



STATE OF UTAH

MATERNAL AND CHILD HEALTH NEEDS ASSESSMENT FY2010



UTAH DEPARTMENT OF
HEALTH

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Section 1: Five Year Needs Assessment

Introduction

Utah's Maternal and Child Health Bureau recognizes the importance of assessing its programs on an ongoing basis. The Health Resources and Services Administration require states to conduct comprehensive needs assessment every five years. The purpose of the needs assessment is to review the health status of Utah's MCH/CSHCN population and to identify emerging needs and gaps in services as we develop plans for the next five years. The goal guiding the assessment is to utilize the information from the needs assessment to formulate a plan of action to address the needs for women, mothers, infants, children, youth in Utah, including those with special health care needs, and families. The needs assessment helps us identify key needs for the three populations we serve as well as identify priorities needing attention and mechanisms to address the priorities.

The Department of Health's vision is "a place where all people can enjoy the best health possible, where all can live, grow and prosper in clean and safe communities". The Title V vision is that all women, mothers, children, youth, including those with special needs, and families in Utah are healthy. These visions guided the framework of FY2011 MCH needs assessment process.

MCH Needs Assessment Leadership Team

The leadership team was established to oversee the development and implementation of the needs assessment. The leadership team consisted of the MCH and CSHCN Directors, MCH epidemiologist, key program managers and data staff. The Title V/MCH Director led the initiative and organized a series of planning meetings to discuss and set the direction and goals of needs assessment. The leadership team established process, activities, and timelines. Each member of the leadership team had specific assignments. The leadership team met on a regular basis to track progress and ensure assignments were completed on time. A separate data team was established to conduct various data activities related to needs assessment process. The data team was comprised of CSHCN information analyst, PRAMS data manager, an epidemiologist, two graduate student interns and the MCH epidemiologist. The data team met monthly and worked with program subject matter experts (SME) to complete several needs assessment tasks. The progress of data team was presented at each leadership team meeting to coordinate activities and to get further guidance.

Needs Assessment Methodology

The FY2011 - 2016 needs assessment is based on multi-faceted approach to collect, review, and analyze information. The overall process consisted of three major components: 1) review of literature of needs assessment methodologies, 2) review of various survey reports and trend data for all performance measures and indicators, and 3) collection of new data from stakeholders using surveys and interviews. Utah's needs assessment process included both quantitative and qualitative data.

The initial planning process included a review of the previous needs assessment processes as well as methodologies used by other states. After review of a number of different processes, the needs assessment leadership team decided to use some of its previous processes and to enhance the scope of information gathering from external stakeholders through different methods.

The data team was charged with reviewing various data sources and updating all National and State Performance Measures, Health Status Indicators, Health System Capacity Indicators, and Outcome Measures with five to ten years of data and compare with HP2010 goals. The interns were responsible for compiling the data and developing trend charts. All measures were categorized for the three Title V MCH population groups (pregnant women, mothers and infants; young children and adolescents; and children and youth with special health care needs). The data team worked very closely with key program staff to prepare narratives on assessment of health status for each of the three MCH populations. The leadership team reviewed the trend data and narratives on three populations to determine progress and to identify strengths and challenges in meeting the needs of the MCH populations in Utah. The leadership team reviewed what worked to enhance health and wellness and what did not.

The leadership team then developed a plan to collect new data for this needs assessment from a broad range of stakeholders. In our discussions, we decided to ensure that we had input from individuals representing a broader view of health needs and issues for mothers and children in the state. The plan included collection of data using surveys and interviews. The leadership team developed three different surveys: a) general stakeholder survey, b) children and youth with special health care needs parent survey and c) a series of key informant interviews with community partners.

Stakeholder Survey

The stakeholder survey was developed by revising and modifying the previous 2005 MCH Needs Assessment Survey. We enhanced the stakeholder survey by adding more issues related to the health needs of mothers, children and youth, including those with special health care needs. The survey instrument was consisted of 14 questions. The survey asked opinions of the general public or stakeholders on key health issues in four areas: mothers and infants; young children and adolescents; children and youth with special health care needs; and health care access. Even though most questions were closed-ended and asked respondents to select important health issues, open-ended questions were also used to collect perceptions of general public on most important health needs and healthcare access problems in their community. Respondents were allowed to identify issues not listed on the survey. The survey instrument is provided in Appendix A. This survey was administered on-line.

Email invitations with survey URL were sent to an extensive list of potential stakeholders for their input. Email contact list included parents, parents of children and youth with special needs, local health departments, community health centers, advocacy groups, and

members from all advisory committees that relate to MCH or CYSHCN issues. This year we obtained contact information for providers in Utah from Utah Department of Professional Licensing (DOPL). DOPL regulates licenses for medical and other professions in the state of Utah. The types of providers contacted via email included: Nurse, Osteopathic Physician, Certified Nurse Midwife, Naturopathic, Physician Assistant and others. A total of 2684 individuals were contacted directly by email to participate in the survey. We also requested and encouraged recipients to forward the survey to anyone they thought might be interested in providing input so that we could obtain as many responses as possible. Additionally, to increase public awareness about this survey, we posted the survey link on MCH Bureau website. Seven hundred and ninety three individuals completed the survey with an estimated response rate of 29.5%. This is an estimated rate as respondents may include others we did not directly contact.

CSHCN Parent Survey

The leadership team selected the topics for the Parent Survey. The survey was developed by adding questions from the National CSHCN Survey and a previous Utah Family Voice Survey. The survey included families whose children were up to 21 years of age. The survey consisted of 35 questions and topics included: insurance coverage; healthcare financial expenses; primary care providers and care coordination; type of needed health care specialists; availability of community services; transportation issues; and identification of community programs that were working well. The CSHCN bureau pursued several avenues to seek input from parents. The survey was administered using a web-based design. Email invitations to complete the survey as well as postcards with survey link were mailed to potential respondents from Utah Parent Center, Family Voices, CSHCN clinics, Early Intervention programs, child advocacy organizations, disability specific organizations, charities, and listservs for families with disabilities. CSHCN provided a 1-800 line and bilingual staff to assist Spanish speaking families and/or families who did not have access to a computer. A total of 4975 individuals were contacted either by email or direct mail. More than a thousand surveys (1013) were completed with an estimated response rate of 20.4%.

Key Informant Interview

An in-depth interview process was designed to complement other data collected for Needs Assessment. Interviews were conducted with key stakeholders in Utah who could offer a broad perspective based on their extensive experience in maternal and child health issues. Interview participants were identified by the Utah MCH director, who personally emailed invitations to them requesting their involvement. This laid the ground work for the consultants to schedule the interviews. Two skilled interviewers from Utah State University who were well versed in MCH systems conducted the interviews, and two public health graduate students served as note takers. Interviews were conducted via telephone at times selected by the respondents. Ten interviews were completed with respondents from the following organizations: local public health departments; a large private health care plan that also serves children on Medicaid; Utah Chapter of American Academy of Pediatrics; Planned Parenthood of Utah; Voices for Utah Children, March of

Dimes, University of Utah Department of Family and Preventive Medicine; American College of Obstetricians and Gynecologists; the Legislative Coalition for Persons with Disabilities. Within these organizations, respondents included a practicing physician, nurse, and nurse practitioner. Participants received letters of information describing the purpose of the interview and procedures that would be taken to ensure their confidentiality. Prior to the interview, findings from the Stakeholder Survey were sent to respondents to review. Each interview lasted approximately 30-40 minutes. The respondents were asked to comment on issues pertaining to the constituency most relevant to their work. These interviews provided us an opportunity to engage stakeholders and partners and obtain their unique perspectives and contributions (see Appendix C).

Prioritization Process

The data team analyzed the stakeholder and parent survey data and rank ordered the health issues for each of the three MCH populations, mothers and infants; children and adolescents; and children & youth with special needs. The open-ended comments were tabulated by interns to incorporate in the analyses. Summary reports with survey findings were sent to team members to review prior to the leadership team meetings. The leadership team reviewed the top 10 priority needs for each of the three populations as identified by Stakeholder survey, CSHCN Parent Survey and Key Informant Interviews. The team assigned key program managers to meet with their respective program staff to narrow the list and to recommend top 3 or 4 priority needs taking into consideration the following criteria: magnitude of the problem; ability of the program to address the issue; and if the issues being address by program or another agency.

Program managers held separate work group meetings to select their priorities and submitted to the leadership team. We started with 26 priority issues and through discussion and review of impact, numbers affected, appropriateness for the Department of Health to address versus another state entity, measurability and availability of data to measure, whether the issue was already covered in a National Performance Measure, and ability to influence, we narrowed the list to 10 (see Section 5 for detail).

