family reporting that care was delayed or forgone due to language difficulties. Having an income less than 200 percent FPL was a significant predictor that care would be delayed or forgone because a provider was not accessible (OR=4.36, CI=1.1–16.2). Having a male child was significantly associated with reporting that financial problems caused care to be delayed or forgone (OR=0.06, CI=0.0–0.5).

One of the primary obstacles to care that the focus groups reported was the shortage of providers in rural areas, particularly pediatric specialists and dentists willing to serve the needs of C/YSHCN. Two rather alarming comments came from two different locations. One mother reported that the local hospital was unable to care for her child when he was hospitalized (the child was ventilator-

¹²⁹ SPSS Inc., Chicago; version 13.0.

dependent) and the child was always air-evacuated to Phoenix for any type of ailment, causing a significant disruption for the family. In another small community, numerous parents reported on the lack of dentists willing to treat their children, they were always referred to Phoenix and although transportation was paid for, the families had to rely on buses and it required an overnight stay in Phoenix. Families also reported the lack of qualified nurse and case management personnel and a high degree of turnover. There is no doubt that this latter shortage contributed to their reporting of insufficient, inadequate, and disorganized screening and case management services.

Related to the provider shortage was the need for less traditional therapy modalities. Several members of the focus group in Page reported the need for music therapy, a therapy modality that was deemed not medically necessary by the managed care companies. The parents felt that there needed to be a formal study of the efficacy of non-verbal therapies, and one local provider volunteered to assist in designing and implementing such a study. The parents uniformly felt that the range of services offered by the providers, or authorized by the insurance companies, were standardized and seldom flexible enough to meet the specific needs of their children. Many of the parents in the focus groups reported having children with severe developmental disabilities and a full range of autistic behaviors, and they felt that the reliance on traditional learning modalities and cognitive therapy from their mental health providers was not appropriate for this population.

The lack of individualization of services is shown rather pointedly in the following example related by a mother in the border community of Somerton. Her daughter was developmentally delayed, had a seizure disorder, and was lactate intolerant. She required a special diet which the principal seemed to understand, but every day the kitchen staff gave the girl milk to drink and everyday the girl regurgitated the food she ate which the maintenance staff cleaned up. The kitchen staff reported that they could not change the diet of a child without a written order from her doctor. The doctor would not write a letter without an appointment. A letter from the Mom was not sufficient for the school; they needed a physician's letter, even for food allergies. One day when the mother was attending some function at school, the maintenance man approached the mother and complained of always having to clean up after her daughter. The mother explained why this was occurring; that her daughter could not drink milk, and that despite multiple attempts to communicate this, the kitchen staff continued to provide her with milk. The maintenance man spoke with the kitchen staff and the girl was never given milk again. One man solved his problem, but the solution speaks volumes about the lack of appropriate communication among professionals and those that provide other services.

The lack of access to behavioral health providers was in part due to the limited number of providers in the rural communities, but also the lack of confidentiality in small rural communities served as a deterrent for many individuals. The lack of professional care coordination was rated high as an unmet need, and

in the words of one mother, it ranged from poor to bad. The families reported a consistent lack of trained professionals, particularly in the rural areas. There was a lack of coordination between the multiple entities involved in the provision of services for the children. Some parents did not feel that the Arizona Early Intervention Program providers coordinated team activities. Numerous examples were reported of what was perceived to be a lack of quality (consistency) in the development and implementation of the Individualized Family Services Plan (IFSP).

PROVIDER REPORTS OF BARRIERS TO MEETING THE NEEDS OF C/YSHCN

Providers were asked to rate a variety of unmet service needs for C/YSHCN. For each service need that represented an unmet need, providers were asked to indicate the most important reason the need was not met. As seen in table 31, the providers rated psychiatric or psychological services for both the patient and the family as the highest unmet need (87 and 80 percent, respectively). This was followed by routine and emergency dental services (73 and 67 percent, respectively) and respite care (53 percent). The primary reason given for a C/YSHCN having an unmet need was the lack of insurance coverage; surprisingly, the out-of-pocket costs or co-pays were rated as the lowest reason for all of the services. The lack of service/provider availability was rated high for psychiatric and psychological services (47 percent for both services for the child/youth and for the family) and for dental service (33 percent for routine dental and 27 percent for emergency dental services).

Table 31. CRS Providers' Ratings of Unmet Service Needs and the Reasons							
Unmet Service Need	Service	The Reason for the Unmet Need					
		No insurance coverage %	Insurance co-pays or deductibles are too high %	Service not available or no providers %	Too long of a wait time %	Service of insufficient duration %	Transportation %
73.3	Routine dental check-ups	53.3	6.6	33.3	26.6		26.6
66.7	Emergency dental services	33.3	6.6	26.6	13.3		20.0
6.7	Durable medical equipment	6.6	6.6				6.6
26.7	Physical therapy	13.3	6.6	20.0	6.6		6.6
26.7	Occupational therapy	6.6	6.6	13.3	13.3		6.6
46.7	Speech therapy	13.3		13.3	13.3		6.6
26.7	Vision services	6.6		13.3	6.6		
20.0	Hearing services	13.3		6.6	6.6		6.6
86.7	Psychiatric/psychological services for the identified patient	53.3	6.6	46.6	40.0	33.3	20.0
80.0	Psychiatric/psychological services for the entire family	53.3	6.6	46.6	40.0	26.6	
40.0	Home health services	13.3		6.6	13.3	6.6	
53.3	Respite care	26.6	6.6	13.3	13.3	6.6	
53.3	Day treatment	20.0	6.6	26.6		6.6	26.6
20.0	Emergency medical services	13.0				6.6	6.6

OTHER UNMET NEEDS

The Robert Wood Johnson Foundation, in collaboration with the Foundation for Accountability, conducted a survey of 2,000 adolescents ages 13 to 17 in May 2001 to learn from teens who is thriving as well as those who are at risk and how interventions, particularly among health care providers, can help teens through their transition to adulthood.¹³⁰ The significance of this study is that they included a group of teens with special health care needs, defined as those with a chronic physical, mental, emotional, or behavioral condition for which the teen experienced significant functioning problems and/or required health and health-related services of an amount and type beyond that required by teens generally. These adolescents with special health care needs were compared with adolescents engaging in one or more behaviors that presented risks to their health such as smoking or substance use and to another group of adolescents that reported significant symptoms of depression. The study found that all three of the at-risk groups were less healthy, had less self-confidence in handling life situations, and had less connection with their communities and schools than adolescents not in one of the three risk groups. Adolescents with a special health care need were more likely to also belong to another risk group and were more likely than children without a special health care need to engage in risky health behaviors and report symptoms of depression.