Each priority was then developed into a state performance measure (SPM). Members of the team worked in groups and individually with MCH programs to identify data sources and reporting criteria of each measure. For each new SPM staff was assigned to write a draft proposal of the annual plan including program activities designed to impact the performance measures.

In summary, through a review of a variety of data sources and measures required for the grant, along with input from families and the public, we were able to identify key issues for each of the three populations.

Resource allocation will be reviewed after the grant is submitted for review. Given the changes in state priorities and state performance measures, we will have additional work to do to determine the best ways to address the needs. For example, multivitamin use was

identified as a high priority since so few Utah women take them prior to conception. We have not allocated any funding to prevention activities for several years and plan to reallocate funding for this activity.

Data Sources

The following data sources were used to obtain a comprehensive picture of the needs of Utah mothers, women, children and children with special health care needs and their families and to identify gaps in the service systems:

Population-based Data

- Vital records (birth, death and stillbirth data)
- Hospital discharge data
- U.S. Census
- ACS

Survey Data

- National Immunization Survey
- National Survey for Children's Health
- National Survey Children with Special Health Care Needs, 2001 & 2005/06
- National Survey of Children's Health, 2005 & 2007
- Utah Healthcare Access Survey
- Utah PRAMS
- Utah YRBSS
- Utah BRFSS

Program Data

- Medicaid
- CHIP
- Utah Newborn Hearing Screening Data-Hi*Track
- Utah Newborn Blood Screening Data-NLIMS
- Utah CSHCN Billing Database, Megawest
- Utah BabyWatch Early Intervention Program Data- BTOTS
- Utah Foster Care Databases, Health Sections-SAFE
- Utah Registry for Autism and Developmental Disorders database-URADD
- Utah Birth Defect Network
- Perinatal Mortality Review data
- STD/HIV surveillance data
- PedNSS
- PregNSS
- Head Start
- Local Health Department service data
- Oral Health Survey data
- WeeCare Program data
- Department of Human Services data sets

Methods for Assessing State Capacity

Assessing state capacity included a review of status of progress, review of key elements and components of a state Title V agency, capacity to address gaps in service delivery or other means to impact health status, available resources, such as Medicaid and CHIP eligibility levels. With Utah having one of the most restrictive income eligibility levels for prenatal and infant health care along with a strict asset test, we know that there are many women and young children who cannot access needed services because of lack of insurance. We know that the demand for services, especially specialty services, for children and youth with special health care needs is high but not fulfilled due to lack of specialty providers in rural areas of the state and due to health provider shortages throughout the state for a number of health care professions. Through review of data on numbers served, access to services, review of various data sets, we are able to assess state capacity. We included Health Professional Shortage Area analysis, hospital levels of care, access to care, insurance coverage among many other data elements.

Linkages between Assessment, Capacity, and Priorities

As we reviewed the strengths, progress toward health and wellness, needs and challenges, and capacity, we identified priorities based on the input we received and the data trends. We developed the State Priorities based on the data review, assessment of our strengths and needs for the three populations we serve. Review of the state and national Performance Measures, other data sets, work that we have done on various elements of needs of the three populations, input from the surveys all played a role in our discussions of needs. We considered in our discussions the ability to impact, numbers impacted, shortages of services and significance of the issue.

Strengths and Weaknesses of Process

The strength of the process for us was the availability of numerous data sets, data set linkages, and qualified, experienced staff. The number of responses that we received on the three surveys was a great success for us. We believe that our attempts to get input from a broader range of people were successful. We were particularly pleased with the high number of responses for both stakeholder and parent surveys. The strong collaboration among MCH and CSHCN programs as well as the manner in which community partners shared relevant information greatly enhanced the final outcome of the needs assessment.

We faced a number of challenges in the process of conducting the needs assessment. For the stakeholder survey, the way a few questions were worded, it did not give us the information that we thought we were seeking. Some of the open-ended questions from the CSHCN Parent Survey had more than 900 possible responses, making coding for analysis challenging. However, we still received valuable information on the public's opinion of health issues for mothers and children.

The most significant challenge of the process was the requirements for conducting the needs assessment. This assessment was time consuming and demanded continuous involvement of a number of key staff. A substantial proportion of Title V funding goes into needs assessments and annual applications. The duplication of content between the needs assessment and the annual application/report, was extremely tedious. MCHB may consider reviewing the entire process of the needs assessment, annual application and reporting to simplify and reduce the high level of redundancy. Streamlining the requirements and eliminating the redundancy would make the document more concise and meaningful for states, reviewers, and the public.

Section 2: Needs Assessment Partnership Building and Collaboration

We build partnerships with the public and private sector in a variety of different ways: participation on advisory committees, participation in specific projects, participation of state staff on partnering agency advisory boards and committees, etc. The Department meets regularly with the local health officers, nursing directors, WIC Directors and health educators. We maintain a number of formal agreements between agencies to assist us in doing our work.

State and Local MCH Programs

The State Title V agency in the Utah Department of Health (UDOH) includes both MCH and CSHCN programs in the same Division, facilitating collaboration between the two areas of Title V. In addition, Department efforts for teen pregnancy prevention and family planning are included in the MCH Bureau. Both of these state level efforts are funded with Title V dollars as there is no other funding source in the state for this work.

The State Title V agency works closely with the Title X agency, Planned Parenthood Association of Utah (PPAU). PPAU CEO, Karrie Galloway, participates on committees dealing with family planning issues, such as the Perinatal Taskforce. Karrie has been a partner with UDOH for many years and has supported efforts to improve the health of mothers and children throughout that time. Members of the PPAU staff also participate in work we do around these issues. PPAU is a member of the Association of Utah Community Health (AUCH). PPAU operates the Weber Community Health Center in Ogden.

The State Title V agency supports local health departments (LHD) in ensuring services for mothers and children throughout the state. Each LHD receives Title V funding through a contract to provide needed health services for mothers and children in their district. The twelve local health departments are autonomous and as such, each provides a different array of services. The Department contracts with LHDs for other services, such as support for CSHCN rural clinics, immunizations, etc. The relationship between the Department and LHDs has been very strained the past couple of years due to a conflict of views about allocation of federal funds, requesting participation in projects that add additional work for staff, and so on.

The LHD Health Officers worked with the 2008 Legislature to pass a bill requiring the UDOH to work with LHD Health Officers on review of federal grants, role of state and local agencies in grant and allocation of funding. Dr. Sundwall established the Governance Committee as a forum for these discussions. Three UDOH leaders and three LHD Health Officers comprise the committee. The Governance Committee has identified approximately 8 federal grants to review and determine if UDOH is appropriately allocating funding to LHDs. Key to the discussions has been a lack of awareness of federal grant requirements and the purpose of the grants. At dispute is the definition of “state” and “statewide”. At issue is do these terms imply that LHDs are a partner in fulfilling grant activities, and therefore receive funding, or does the term mean that the Department establishes a “statewide” plan means that it is developed and implemented at

the state level only. The LHD Health Officers have listed the Title V Block Grant, but is not one of the 8 federal grants in contention.

Other Governmental Agencies

The Division has a very strong and collaborative relationship with the state Medicaid agency. We are very fortunate that Medicaid is a sister Division within the UDOH. In addition, the CHIP program, while a stand-alone program, is administered by Medicaid. We have an excellent working relationship with Medicaid and often do joint work, seek input from Medicaid staff members on a variety of issues. We have worked with Medicaid staff for a number of years to explore submitting a family planning waiver, however, we have not yet succeeded due to a number of challenges. We plan to continue working on the waiver. Division staff frequently works with Medicaid and/or CHIP (Utah's CHIP Program, while separate from Medicaid, is administered by Medicaid) on projects or initiatives of mutual interest and commitment. Medicaid in Utah has demonstrated a clear commitment to children in the state and has previously been involved in several grant opportunities related to children's health, such as the Commonwealth's ABCD I and II projects focusing on developmental and social-emotional screenings for young children. From these efforts, Division staff worked with Medicaid staff to change policy on evidence-based screening tools to be used by providers as part of EPSDT services.

The Title V agency has strong relationships with the Department of Human Services, especially the Division of Child and Family Services (DCFS). DCFS contracts with CSHCN to provide case management services to children as they enter the foster care system. CSHCN nurses located throughout the state ensure that the children receive initial health examinations and needed health services. The UDOH also works with DCFS on child abuse prevention and domestic violence prevention.

The UDOH works with the Division of Substance Abuse and Mental Health in the Department of Human Services, community mental health centers, Child Protective Services and others to promote the importance of mental health as it relates to early childhood development, social emotional health, family well-being with mixed success. Former Governor Huntsman had established a "Child and Family Cabinet" that was headed by the Executive Director of the Department of Human Services to address issues related to children and their families, including early childhood, mental health, domestic violence, child abuse, etc. Title V has been included, but the Cabinet Council has not met since Governor Huntsman left office.

The Division also works with the Department of Workforce Services (DWS) on early childhood issues. DWS provides funding to the Bureau of Child Health and Safety/Child Care Licensing for its responsibilities in overseeing child health and safety in licensed day care settings.

The Utah State Office of Education, an agency that does not report to the Governor, but rather to the State Board of Education, has been very difficult to engage with. While we

have been able to find several staff to work with on specific projects, we really have not been able to engage higher level administrators in our work. This is unfortunate, as there is a lot we could do together.

Other HRSA Programs

The state Title V agency has strong partnerships with other HRSA-funded programs, such as Primary Care, Rural Health, and HIV/AIDS, other programs in the Department, such as health promotion, Medicaid, CHIP, vital records and health statistics (known in Utah as the Center for Health Data, Office of Vital Records and Statistics, and Office of Healthcare Statistics), injury prevention and control, WIC, immunizations, etc. The Division of Family Health and Preparedness (DFHP) also includes the Office of Primary Care, Office of Rural Health, Center for Multi-cultural Health, Emergency Medical Services, and Preparedness.

The Office of Primary Care is part of the new Division of Family Health and Preparedness created in fall 2009 as a result of the Department reorganization. With the Primary Care Office being part of the same Division, we anticipate a closer working relationship with the office.

The Division of Family Health and Preparedness includes WIC and Utah's Part C program, BabyWatch/Early Intervention, which affords us great opportunity to work together to accomplish mutual goals and purposes. WIC is a program within the MCH Bureau and BabyWatch/Early Intervention is a program in the new Bureau of Child Development.

The Division also includes the newly named Bureau of Child Health and Safety/Child Care Licensing, formerly known as the Bureau of Child Care Licensing. This Bureau now includes the early childhood systems work, children's mental health promotion and the Head Start State Collaboration Office. In the future, we hope to expand these efforts to include school health and overall child health.

The state Title V agency works well with the state Primary Care Organization and Association. Staff in MCH participates in review of community grants for primary care, such as safety net clinics, dental care, and family planning services. Through efforts of the State Dental Director, the state loan repayment program was expanded to include dentists in an effort to attract dentists to the rural areas of the state. Division staff has developed a stronger relationship with the State Primary Care Association, State Primary Care Organization and the community health centers by invitations to sit on Division advisory committees, etc. With the Office of Primary Care now part of the same Division, we anticipate a closer working relationship with the office and association.

MCH/CSHCN established a partnership with the Bureau of Communicable Diseases on issues related to STDs, HIV/AIDS, and teen pregnancy prevention. The Bureau of Communicable Disease is in a sister division in the Department, thus collaboration is important in moving forward on areas that impact women of reproductive age and youth.

The Immunization registry (USIIS –Utah State Immunization Information System) now part of the new Division of Disease Prevention and Control, works closely with the DFHP’s CHARM efforts to enable access to a child’s immunization, newborn blood screening and newborn hearing screening results.

Other State and Local Public and Private Organizations

Relationships with other state and private agencies are strong and broad-based. Much of the work that Title V is engaged in involves collaboration with key partners, so this is a real strength of Utah’s Title V agency.

We work with community organizations, such as Voices for Utah Children, March of Dimes, Utah Perinatal Association, Intermountain Pediatrics Society (Utah’s AAP), and many others to accomplish our goal of improving the health of mothers and children.

MCH and CSHCN have a strong reciprocal relationship with Utah Family Voices as well as the larger network of Family Voices throughout the country. CSHCN has involved Family Voices representative for almost two decades. Activities have included parent representation on state level advisory committees, block grant reviews, needs assessment planning and associated activities. A Family Involvement and Leadership Coordinator position was created eight years ago to employ the Utah Family Voices director to provide family advocacy, support and information to families and CSHCN programs as well as consult on other MCH initiatives. A toll-free number was established for families’ statewide to access the support and information from the coordinator. Title V has supported the creation and sustainability of the MCHB Family-to-Family Health Information center in collaboration with Utah Family Voices and the Utah Parent Center (Utah’s federally funded Parent Training and Information Center funded by the Offices of Special Education and Rehabilitative Services.) This partnership has created a forum for individuals and families of children and youth with special health care needs to effectively participate in essential policy and program developments and changes. Family leadership continues to expand in Medical Home, Medicaid and Early Intervention programs through the continued collaboration

The stakeholders involved in the 2011 Needs Assessment included representatives from Department programs that serve women, mothers and children, such as Tobacco Control and Prevention, Violence and Injury Prevention, external partners, such as local health departments, community based organizations. A parent advocate was part of the Leadership team for the grant. She played a key role in contributing to the parent survey development, distribution and development of priorities.

The role that key partners played in the needs assessment included: participation on advisory committees, completion of the stakeholder survey, participation in key informant interviews and providing information to be included in the needs assessment. The stakeholder survey was widely distributed to members of Department advisory committees, local health departments and local agencies, partner agencies, and parents.

Summary

In all the work we do, we engage key partners in activities, feedback, and development of strategies or programs. Their input is critical to the work we do. The strength of the state collaborative efforts is that we have engaged more partners, especially the private provider community, the University of Utah Department of Pediatrics, Department of Obstetrics and Gynecology and the Department of Family and Community Medicine as well as health care professional organizations in our work. The Division has a strong relationship with the March of Dimes chapter, especially in the area of prematurity prevention. We now have a stronger relationship with the mental health community than in the past – we are at the table of discussions around building the infrastructure for children’s mental health, a major advance in relationships since mental health is under the purview of another state Department.

Key partners will be involved in crafting implementation strategies to carry out the requirements of the grant. Partners will include representatives of local health departments, advocacy organizations, and existing advisory committees.

Recognizing that the needs assessment is an ongoing process, the Title V leadership team will continue, as it has in the past, to monitor Utah’s progress in the priority areas identified through the needs assessment process. Each year as additional data become available, program staff reviews the data and seek strategies to address the findings that have changed.

As we go about the work ahead for the next five years based on priority needs, we will review the relationship of partner agencies and organizations and determine ways that they can be strengthened and enhanced for us to fulfill the work of healthy mothers and children. The weakness of the state collaborative efforts is that we have had difficulty in engaging some partners in our work for a variety of reasons, including “we’re too busy”, different focus of work (prevention versus treatment), etc. The relationship with the State Office of Education has improved, but we need to continue our efforts in working with them.

The collaborative efforts of the Utah Title V agency have been extensive, and often we meet key players in multiple meetings. Collaborative efforts take time, involve more effort, but are extremely worthwhile for producing a finer work product or service than if done without the input of key partners. For Utah, this is a real strength. In summary, partners played a key role in helping us identify new state priorities on which to focus over the next five years.

Section 3: Strengths and Needs of Maternal and Children Health Population Groups

Overview of the State's Demographics

Utah is largely a rural and frontier state, with the majority of the state's population residing along the Wasatch Front, a 75-mile strip running from Ogden (north) to Provo (south) with Salt Lake City, the state's Capital, in between. The Wasatch Front comprises only 4% of the state's landmass, but 76% of the state's population resides here. The rest of the population (24%) resides in the remaining 96% of the state's land mass comprised of the rural areas of more than six, but less than 100 persons per square mile and frontier areas of less than six persons per square mile. Five percent of the state's population lives in the frontier area (70% of the land mass), and 19% lives in the rural portion (26% of the land mass). The geographic distribution of the state's population presents significant challenges for accessing health care services for those living in the rural and frontier areas as well as for delivery of health care services. In the rural and frontier areas, many residents are not able to readily access health care services due to long travel distances and lack of nearby hospital facilities and health care providers, especially specialists. Specialists are not available to rural/frontier residents except by traveling hundreds of miles. In addition residents living in the rural/frontier areas may be reluctant if not unwilling to utilize certain local services, such as family planning, mental health, because of concern for confidentiality and anonymity in seeking these services in a very small town.