With respect to healthy lifestyles, teens with special health care needs were the least likely to report engaging in regular exercise; however, no more than two-thirds in any of the groups reported regular physical activity. Typical protective factors such as participation in extracurricular activities and having friends that do not participate in risky behaviors were low among all of the groups.

In the past several decades, several studies have shown that children with special health care needs or disabilities are significantly more exposed to risk factors and have significantly fewer protective factors.¹³¹ For example, data from the National Longitudinal Study of Adolescent Health, where physical disabilities were measured in terms of functional limitations and activity restrictions, found that although disabled adolescents are slower in pubertal development and more socially isolated, they were as sexually experienced as their non-disabled counterparts. Severely disabled adolescents are less sure of their sexual preference and adolescents with mild disabilities had a higher tendency for same sex attraction than do the non-disabled. Adolescent girls with physical disabilities

¹³⁰ Foundation for Accountability & The Robert Wood Johnson Foundation, 2001. A Portrait of Adolescents in America, 2001. Portland, OR: FACCT—Foundation for Accountability. Available online at <http://www.facct.org>.

¹³¹ Blum, R. W., Kelly, A., & Ireland, M. "Health-Risk Behaviors and Protective Factors Among Adolescents with Mobility Impairments and Learning and Emotional Disabilities." Journal of Adolescent Health 6 2001: 481-490.

consistently have higher odds of experiencing forced sex.¹³² Yet data from the Health Behaviors in School-Aged Children, a World Health Organization Cross-National Study, found that Canadian adolescents with physical disabilities reported they had not received information on parenthood, birth control, or sexually transmitted diseases.¹³³

To determine if Arizona providers felt there was insufficient public health education for C/YSHCN, CRS providers were asked to rate the level of importance of several areas of public health education for children with special health care needs. As seen in table 32, the highest rankings were given to obesity (87 percent), nutrition (80 percent), and physical activity (80 percent), followed by sex education, dental education, injury prevention, and bullying the school or community (73 percent). The lowest rating was given to smoking prevention (47 percent).

Public Health Issues	N*	%
Smoking Prevention	7	46.7
Substance Abuse/Use	10	66.7
Sex Education	11	73.3
Nutrition	12	80.0
Dental Education	11	73.3
Physical Activity	12	80.0
Obesity	13	86.7
Sun Safety	10	66.7
Injury Prevention	11	73.3
Bullying in School or Community	11	73.3

* Providers rated public health issue as very important

¹³² Cheng, M. M. & Udry, J. R. "Sexual Behaviors of Physically Disabled Adolescents in the United States." *Journal of Adolescent Health* 1 2002: 48-58.

¹³³ Steven, S. E., Steele, C. A., Jutai, J. W., Kalnins, I. V., Bortolussi, J. A., & Biggar, W. D. *Journal of Adolescent Health* 2 1996: 157-164.

TITLE V PRIORITY NEEDS

The Title V Maternal-Child Health Needs assessment was largely data driven. However, because resources are limited and depend upon policy-making and program development, it is important to obtain input from stakeholders to set priorities and define strategies. Through a series of public meetings and other communications, priorities were established that the community and the Title V agency jointly identified as important and are within their capability to address.

Many issues were raised during public input sessions that affect the health and well being of the maternal-child health population that are beyond the scope of Title V services. For example, affordable housing, general educational attainment, opportunities for economic and social activities for youth, and parental involvement with their own children were all recognized as important contributing factors to women's and children's health. The themes of home, school, and neighborhood environments may not be specifically reflected in the top priorities identified, however opportunities to work with schools, parents, and the larger community on issues that affect health will continue to permeate programmatic activities and remain top priorities in themselves.

The Governor's Commission on Women made the following recommendations:

- Increase access to health care for the women of Arizona by achieving comprehensive, continuous health insurance coverage throughout the life cycle, integrating dental and behavioral health with physical medicine, increasing access to family planning services for low-income women in Arizona, and promoting cultural and linguistic competency among the health care community to achieve appropriate care for diverse populations.
- Improve the health and well being of women in Arizona by increasing women's awareness of how they can positively impact their health and well being.
- Reduce the teen pregnancy rate in Arizona, with a particular emphasis on reducing the number of second pregnancies to teens.
- Increase prenatal care and pre-conception care for women in Arizona by: increasing the number of women who access early prenatal care to improve birth outcomes, increasing access to better oral health to improve birth outcomes, and promoting healthy preconception lifestyles to women.