Population Growth

Utah's population estimate for 2008 was 2,736,424, which represents a 22.5% increase over the 2000 Census numbers (see Table 1). Utah has the highest birth and fertility rates in the nation. Utah continues to have the youngest population in the nation with a median age of 28.7 years (see Table 2). The American Community Survey Summary indicated that 34.4% of the Utah population was under the age of 19 years in 2008. Utahns on average are younger than the rest of the U.S. population, which is important in planning for the public health of the population.

Table 1 Utah Population Estimates 1990-2008

Population Estimate	1990	2000	2008
Utah	1,722,850	2,233,169	2,736,424
U.S.	248,709,873	281,421,906	304,059,724

U.S. Census Bureau, 2000 and 2008 American Community Survey

According to the U.S. Census Bureau, Utah was the second fastest growing state in the nation during 2009 with a rate of 2.1%. Over the past decade, net migration accounted for about 35% of population growth, indicating the state's rich opportunity.

Table 2 Utah Demographics, Gender and Age, Population Estimates 2000-2008

Gender	UT (2000)	UT (2008)	US (2008)
Male	50.1%	50.4%	49.3%
Female	49.9%	49.6%	50.7%
Age			
Under 5 years	9.4%	9.8%	6.9%
5-9 years	9.4%	8.8%	6.5%
10-14 years	8.6%	7.9%	6.7%
15-19 years	8.6%	7.9%	7.2%
20-24 years	9.7%	8.8%	6.9%
25-34 years	10.1%	16.2%	13.3%
35-44 years	14.6%	11.9%	14.1%
45-54 years	13.4%	11.5%	14.6%
55 years and older	14.9%	17.2%	23.9%
Median Age	27.1	28.7	36.9

U.S. Census Bureau, 2000 and 2008 American Community Survey

Race/Ethnicity

The majority of Utahns (97.9%) selected only one race on the Census 2000. This percentage has remained the same in 2008 (see Table 3). Asians were the second largest race in 2008. Hispanics, Asians and Blacks/African Americans are growing at a faster rates compared to state population as a whole. Utah's Hispanic population as a percent of total continued to increase, from 9.0% of the population in 2000 to 12.0% of the population in 2008. This represents an increase of 33% since 2000 (see Table 4). Mexicans continue to be both the largest and fastest growing group of Hispanics in the state.

Table 3 Utah Demographics, Race, Utah/US 2000-2008

Race	UT (2000)	UT (2008)	US (2008)
One Race	97.9%	97.9%	97.7%
White	89.2%	91.0%	75.0%
Black or African American	0.8%	1.1%	12.4%
American Indian / Alaska Native	1.3%	1.1%	0.8%
Asian	1.7%	2.0%	4.4%
Native Hawaiian / Pacific Islander	0.7%	0.7%	0.1%
Two or more races	2.1%	2.1%	2.3%

U.S. Census Bureau, 2000 and 2008 American Community Survey

Table 4 Utah Demographics, Ethnicity, Utah/US 2000-2008

Ethnicity	UT (2000)	UT (2008)	US (2008)
Hispanic or Latino	9.0%	12.0%	15.4%
Mexican	6.1%	9.1%	10.1%
Puerto Rican	0.2%	0.2%	1.4%
Cuban	0.0%	0.1%	0.5%
Other	2.7%	2.7%	3.4%
Not Hispanic or Latino	91.0%	88.0%	84.6%

U.S. Census Bureau, 2000 and 2008 American Community Survey

Refugee populations in Utah are growing, along with the Hispanic populations, with resultant increasing need for language translation services. The growth in non-English speaking population impact the health care system’s ability to adequately address the needs of the diverse populations and they often experience barriers to receiving culturally sensitive and appropriate health care. Because of this and other social factors (e.g., proportion of workers in “blue collar” jobs without health benefits, lack of trust in the health care system), the health status of non-white ethnic groups is often poorer than that of the mainstream population. Reducing racial and ethnically-based health disparities is an overarching goal of the U.S. Public Health Service’s Healthy People 2010 initiative. Utah was recently reported to have the highest proportion of multi-racial populations in the country. Utah can improve the health of all its residents, white or otherwise, through promotion of healthy lifestyles and improving access to timely health care that includes routine screening and effective treatment of physical and mental health problems when indicated.

Language and Nativity

The proportion of Utahns who speak a language other than English increased by 12.0% since 2000 (see Table 5). Among people at least 5 year of age living in Utah in 2008, 14.0% spoke a language other than English at home. Of those speaking a language other than English, 65.0% spoke Spanish and 35.0% spoke some other language. There were 8.3% of Utahns in 2008 reported to be foreign born,

Table 5 Language and Place of Birth, Utah/US 2000-2008

Language Spoken at Home	UT (2000)	UT (2008)	US (2008)
English only	87.5%	86.0%	80.3%
Language other than English	12.5%	14.0%	19.7%
Place of Birth			
Native Born	92.9%	91.7%	87.5%
Foreign Born	7.1%	8.3%	12.5%
Naturalized U.S. Citizen	2.2%	2.7%	5.4%
Not a U.S. Citizen	4.9%	5.6%	7.1%

U.S. Census Bureau, 2000 and 2008 American Community Survey

Economy

In 2008, approximately 11% of all households in Utah were “low income” or with household incomes less than \$25,000 (see Table 6). By comparison, approximately 4% were “very high income” households at \$200,000 or more. Utah’s median family income increased from \$51,022 in 2000 to \$65,225 in 2008. The median family income when adjusted for inflation for the last decade (1990-2000) reflects a 14.2% growth, placing the state fourth highest in income growth. When adjusted for inflation, this change reflects a 14.2% growth, placing the state fourth highest in income growth. During the recent recession as with most states, income levels dropped off and unemployment rates have dramatically increased. However, there are programs such as Medicaid, Primary Care

Network, and CHIP (Children’s Health Insurance Program) that pay for health care for eligible children and adults. The American community survey comparing 2000 and 2008 data show an increase of percent of children in poverty probably due to the recession.

Table 6 Income, Utah/US 2000-2008

Family Income	UT (2000)	UT (2008)	US (2008)
Less than \$10,000	3.5%	2.5%	4.3%
\$10,000 to \$14,999	3.2%	2.2%	3.2%
\$15,000 to \$24,999	9.7%	6.2%	8.2%
\$25,000 to \$34,999	12.4%	8.5%	9.1%
\$35,000 to \$49,999	19.7%	15.0%	13.6%
\$50,000 to \$74,999	25.4%	24.3%	20.2%
\$75,000 to \$99,999	13.2%	16.6%	14.7%
\$100,000 to \$149,999	8.7%	16.1%	15.4%
\$150,000 to \$199,999	2.1%	4.6%	5.7%
\$200,000 or more	2.1%	3.9%	5.6%
Median family Income (\$)	51,022	65,226	63,366

U.S. Census Bureau, 2000 and 2008 American Community Survey

Table 7 Labor Force, Utah/US 2000-2008

Labor Force	UT (2000)	UT (2008)	US (2008)
In Labor Force	69.0%	70.0%	65.9%
Civilian Labor Force	68.7%	69.4%	65.4%
Employed	65.3%	66.6%	61.3%
Unemployed	3.4%	2.8%	4.2%
Armed forces	0.3%	0.6%	0.5%
Not in Labor Force	31.0%	30.0%	34.1%

U.S. Census Bureau, 2000 and 2008 American Community Survey

Poverty

In 2008, almost ten percent (9.6%) of Utah populations were living in poverty (see Table 8). Nearly ten percent (9.5%) of children under 18 were below the poverty level. Close to twenty-two percent (21.8%) of families with female householders (no husband present) have incomes below the poverty level. Poverty takes into account both income and family size, and has both immediate and long-lasting effects on health. Income provides an assessment of the financial resources available to individual persons or families for basic necessities (e.g., food, clothing, and health care) to maintain or improve their well-being.

Table 8 Poverty, Utah/US 2000-2008

Poverty	UT (2000)	UT (2008)	US (2008)
Total Population	9.4%	9.6%	13.2%
All Families	6.5%	6.6%	9.7%
Families with children under 18	8.7%	9.5%	15.0%
Families with children under 5	10.9%	11.2%	16.3%
Families female only householder	22.1%	21.8%	28.0%

U.S. Census Bureau, 2000 and 2008 American Community Survey

Children born into poverty maybe less likely to have regular health care, proper nutrition, and opportunities for mental stimulation and enrichment. Persons who have lower incomes are less able to afford health care and may have less healthy lifestyles. For instance, persons with lower education and income levels are more likely to smoke cigarettes and less like to get regular exercise.

Family Structure

In 2008, families made up 74% of the households. This percentage includes married couple families (60.5%) and single householder families (13.5%). Non-family households accounted for 26% and included people living alone and non-related members. Utah continued to have the largest household size in the nation, with 3.2 persons per household in 2000, compared to 2.6 nationally (see Table 9). This household size is a slight increase over Utah's 3.1 people per household in 2008. The number of households in the state reached 854,244 in 2008, a 2.9% average annual increase since 2000.

Table 9 Family Structure, Utah/US 2000-2008

Households with Families	UT (2000)	UT (2008)	US (2008)
Family Households	76.3%	74.0%	66.3%
Married-couple	63.2%	60.5%	49.2%
Male Householder, no wife	3.7%	4.3%	4.6%
Female Householder, no husband	9.4%	9.2%	12.5%
Non-family households	25.7%	26.0%	33.7%
Average Household Size	3.1	3.2	2.6
Average Family Size	3.6	3.7	3.2

U.S. Census Bureau, 2000 and 2008 American Community Survey

The percent of households of married couples, with or without children, has declined from 69.0% in 1980, to 65.0% in 1990 and 60.5% in 2008. Despite these trends, in 2008 Utah ranked first in the nation in percent of family households (74.0%) and percent of married couple families (60.5%).

Education

In 2008, close to ten percent (9.6%) of Utah population of age 25 and older had less than high school education. Utah had a higher proportion of adults with some college education compared to U.S. (27.4% vs. 21.3%, see Table 10). In addition, 29% had bachelor's degree or higher. The dropout rate for SY 2007-08 was 3.8% which is much lower than the previous SY 2006-2007 rate of 4.5%.

Table 10 Education (ages 25 and older), Utah/US 2000-2008

Educational Attainment	UT (2000)	UT (2008)	US (2008)
Less than 9th grade	3.2%	3.3%	6.4%
9th to 12 grade, no diploma	9.1%	6.3%	8.7%
High School Graduate (includes equivalency)	24.6%	24.4%	28.5%
Some College, no degree	29.1%	27.4%	21.3%
Associate's degree	7.9%	9.5%	7.5%

Bachelor's degree	17.9%	19.7%	17.5%
Graduate or professional degree	8.3%	9.4%	10.2%

U.S. Census Bureau, 2000 and 2008 American Community Survey

Overview of Maternal and Child Health Population Groups

Health Status of Utah Pregnant Women, Mothers, and Infants

Unintended Pregnancy

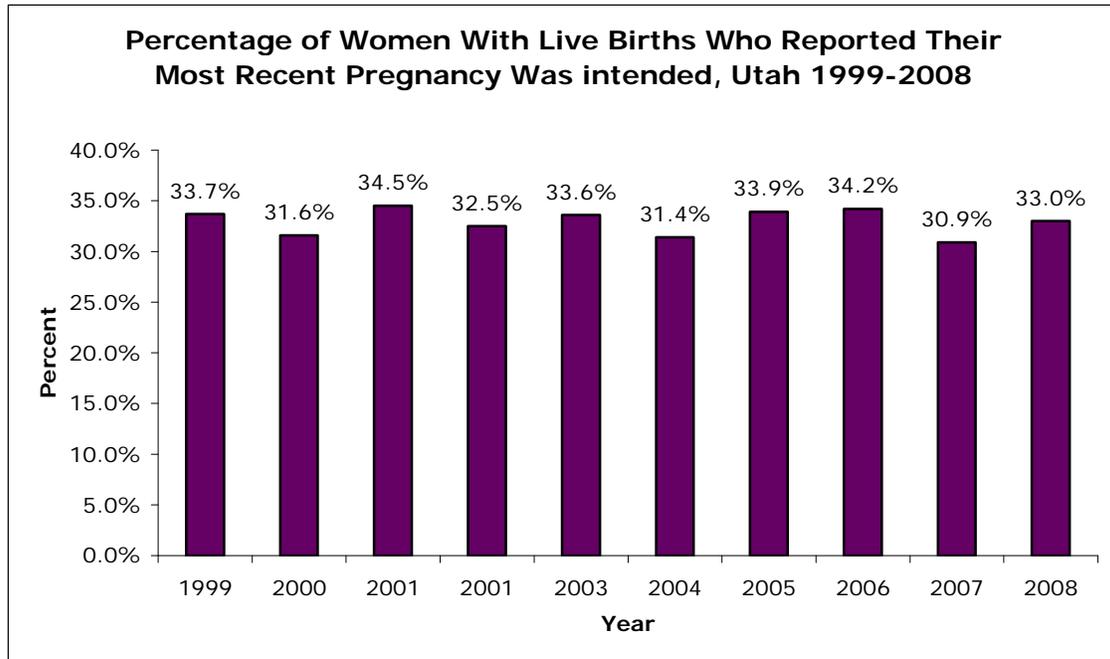
In the United States, unintended pregnancy is a major public health problem. Unintended Pregnancy is a general term that includes pregnancies that are either mistimed or unwanted at the time of conception. Women with an unintended pregnancy are less likely to seek early prenatal care or receive adequate prenatal care, more like to smoke or drink during pregnancy, and are less likely to initiate or maintain breastfeeding. Furthermore, they fail to take multivitamins since they had not intended the pregnancy. Unintended pregnancy also is associated with higher rates of postpartum depression.

In 2008, 33.0% (17,800) of Utah women reported their pregnancy was the result of an unintended pregnancy. Although this figure is near the Healthy People 2010 goal of 70% (intended pregnancies), much higher rates of unintended pregnancy are noted among younger, non-White, Hispanic, and unmarried women. Women who were covered by Medicaid prior to conception were also more likely to report their birth as unintended yet these women have Medicaid prior to conception were also more likely to report their birth as unintended yet these women have Medicaid coverage for family planning services. Of the women you reported their pregnancies as unintended, 58.4% said they were using birth control at the time of conception. Contraceptive failure rates are reportedly low and vary among methods used, failure often results from improper use, or lack of use. Figure 1 illustrates the trend of unintended pregnancies in Utah, which has remained relatively stable of the past decade.

Inter-pregnancy spacing

Adequate spacing of pregnancies is emerging as an important issue for poor pregnancy outcomes, such as low birth weight and prematurity. Birth data reveal that 5.4% of multiparous women who delivered in 2008 had an inter-pregnancy interval (IPI) of less than six months (time from birth of previous child to conception of the current child). The HP2010 goal is for no more than 6% of births to occur within 24 months of the previous birth, meaning an IPI of approximately 15 months. Utah well exceeds this rate with 21.3% of repeat births conceived within 15 months of the last live birth.

Figure 1



Data Sources

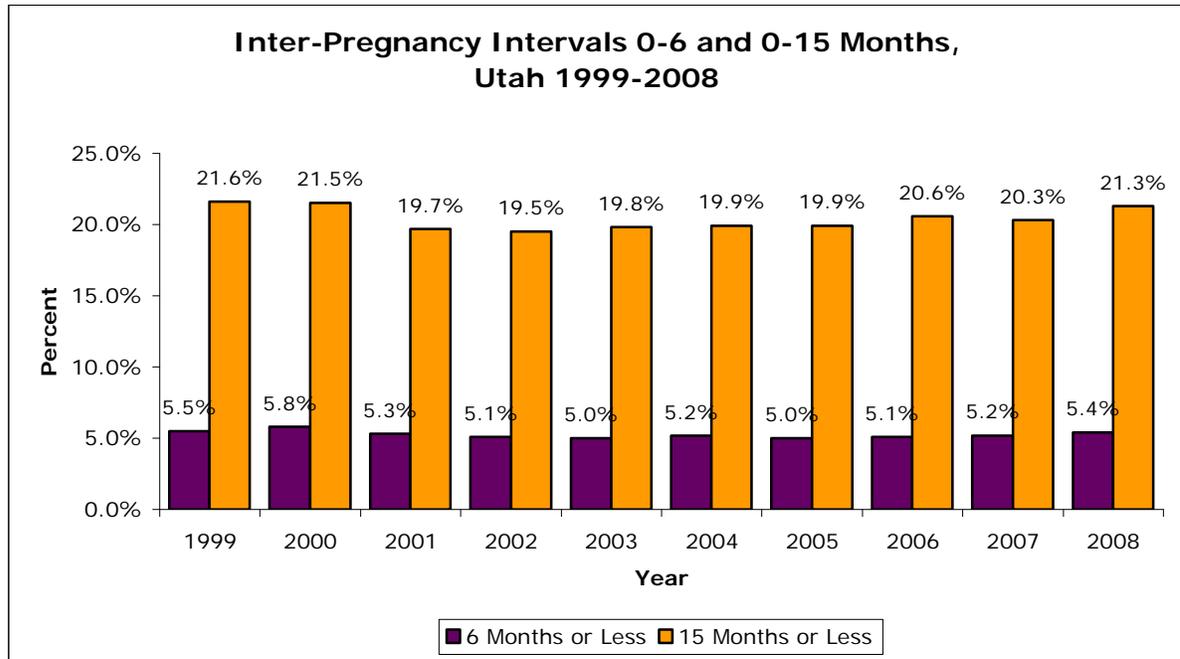
Utah Pregnancy Risk Assessment Monitoring System (PRAMS), Utah Department of Health

Based on PRAMS data from 2000-2003, the majority of women with very short IPIs reported their pregnancy as unintended yet 60% of these women were using some form of birth control at the time of conception. Women with the shortest IPIs (0-6 months) were more likely to be:

- younger
- from a non-white racial group
- unmarried
- no insurance prior to pregnancy or
- Medicaid prior to pregnancy
- incomes less than 100% of the federal poverty level and
- enrolled in WIC during pregnancy

Figure 2 illustrates the trend in very short inter-pregnancy intervals in Utah over the past decade.