Taking into account the Governor's initiatives, input from stakeholders, and review of state-specific data and capacity, ten top priorities emerged for the Title V program:

1. Reduce teen pregnancy and increase women's access to reproductive health services
2. Reduce obesity and overweight among women and children
3. Reduce preventable infant mortality
4. Reduce the rate of injuries, both intentional and unintentional
5. Increase access to prenatal care among the underserved
6. Improve oral health of children, especially among high-risk populations
7. Integrate Mental Health with General Health Care
8. Increase the accessibility and availability of individualized health and wellness resources for children and youth with special health care needs
9. Increase the availability of a cohesive and stable continuum of resources within a medical home that includes an improved quality of life approach
10. Increase the recognition of families as integral partners in the care of their children's health and wellbeing

PRIORITY 1: REDUCE TEEN PREGNANCY AND INCREASE WOMEN'S ACCESS TO REPRODUCTIVE HEALTH SERVICES

A recurrent theme that was heard at each of the public input sessions was that there is a need for enhanced teen pregnancy prevention, sexuality education, and family planning services to prevent unwanted pregnancies and sexually transmitted diseases. Teen pregnancy was seen as important both as an outcome and as a cause. In addition to the consequences that pregnancy has for the teenager's health and life chances, babies born to teenagers are less likely to get a healthy start at life. There was a recognition that services should be aimed at delaying the onset of sexual activity as well as supporting responsible choices among sexually active teens.

Family planning for women of all ages plays an integral role in bolstering the health and well being of women and children. In fact, during public input sessions, a WIC director from one of the American Indian tribes stated that spacing of children was the most important nutrition issue they faced. In addition, the ability to plan pregnancies helps women gain flexibility in education and employment opportunities.

PRIORITY 2: REDUCE OBESITY AND OVERWEIGHT AMONG WOMEN AND CHILDREN

Maintaining a healthy weight through healthy eating patterns and physical activity is a critical component of chronic disease prevention. Over the last decade, strides have been made in increasing the level of physical activity and healthy eating. However, obesity has reached epidemic proportions, affecting all regions and demographic groups.

Being overweight during childhood can carry life-long health consequences. Risk factors for heart disease, such as high cholesterol and high blood pressure, occur with increased frequency in overweight children and adolescents, and type 2 diabetes, which was previously considered to be an adult disease, has increased dramatically in children and adolescents.

PRIORITY 3: REDUCE PREVENTABLE INFANT MORTALITY

Although infant mortality in Arizona has declined, disparities remain in the rates of death among various subgroups of the population. African American, American Indian, and Hispanic infants die at higher rates than White infants, as do infants born to less educated women and teens. While not all infant mortality can be prevented, disparities suggest that interventions directed at excess mortality within high-risk populations provide an opportunity for further progress.

The Office of Women's and Children's Health used the CDC Periods of Risk Model to analyze infant and fetal deaths in Arizona. Excess deaths were analyzed to estimate the proportion of infant deaths that were preventable, and to associate deaths with periods of risk in order to effectively target interventions within high-risk populations. Resources will be directed towards preconception and maternal health. Good nutrition, physical activity, and reducing risk behaviors such as smoking and alcohol use will be promoted for all women of childbearing age. Because a high proportion of deaths were associated with the postneonatal period (after the first month of life through the first year), interventions will emphasize promoting breastfeeding, proper sleep positions, preventing and diagnosing infection and injury, recognition of birth defects and developmental abnormalities, and prevention of sudden infant death syndrome.

PRIORITY 4: REDUCE THE RATE OF INJURIES, BOTH INTENTIONAL AND UNINTENTIONAL

For many years, Arizona's injury mortality has exceeded national rates. Injuries, both intentional and unintentional, are among the leading causes of death among children of all ages and women of childbearing years in Arizona. In addition, nonfatal injuries account for a high volume of inpatient hospitalizations and emergency outpatient visits. The impact of injuries is felt by more than the just the person who is injured. Injuries also affect families, schools and employers. The Arizona Department of Health Services has developed a state injury surveillance and prevention plan.

PRIORITY 5: INCREASE ACCESS TO PRENATAL CARE AMONG MEDICALLY UNDERSERVED WOMEN

Prenatal care is an opportunity to identify risks and mitigate their impact on pregnancy outcomes through medical management. Prenatal visits also offer an opportunity for education and counseling on proper nutrition and risk factors, such as smoking and alcohol use during pregnancy. Prenatal care is more effective when women enter care early in their pregnancy.

Although there has been an upward trend in the proportion of women receiving prenatal care in their first trimester of pregnancy, Arizona continues to lag behind the rest of the nation. The proportion of women who enter prenatal care early in their pregnancies varies in Arizona by race, ethnicity, education, source of payment for delivery, and geographically. Recommendations at each public meeting were made to increase funding to the Health Start Program, which is a program to identify women early in their pregnancies and get them into prenatal care.

PRIORITY 6: IMPROVE THE ORAL HEALTH OF CHILDREN, ESPECIALLY AMONG HIGH RISK POPULATIONS

United States Surgeon General David Satcher dubbed dental disease the “silent epidemic,” yet it is preventable with early intervention and the promotion of evidence-based prevention efforts like dental sealants. In an effort to improve the health and well being of children, it is imperative that interventions be targeted at preventing dental disease, especially in high-risk children. Concern about oral health was expressed at each public meeting. In fact, oral health was identified as the number one issue for one of the Indian Tribes, according to a review of medical records.

PRIORITY 7: INTEGRATE MENTAL HEALTH WITH GENERAL HEALTH CARE

Widespread concern was expressed at every public input meeting about the need to integrate mental and physical health care. Mental and behavioral health screening of women and children in general, and for postpartum depression in particular were consistent themes. It is important for primary care providers to be aware of screening and treatment options.

CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS

The data gathered from numerous sources pointed to the fact that C/YSHCN and their families have many unmet or partially met needs. These needs were for specific services and for system changes to allow better access to services. However, there were also more ephemeral needs such as the need to have a

provider understand the culture of the family, to speak the language of the family, and to engage the family as a partner in the decision making process. Not all of the needs delineated by the survey data, the focus groups, and other information are incorporated into the priority needs. Many of the needs for specific services will be addressed through the Specialty Care subcommittee of the Integrated Services grant and still other issues will be part of the office's strategic plan for 2005-2010.