Figure 2



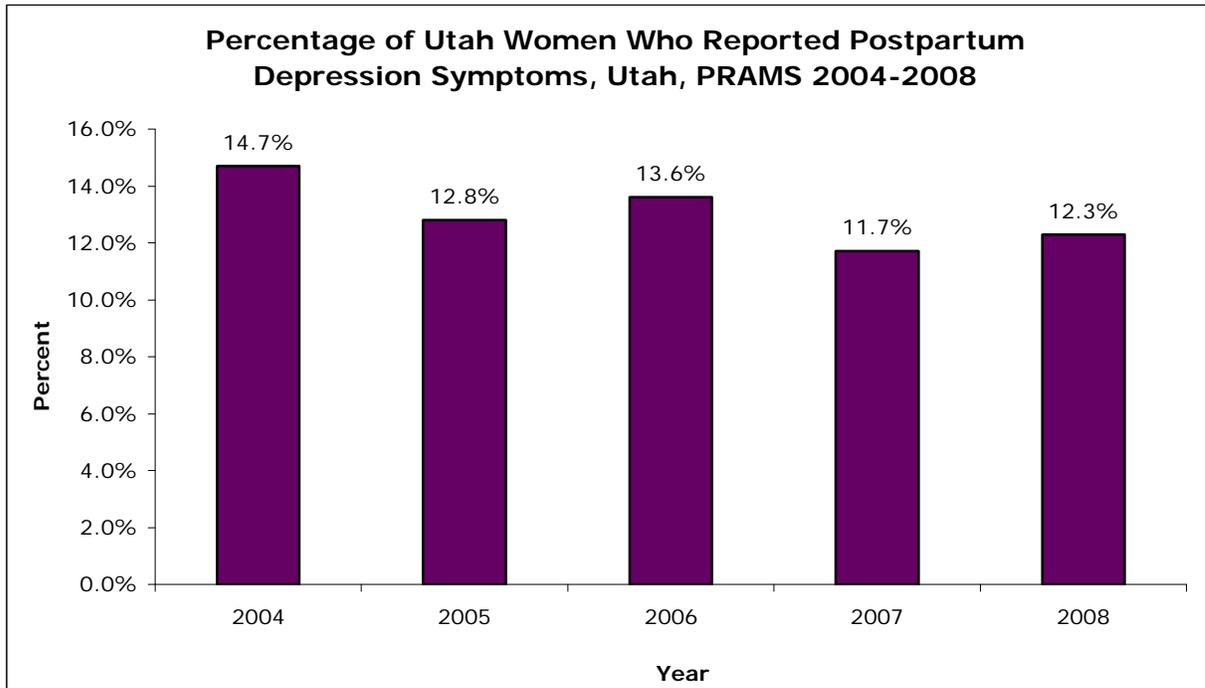
Data Source

IBIS, Utah Birth Certificate Database, Office of Vital Records and Statistics, Utah Department of Health

Postpartum Depression

Postpartum depression is the most common complication related to childbirth. While postpartum depression is treatable, many women who suffer from it remain undiagnosed. Untreated postpartum depression can last as long as one to two years and may affect the ability of a mother to function in normal daily tasks and in family interactions. A variety of reasons may contribute to a woman not receiving treatment for postpartum depression, including the inability to recognize the signs and symptoms as well as the uncertainty of knowing who to ask for help. For 2004-2007, the overall rate of self-reported postpartum depression symptoms in Utah women was 13.2%. Although no national data are available on postpartum depression, CDC PRAMS recently published a study looking at 2004-2005 data from 17 states. They found that the prevalence of self-reported postpartum depression symptoms ranged from 11.7% (Maine) to 20.4% (New Mexico). Utah's rate during 2004-2005 was 13.8%. Figure 3 illustrates the percentage of Utah who reported postpartum depression symptoms from 2004-2008 and Figure 4 illustrates the percentage of these women that sought help from a healthcare provider.

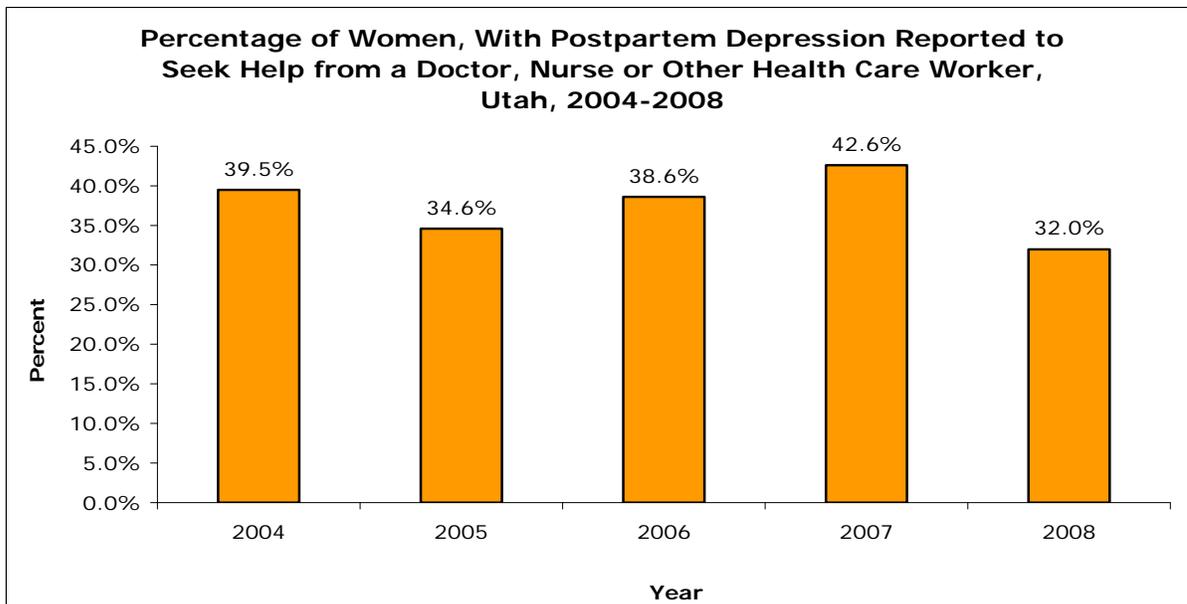
Figure 3



Data Source

Utah Pregnancy Risk Assessment Monitoring System (PRAMS), Utah Department of Health

Figure 4



Data Source

Utah Pregnancy Risk Assessment Monitoring System (PRAMS), Utah Department of Health

Cesarean Section Births

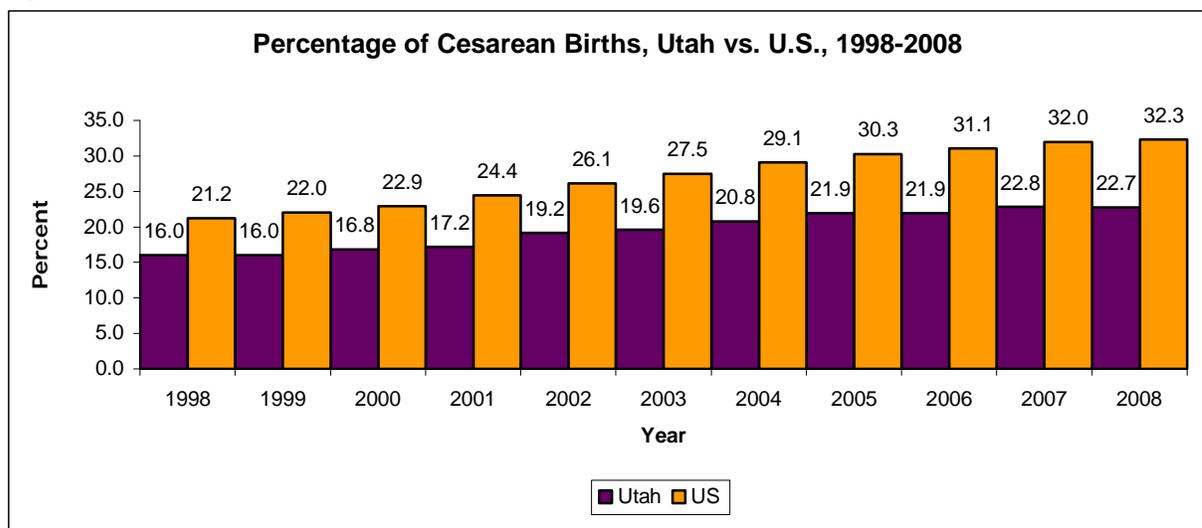
In 2008, nearly one-third (32.3%) of all children in the U.S. were born by Cesarean delivery. This represents a 52% increase over the past decade, from 21.2% in 1998 (see Figure 5). The increases are present in all age groups and for all races and ethnic origins, without identified concurrent sources of increased obstetrical risk.

The increase in Cesarean delivery is an issue of importance for all women, but even more so for first time mothers, as the trend is increasingly to schedule repeat Cesareans for all subsequent births, once a woman has had one Cesarean birth. This trend has implications not only for a woman's entire reproductive life, but also for infants and the entire health care system. "Low risk" refers to women giving birth for the first time, whose baby is term (37 weeks or greater), singleton (not a twin or other multiple-fetus pregnancy), and in the vertex or head down position. By framing the data in this way, eliminating higher risk pregnancies which are more likely to require Cesarean delivery, we can more accurately reflect increases in Cesarean rates for women who have the least medical likelihood of needing a surgical delivery.

In Utah, the rate of Cesarean section in low risk women giving birth for the first time was below the Healthy People 2010 target of 15% until 2003 (see Figure 6). The rate has risen every year since 2000, and has exceeded the HP target since 2003.

Utah's rate for repeat Cesarean among low risk women was below the Healthy People 2010 goal of 63% until 2001, when the rate exceeded this target and began an upward trend. In 2008, 83.3% of the total number of low risk, term vertex, singleton deliveries in Utah were repeat Cesareans; the U.S. rate was 90% in 2006 (most recent data available).

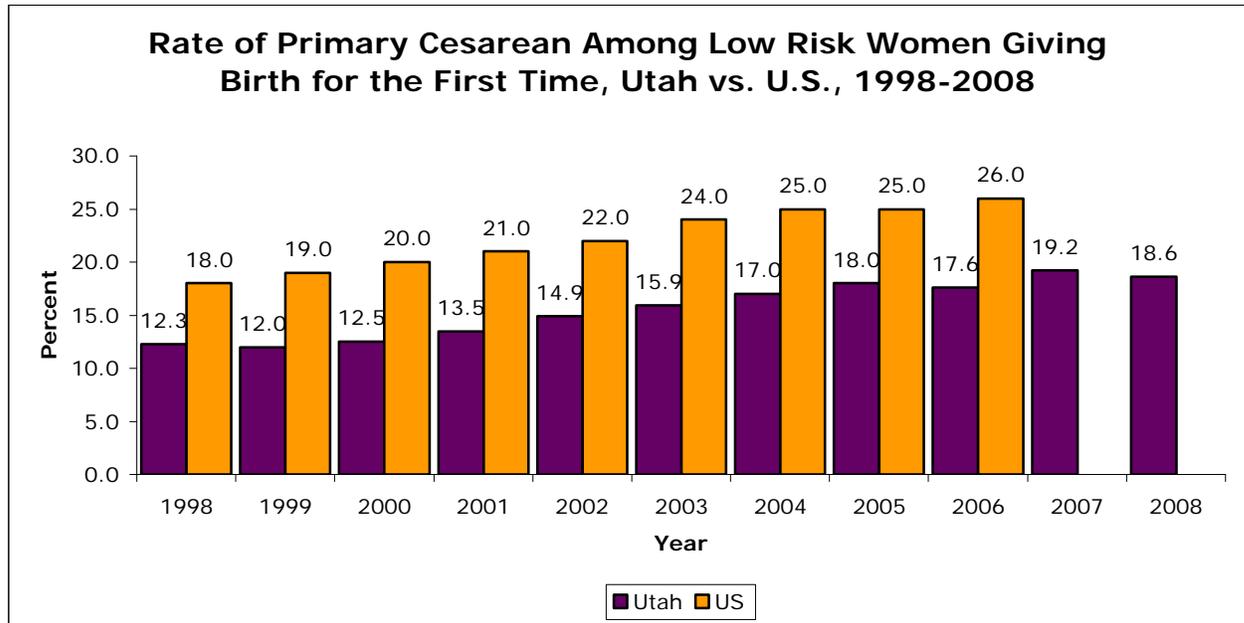
Figure 5



Data Sources

Utah Birth Certificate Database, Office of Vital Records and Statistics, Utah Department of Health; U.S. Center for Disease Control and Prevention, on-line data - CDC WONDER.

Figure 6



Data Sources

Utah Birth Certificate Database, Office of Vital Records and Statistics, Utah Department of Health; U.S. Center for Disease Control and Prevention, on-line data - CDC WONDER.

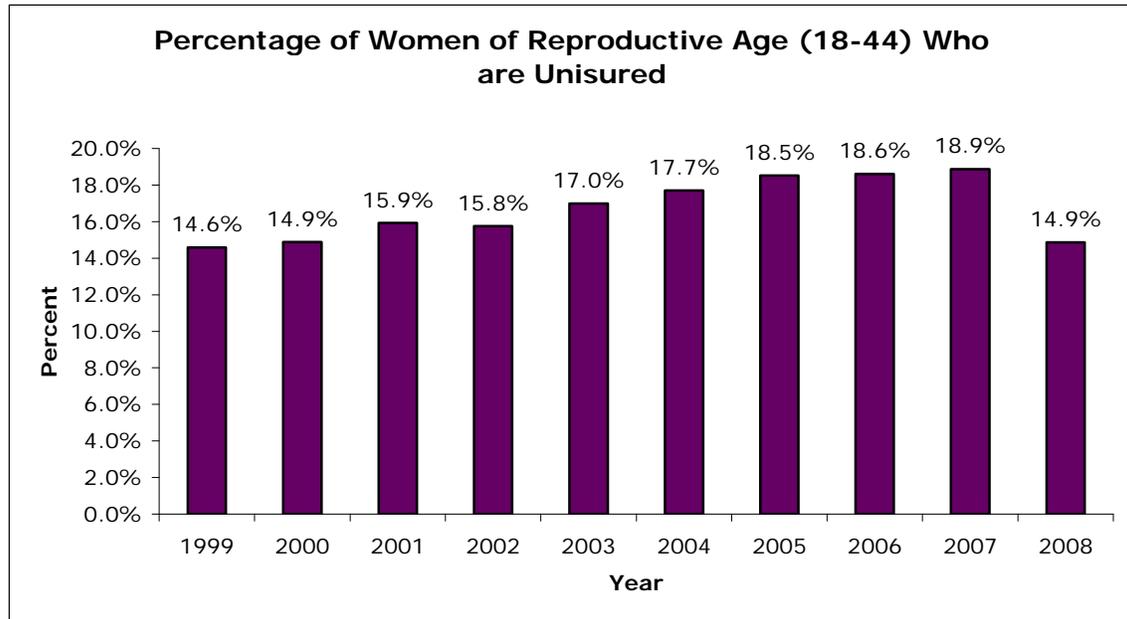
Insurance Coverage among Reproductive Age Women

Women without health insurance are less likely than those with coverage to receive preventive healthcare services. Receipt of preventive healthcare services such as PAP screenings, family planning services, and preconception and early prenatal care are correlated with improved morbidity and mortality and pregnancy outcomes.