The determination of the priority needs for Arizona's C/YSHCN was achieved through a group consensus of the Needs Assessment Planning Group after reviewing the data from the NSCSHCN, the focus groups, and the provider community. While they all agreed there were many specific service and coordination needs, there was very little OCSHCN could do to directly impact those needs. The group decided to address the needs from more of a systems approach that would focus interventions on education of providers as well as the families of C/YSHCN. The following three statements of need for C/YSHCN are the result of that consensus.

PRIORITY 8: INCREASE THE ACCESSIBILITY AND AVAILABILITY OF INDIVIDUALIZED HEALTH AND WELLNESS RESOURCES FOR CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS IN ARIZONA.

PRIORITY 9: INCREASE THE AVAILABILITY OF A COHESIVE AND STABLE CONTINUUM OF RESOURCES WITHIN A MEDICAL HOME THAT INCLUDES AN IMPROVED QUALITY OF LIFE APPROACH.

PRIORITY 10: INCREASE THE RECOGNITION OF FAMILIES AS INTEGRAL PARTNERS IN THE CARE OF THEIR CHILD'S HEALTH AND WELLBEING.

The priorities outlined above will be reflected in the Title V agency's strategic plans and block grant applications over the next five years. Progress will be tracked using a combination of national performance measures, which are required by all states, and new state-defined measures, which reflect Arizona priorities. Details on newly defined state performance measures can be found in the 2006 Title V Block Grant Application accompanying this needs assessment. Subsequent applications will report on the actual measures and discuss accomplishments, activities and plans related to them.

APPENDIX A

ANALYTIC RESULTS

CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS

Table 1: Frequency of Performance Measures by Demographics and Health factors (Bivariate Analyses)

Demographics		Unweighted N	Family as Decision Maker Performance Measure #2		Medical Home Performance Measure #3		Insurance Performance Measure #4		Community-Based Services Performance Measure #5	
			%	SE	%	SE	%	SE	%	SE
Race	White	590	53.4	9.9	53.7**	2.9	58.5	2.9	72.4	4.5
	Non-White	157	46.6	4.9	37.9	5.7	66.8	5.1	67.4	9.0
Ethnicity	Hispanic	193	34.5*	8.1	46.7	4.8	52.0*	4.6	70.7	6.9
	Non-Hispanic	556	57.7	5.5	51.1	3.1	63.2	2.9	70.9	5.2
Age	0-5	130	43.2	9.4	56.5	5.4	59.9	5.1	73.8	9.1
	6-11	307	53.4	7.7	47.9	4.1	58.5	4.2	65.7	7.2
	12-18	314	52.3	6.8	50.5	4.1	63.2	3.7	75.6	5.7
Gender	Male	451	51.1	6.0	48.9	3.4	61.7	3.3	69.1	5.8
	Female	300	51.8	7.1	53.0	4.1	59.3	3.9	73.6	5.8
Poverty status %FPL	<200%	265	47.7	8.2	43.6*	4.3	51.3**	4.4	62.6	7.5
	>= 200%	421	54.8	6.1	55.0	3.5	65.9	3.3	77.9	5.6
MSA status	MSA	680	50.5	4.7	51.2	2.7	60.0	2.6	70.2	4.4
	Not in MSA	71	59.2	16.6	43.3	8.5	68.5	7.0	76.6	11.7
Severity	Mild	236	66.2	7.3	61.5***	4.6	67.5	4.6	85.4*	4.7
	Moderate +	318	49.3	6.6	57.7	3.8	61.3	3.7	71.6	5.5
	Severe +	194	41.9	10.1	26.6	3.9	52.9	5.1	56.0	10.3

* p < 0.05

** p < 0.01

*** p < 0.001

FPL – Federal Poverty Level

MSA – Metropolitan Statistical Area

+ Compared with Mild Severity

Table 2: Adjusted Odds for Meeting Performance Measures and Associated Reasons

Demographics		Family as Decision Maker Performance Measure #2	Medical Home Performance Measure #3	Insurance Performance Measure #4	Community-Based Services Performance Measure #5
		OR (95% CI)	OR (95% CI)	OR (95% CI)	OR (95% CI)
Race	White				
	Non-White	0.96 (0.3-2.7)	0.71 (0.4-1.2)	2.06 (1.1-3.7)	0.82 (0.3-2.2)
Ethnicity	Non-Hispanic				
	Hispanic	0.31 (0.1-0.8)	1.01 (0.6-1.6)	0.58 (0.3-0.9)	1.03 (0.3-2.7)
Age	0-5				
	6-11	1.38 (0.5-3.7)	0.75 (0.4-1.3)	0.89 (0.4-1.6)	0.76 (0.2-2.5)
	12-18	1.21 (0.4-3.1)	0.91 (0.5-1.5)	1.21 (0.6-2.1)	1.04 (0.3-3.3)
Gender	Female				
	Male	1.06 (0.4-2.3)	0.89 (0.5-1.3)	1.27 (0.8-1.9)	0.86 (0.3-2.0)
Poverty status %FPL	>=200%				
	< 200%	1.03 (0.4-2.4)	0.81 (0.5-1.2)	0.54 (0.3-0.8)	0.52 (0.2-1.3)
MSA status	Not in MSA				
	MSA	0.66 (0.1-3.2)	1.07 (0.5-2.2)	0.51 (0.2-1.0)	0.47 (0.1-3.9)
Severity	Mild				
	Moderate	0.51 (0.2-1.2)	0.83 (0.5-1.3)	0.74 (0.4-1.2)	0.59 (0.2-1.6)
	Severe	0.30 (0.1-0.8)	0.22 (0.1-0.4)	0.54 (0.2-1.0)	0.30 (0.1-0.9)

Bold represents statistically significant results

FPL – Federal Poverty Level

MSA – Metropolitan Statistical Area

CI – Confidence Interval

Each multivariate model has race, ethnicity, age, gender, poverty status, MSA status, and severity of health condition in the model

Table 3: Prevalence of Unmet Need by Demographic Factors (Bivariate Results)

Prevalence of Unmet Need		Unweighted N	Routine Preventive Care		Specialist Care		Dental Care		Mental Health Care		PT/OT/Speech		Eyeglass, Vision Care	
			%	SE	%	SE	%	SE	%	SE	%	SE	%	SE
Prevalence			3.5	1.0	9.5	2.1	10.0	1.5	20.3	3.6	15.3	3.5	4.4	1.5
Race	White	590	3.4	1.2	8.8	2.1	10.0	1.8	20.9	4.3	15.7	4.4	4.8	1.7
	Non-White	157	3.9	2.2	11.4	5.6	10.2	2.8	20.3	7.1	15.6	6.1	3.0	1.9
Ethnicity	Hispanic	193	5.2	2.1	6.0	2.4	15.5 *	3.2	36.5	8.1**	19.7	6.8	5.6	2.5
	Non-Hispanic	556	3.0	1.2	10.5	2.6	8.7	1.7	16.0	3.8	14.2	4.2	4.1	1.8
Age	0-5	130	1.8	1.1	9.1	4.1	12.4	4.4	24.6	13.0	10.5*	6.2	8.7	5.7
	6-11	307	3.7	1.7	9.8	4.0	9.3	2.0	21.5	5.5	8.7	3.5	2.9	1.4
	12-18	314	4.0	1.9	9.4	2.9	10.0	2.4	18.7	5.1	27.9	8.7	5.0	2.4
Gender	Male	451	3.5	1.3	6.4*	1.8	10.1	1.8	19.4	4.2	14.7	4.1	5.5	2.3
	Female	300	3.4	1.7	14.8	4.7	9.7	2.6	22.4	6.9	16.8	6.5	2.5	1.2
Poverty status %FPL	<200%	265	5.5	1.8	18.8**	5.4	17.4**	3.6	31.8	6.7*	17.8	5.7	6.3	2.3
	>= 200%	421	2.7	1.4	5.2	1.5	6.8	1.6	14.7	4.0	13.2	4.6	3.6	2.3
MSA status	MSA	680	3.1	1.1	10.3***	2.3	10.6**	1.6	19.8	3.8	16.0	3.8	5.0	1.7
	Not in MSA	71	6.7	4.4	2.4	1.5	3.9	1.9	25.5	11.0	9.7	8.6

* p < 0.05

** p < 0.01

*** p < 0.001

FPL – Federal Poverty Level

MSA – Metropolitan Statistical Area

Table 4: Adjusted Odds Ratio (95% Confidence Interval) for Unmet Need by Demographic Variables

Demographics		Routine Preventive Care	Specialist Care	Dental Care	Mental Health Care	PT/OT/Speech	Eyeglass, Vision Care
Race	White						
	Non-White	0.73 (0.1-4.7)	1.39 (0.4-4.7)	0.63 (0.3-1.3)	0.65 (0.2-1.7)	0.78 (0.3-2.0)	0.37 (0.1-2.2)
Ethnicity	Non-Hispanic						
	Hispanic	1.51 (0.4-5.1)	0.27 (0.1-1.1)	1.64 (0.8-3.2)	2.57 (1.0-6.5)	1.42 (0.5-3.9)	1.46 (0.3-6.0)
Age	0-5						
	6-11	2.93 (0.5-16.4)	1.37 (0.3-5.0)	0.65 (0.2-1.7)	0.57 (0.1-3.7)	1.49 (0.2-9.2)	0.16 (0.0-1.5)
	12-18	2.59 (0.5-13.3)	1.24 (0.3-4.3)	0.79 (0.2-2.1)	0.46 (0.1-2.9)	5.69 (0.9-35.6)	0.45 (0.1-2.6)
Gender	Female						
	Male	1.00 (0.2-4.1)	0.46 (0.1-1.1)	1.09 (0.5-2.2)	0.86 (0.3-2.3)	0.85 (0.2-3.0)	4.37 (0.9-20.0)
Poverty status %FPL	>=200%						
	< 200%	2.00 (0.5-7.4)	5.25 (2.0-13.7)	3.45 (1.6-7.3)	2.47 (1.0-6.0)	1.68 (0.5-5.2)	2.24 (0.5-9.1)
MSA status	Not in MSA						
	MSA	0.59 (0.1-3.2)	6.98 (1.2-40.3)	4.35 (1.3-13.7)	1.15 (0.3-4.4)	1.66 (0.2-10.4)	...

Bold represents statistically significant results

FPL – Federal Poverty Level

MSA – Metropolitan Statistical Area

CI – Confidence Interval

Each multivariate model has race, ethnicity, age, gender, poverty status, and MSA status in the model

Table 5: Delayed or Forgone Care and Associated Reasons

Reasons for Delayed or Forgone Care	Arizona				Nation	
	N	Weighted N	Weighted %	SE	Weighted %	SE
Child's health care delayed or forgone in the past 12 months	88 ^a	19,398	12.64	1.77	9.73	0.32
Reason for delayed care						
Provider not accessible	35	5,632	3.67	0.77	2.97	0.21
Could not reach provider office by telephone	9	1,239	0.81	0.34	1.14	0.11
Could not get appointment soon enough	19	2,604	1.70	0.44	2.13	0.16
Child has to wait too long to see provider	21	3,722	2.43	0.68	2.01	0.19
Financial problems	71	14,670	9.56	1.57	7.82	0.29
Has transportation problem	12	2,134	1.39	0.56	1.71	0.15
Did not have money to pay provider	49	10,788	7.03	1.45	6.09	0.25
Type of care not covered by health plan	34	6,313	4.12	0.91	3.87	0.19
Could not get approval from health plan or doctor	21	4,660	3.04	0.88	2.98	0.20
Time conflicts	34	8,252	5.38	1.36	4.01	0.22
Appointment conflicted with other home or work responsibilities	25	5,427	3.54	0.93	3.32	0.21
Clinic or office not open when they could go	15	3,919	2.55	1.08	1.75	0.15
Lack of medical specialty	24	4,277	2.79	0.71	2.65	0.17
Type of care needed not provided in the area	19	2,958	1.93	0.53	2.08	0.15
Provider did not have skills child needed	13	2,823	1.84	0.62	1.47	0.12
Had language, communication, or cultural problems with provider	6	852	0.56	0.26	0.49	0.07

^a The number of individual reasons listed adds to more than the total number of respondents because respondents could list more than 1 reason for delayed or forgone care

Table 6: Frequency for Delayed or Forgone Care by Demographics and Health Factors (Bivariate Analysis)

Demographics		Unweighted N	Delayed or Forgone Care		Provider Not Accessible		Financial Problems		Lack of Medical Specialty		Time Conflicts		Language, Communication or Cultural Problems With Provider	
			%	SE	%	SE	%	SE	%	SE	%	SE	%	SE
Race	White	590	13.6	2.1	3.9	0.9	10.6	1.9	3.0	0.9	5.5	1.6	0.6	0.3
	Non-White	157	9.9	3.2	3.2	1.3	6.5	2.2	2.2	1.1	5.2	2.6	0.3	0.3
Ethnicity	Hispanic	193	8.9	2.2	4.6*	1.5	8.4*	2.2	2.1	1.0	4.6	1.5	2.2***	1.1
	Non-Hispanic	556	13.8	2.2	3.4	0.9	10.0	1.9	3.0	0.9	5.7	1.7	0.1	0.1
Age	0-5	130	10.3	3.5	2.0	1.1	5.7	2.2	1.5	0.9	1.5	1.3	0	-
	6-11	307	9.1	1.9	3.7	1.1	7.9	1.7	2.9	6.2	3.7	1.1	1.1	0.6
	12-18	314	16.6	3.3	4.2	1.4	12.5	3.0	3.2	1.2	8.3	2.8	0.3	0.2
Gender	Male	451	12.6	2.3	3.3	0.8	8.2**	2.0	2.6	0.8	5.9	2.0	0.8	0.4
	Female	300	12.7	2.7	4.3	8.4	11.9	2.6	3.1	1.4	4.4	1.5	0.2	0.2
Poverty status %FPL	<200%	265	17.5*	3.3	6.8	2.0	14.3	2.9	3.8	1.6	8.5	2.5	1.3*	0.7
	>= 200%	421	9.9	2.3	1.8	0.6	6.8	2.1	1.8	6.4	3.6	1.8	0.1	0.1
MSA status	MSA	680	11.8	1.8	3.5	0.8	9.3	1.7	2.5	0.7	4.2*	1.3	0.6	0.3
	Not in MSA	71	21.4	6.9	5.5	2.5	12.4	4.3	5.9	3.1	16.4	6.5	0	-
Severity	Mild	236	7.6***	2.5	1.3	0.8	5.4	2.0	1.0	0.6	1.2	0.7	0.2	0.2
	Moderate	318	9.5	2.1	3.2	1.0	6.8	1.8	3.2	1.3	3.7	1.3	0	-
	Severe	194	23.4	4.7	7.2	2.2	18.6	4.4	4.1	1.4	12.7	4.3	1.9	0.9
Mother's Education	<= High School	466	10.8	1.9	3.4	0.9	7.1	1.4	2.5	0.8	3.2	0.9	0.5	0.4
	> High School	261	15.0	3.3	3.8	1.3	12.7	3.1	3.3	1.3	8.4	2.9	0.7	0.3

* p < 0.05

** p < 0.01

*** p < 0.001

FPL – Federal Poverty Level

MSA – Metropolitan Statistical Area

Table 7: Adjusted Odds Ratio for Having Delayed Care or Forgone Care

Demographics		Delayed or Forgone Care	Provider Not Accessible	Financial Problems	Lack of Medical Specialty	Time Conflicts	Language, Communication or Cultural Problems With Provider
		OR (95% CI)	OR (95% CI)	OR (95% CI)	OR (95% CI)	OR (95% CI)	OR (95% CI)
Race	White						
	Non-White	0.57 (0.2-1.3)	0.90 (0.1-4.5)	0.16 (0.02-1.3)	0.77 (0.1-4.6)	0.98 (0.2-3.9)	0.49 (0.0-14.7)
Ethnicity	Non-Hispanic						
	Hispanic	0.54 (0.2-1.2)	1.86 (0.3-10.2)	11.56 (0.4-312.4)	0.78 (0.1-3.0)	0.82 (0.1-4.2)	18.46 (2.1-155.4)
Age	0-5						
	6-11	0.84 (0.2-2.3)	7.72 (0.6-91.4)	1.15 (0.1-15.2)	4.41 (0.4-40.3)	8.18 (0.5-123.2)
	12-18	1.74 (0.6-4.7)	2.60 (0.2-27.3)	0.74 (0.1-9.6)	1.39 (0.1-11.7)	5.61 (0.4-71.3)
Gender	Female						
	Male	0.86 (0.4-1.7)	1.08 (0.3-3.8)	0.06 (0.0-0.5)	0.83 (0.2-3.3)	2.42 (0.6-8.8)	3.51 (0.2-50.8)
Poverty status %FPL	>=200%						
	< 200%	1.85 (0.8-3.8)	4.36 (1.1-16.2)	1.99 (0.4-9.7)	1.06 (0.2-4.7)	1.44 (0.2-7.0)	5.95 (0.6-53.9)
MSA status	Not in MSA						
	MSA	0.68 (0.2-1.6)	1.17 (0.2-6.5)	2.92 (0.3-22.6)	1.37 (0.2-7.2)	0.25 (0.1-1.2)
Severity	Mild						
	Moderate	1.27 (0.4-3.3)	2.04 (0.3-11.8)	0.50 (0.0-7.2)	7.12 (1.0-48.9)	3.36 (0.4-26.1)
	Severe	3.87 (1.4-10.0)	2.37 (0.4-13.9)	1.04 (0.1-14.9)	5.29 (0.7-39.9)	6.73 (0.9-46.7)
Mother's Education	>= High School						
	<High School	0.80 (0.3-1.6)	2.72 (0.7-9.4)	0.30 (0.1-1.7)	1.91 (0.4-7.8)	0.80 (0.2-3.1)	8.36 (1.2-55.1)

Bold represents statistically significant results

FPL – Federal Poverty Level

MSA – Metropolitan Statistical Area

CI – Confidence Interval

Each multivariate model has race, ethnicity, age, gender, poverty status, MSA status, severity, and mother's education in the model

APPENDIX B
OCSHCN PARTNERSHIPS

ARIZONA DEPARTMENT OF ECONOMIC SECURITY

As one of the five participating agencies within the Arizona Early Intervention Program (AzEIP), ADHS/OCSHCN partners with the lead agency, Arizona Department of Economic Security (ADES), to implement and monitor services provided to eligible infants and toddlers. Effective May 1, AzEIP eligible children who are enrolled in AHCCCS are being referred to their AHCCCS health plan for medically necessary Early Periodic Screening, Development, and Treatment (EPSDT) services.

GOVERNOR'S OFFICE

The Governor's Efficiency Review Report requires the Department of Economic Security, the Arizona Health Care Cost Containment System (AHCCCS) and the Department of Health Services to establish procedures that will streamline application processes for children born with severe birth defects. The Governor's Efficiency Review Report specifically identifies (1) AHCCCS (specific programs not identified), (2) Newborn Intensive Care Program, (3) Children's Rehabilitative Services, (4) Division of Developmental Disabilities and (5) the Arizona Early Intervention Program.

The objective is to develop an automated screening and application system that is accessible to all families and fulfills two primary functions (1) informs the family of the programs for which they may be eligible/interested (i.e. screening for potential eligibility for identified programs and resources), and (2) completes and electronically submits an application(s) for the program(s) in which the family is interested. Ideally, applications submitted electronically would automatically populate the database(s) or the program(s) for which the family applies. Implementation options are currently being explored.

GOVERNOR'S COUNCIL ON DEVELOPMENTAL DISABILITIES

OCSHCN community teams are working with the Council on education regarding self-advocacy and community-based services for children and their families. OCSHCN works to inform parents and students with disabilities on their roles, rights, and responsibilities in the area of transition and the development of the student's own IEP.

GOVERNOR'S COUNCIL ON HEAD AND SPINAL CORD INJURIES

In 1997, the ADHS/OCSHCN and the Arizona Governor's Council on Spinal and Head Injuries established a partnership to address the unmet needs of children with traumatic brain injuries. In 2005, this cooperative effort expanded to include services to children and youth with spinal cord injuries.

ARIZONA DEPARTMENT OF EDUCATION (ADE)

OCSHCN participates on the Arizona Transition Leadership Team (ATLT), developed by the ADE to build consensus on a vision, common goals, and core principles that families, educators, agencies, advocates and others could rally around. This group focuses on the development of statewide policies to ensure timely evaluations to enter and access post-secondary disability resources; the design of research to validate the efforts in the schools tied to student post school outcomes; and to build capacity by developing a more results-driven state systems so that youth with disabilities achieve a more desirable post-school outcome.

The National Center on Secondary Education and Transition (NCSET), in partnership with federal agencies and national organizations, co-hosted a second National Leadership Summit on Improving Results for Youth in Washington, DC in June 2005. The goal of this event was to convene state-level teams of policymakers to examine the progress made in the implementation of the strategic action plans developed at the 2003 Summit, and to further build state/territory capacity to improve high school experiences that lead to successful post-school outcomes for all youth. An OCSHCN staff member attended this Summit as part of Arizona's Transition Team.

An OCSHCN staff member is the State Adolescent Health Coordinator and is part of the national network of state coordinators. OCSHCN is also partnering on the ADE state transition conference in September.

INTERAGENCY COORDINATING COUNCIL

In accordance with the Individuals with Disabilities Education Act (IDEA), the Governor established a State Interagency Coordinating Council to advise and assist the lead agency, ADES, in the development and implementation of policies that constitute the statewide system of early intervention services, Part C of the IDEA. Individuals serving on the Council are appointed by the Governor and include parents of infants/toddlers with disabilities, public/private providers, a representative of each of the participating State agencies, the State legislature, Head Start, the State agency responsible for childcare, the State Medicaid program, a representative from the Office of the Coordinator for Education for Homeless Children and Youths, a representative from the State child welfare agency responsible for foster care, and a representative from the State agency responsible for children's mental health.

ARIZONA ADOLESCENT HEALTH COALITION (AAHC)

An OCSHCN staff attends bimonthly Board meetings to provide a link between AAHC and OCSHCN. This link affords the opportunity to share information and have issues/concerns of youth with special health care needs included in the AAHC activities. Through this partnership, a parent of an adolescent with special health care needs was able to attend a pilot training on communicating with adolescents for parents. OCSHCN contributed to the Arizona Adolescent Health Coalition's 2004 "The Status of Adolescent Health in Arizona" publication and coordinated a breakout session at the AAHC 2004 Annual Conference that was led by youth with special health care needs. OCSHCN is creating a fact sheet on Transition that AAHC will make available on their website.

ARIZONA PUBLIC HEALTH ASSOCIATION (AZPHA) SCHOOL HEALTH SECTION

Public health plays a key role in the school environment. School health is a concern for all school age students, especially children and youth with special health care needs. An OCSHCN staff member attends and actively participates in the monthly AzPHA School Health Section Meetings. These meetings provide networking opportunities and sharing of information that can be used to enhance school health for children and youth with special health care needs. The staff coordinated a guest speaker from the Tucson Unified School District to present at one of the monthly meetings on the "Coordinated School Health Model" that is being implemented in Tucson. OCSHCN staff also arranged two speakers for the Fall 2005 AzPHA Conference, School Health breakout session to present on "Integrated Pest Management" and "School Bus/Car Idling." OCSHCN coordinated and provided a handout folder for the School Health breakout session of the Fall 2004 AzPHA conference "Using Data to Paint the Picture of Adolescent Health in Arizona". The handout included material about: the CDC Youth Risk Behavior Survey (YBRS) that was implemented in Arizona in 2003 by the Arizona Department of Education; the Arizona Criminal Justice Commission's "Arizona Youth Survey;" and the Arizona Adolescent Health Coalition's "Status of Adolescent Health in Arizona 2003." In addition, there was data on the Abstinence Program provided by ADHS, Office for Women's and Children's Health, data from the 2003 Arizona Health Status and Vital Statistics from the ADHS, Bureau of Public Health Statistics, and a newsletter describing the National Survey of Children with Special Health Care Needs from OCSHCN.

ARIZONA ACADEMY OF PEDIATRICS (AZAAP)

OCSHCN/CRS Medical Director is a member of the AzAAP. In this capacity, she was appointed as the Arizona liaison for the AAP Council on Children with Disabilities. At the state level, there are plans to initiate a task force to work on improving care for C/YSHCN.

OCSHCN provided feedback to the lead author for their policy revision of "The

Role of the School Nurse in Providing School Health Services” with suggestions to include the role of the school nurse in providing information and coordination of transition activities and with providing education to school personnel on the special health care needs and procedures.

ARIZONA MEDICAL ASSOCIATION (ARMA)

OCSHCN Medical Director is an appointed member of the ArMA Maternal and Child Health Committee. Additional OCSHCN staff participates on the ArMA, Maternal and Child Health Adolescent Subcommittee’s Adolescent Health Community Advisory Group to create a state plan to address how adolescents access appropriate health care. At the request of the Adolescent Health Community Advisory Group, OCSHCN created an adolescent survey that will provide data on the adolescent’s perception and access to health care services. OCSHCN was instrumental in adding representation from the Arizona Department of Juvenile Corrections and the ADHS, Office of Oral Health to the Adolescent Health Community Advisory Group. OCSHCN will also oversee adolescent involvement with the Advisory Group to provide feedback on, and suggestions for the Adolescent Health Plan.

ARIZONA ASTHMA COALITION

Staff from OCSHCN actively participates in the Arizona Asthma Coalition and OCSHCN provides funding to this organization to develop and implement community-based programs to address the needs of children who have asthma. OCSHCN suggested additions to the Comprehensive Asthma Control Plan for the State of Arizona that included:

- Encourage health care providers to utilize an approach that promotes care that is accessible, family-centered, continuous, and coordinated, comprehensive, compassionate, and culturally sensitive. For children, youth, and their families, this approach is referred to by the American Academy of Pediatrics as a Medical Home.
- The school nurse, school nurse practitioner, or physician assistant in the school-based clinic are key team partners to families and physicians.

RAISING SPECIAL KIDS (RSK)

OCSHCN contracts with Raising Special Kids, a statewide advocacy organization, to facilitate training sessions for residents from pediatric and family practice programs that include home visits with families with children/youth with special health care needs (C/YSHCN). Both organizations plan, conduct, and evaluate family-centered training and training materials for CRS staff, student nurses, and dental students. RSK participates in bi-annual CRS statewide conference planning and presentations. RSK staff (who are also parents of children with special health care needs) participate in ADHS/OCSHCN planning, program development, training activities, and any activities requiring family

perspective, including referring parents and youth to become part of OCSHCN's Parent/Youth Leadership Institute.

PILOT PARENTS OF SOUTHERN ARIZONA/PARTNERS IN PUBLIC POLICY MAKING

Pilot Parents of Southern Arizona promotes the CRS Parent Action Council activities within the regional CRS clinic in Tucson by providing assistance in identifying and supporting parents and youth to participate in CRS activities. The activities include participation in medical home initiatives, providing administrative support for OCSHCN community development, parents, youth and physician partners to provide training to pediatric residents at the University of Arizona and service coordinators utilizing OCSHCN parent/physician interaction project modules and resources.

OCSHCN is working with Pilot Parents of Southern Arizona through the Arizona Chapter of Partners in Policy Making program, to recruit parents, youth, and self-advocate graduates to participate in various advocacy activities within OCSHCN. As graduates, they need to continue to show that they are working to advocate for systems improvement for C/YSCHN. Partners in Policy Making provides an innovative leadership training program for parents of children with disabilities and for adults with disabilities. The program is designed to provide information, training, resources, and skill building to people with a disability and the parents of children with disabilities so that they can become better advocates for themselves or their children. Partners provides participants with opportunities to: meet and talk to national leaders in the field, learn how the legislative process works at the local, state and national levels, and how to develop productive partnerships with those in a position to make policy and law.

NORTHERN ARIZONA UNIVERSITY/INSTITUTE FOR HUMAN DEVELOPMENT

The Institute for Human Development offers an Interdisciplinary Graduate Certificate in Disability Policy and Practice. Students from a variety of disciplines are encouraged to apply to the certificate program. The purpose of this program is to prepare students to work with individuals with disabilities across the life span and their families in educational, residential, employment, recreational, and day program settings. OCSHCN provides financial support for parents of children with special health care needs and OCSHCN staff presents twice a year to this group of students. The Flagstaff CRS clinic also arranges for home visits with families. Students will acquire knowledge and skills through the 12-hour program of courses and practicum.