According to Utah Pregnancy Risk Assessment Monitoring System (PRAMS) data, women with no insurance before conception had significantly higher rates of unintended pregnancy and late entry into prenatal care than women with insurance. PRAMS data also indicate that women with no insurance had significantly higher rates of very short interpregnancy spacing (≤ 6 mos. from birth to conception) than those with insurance; 7.9% compared to 3.5%. Unintended pregnancies, late entry into prenatal care, and very short interpregnancy intervals are associated with higher rates of poor pregnancy outcomes.

Chronic disease conditions such as diabetes must be well controlled before pregnancy to improve chances for a healthy outcome. Uncontrolled diabetes is the leading risk factor for congenital anomalies. Lack of insurance is a barrier for the receipt of healthcare services to achieve optimal health prior to pregnancy.

Figure 7



Data Sources

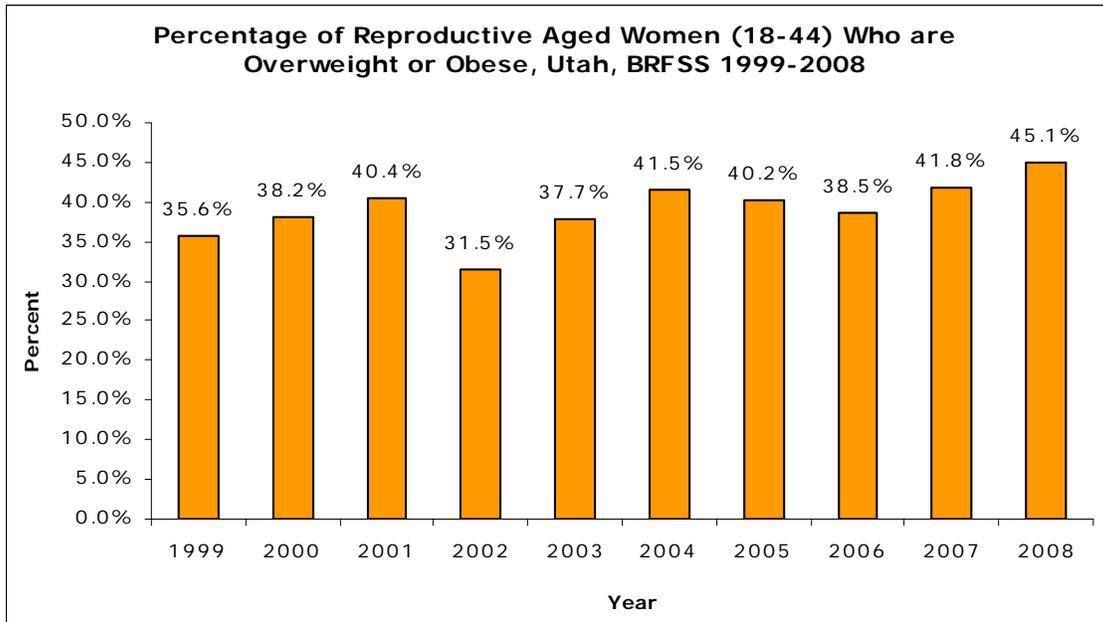
Utah Behavioral Risk Factor Surveillance System, Office of Public Health Assessment, Utah Department of Health

Overweight/Obesity

The proportion of reproductive aged women who are overweight or obese continues to increase in Utah. BRFSS 2008 data indicate that 46% of reproductive aged women reported their BMI as overweight or obese. Figure 8 illustrates this increasing trend.

Women who are not at a healthy weight prior to pregnancy are at increased risk of adverse maternal and infant outcomes. Women who are obese prior to pregnancy have longer hospital stays and higher utilization of medical care during pregnancy. Primary cesarean section rates are higher for obese women than their normal weight peers (16.3% vs. 9.9% in 2008). The percentage of adult women with an obese pre-pregnancy BMI increased from 12.1% in 1999 to 16.0% in 2008, an increase of over 30%. Currently, there are no nationally comparative data on pre-pregnancy BMI as the National Center for Health Statistics does not report on this measure. Figure 9 illustrates the decreasing trend of women at a healthy weight prior to pregnancy over the past decade and figure 10 illustrates the increasing trend of women age 18 and greater that had an obese BMI prior to pregnancy.

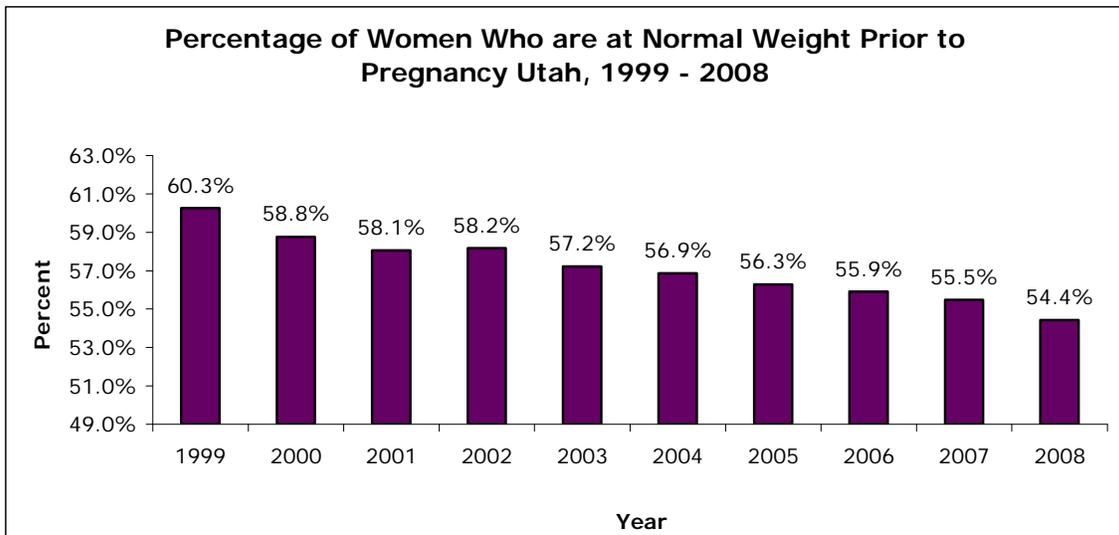
Figure 8



Data Sources

Utah Behavioral Risk Factor Surveillance System, Office of Public Health Assessment, Utah Department of Health

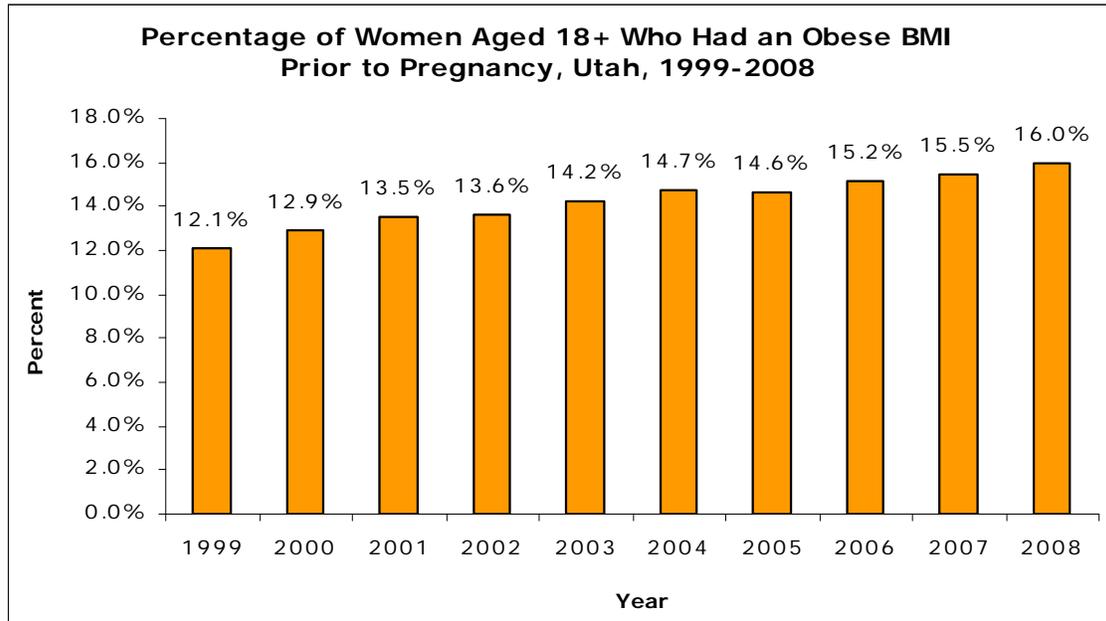
Figure 9



Data Source

Utah Pregnancy Risk Assessment Monitoring System (PRAMS), Utah Department of Health

Figure 10



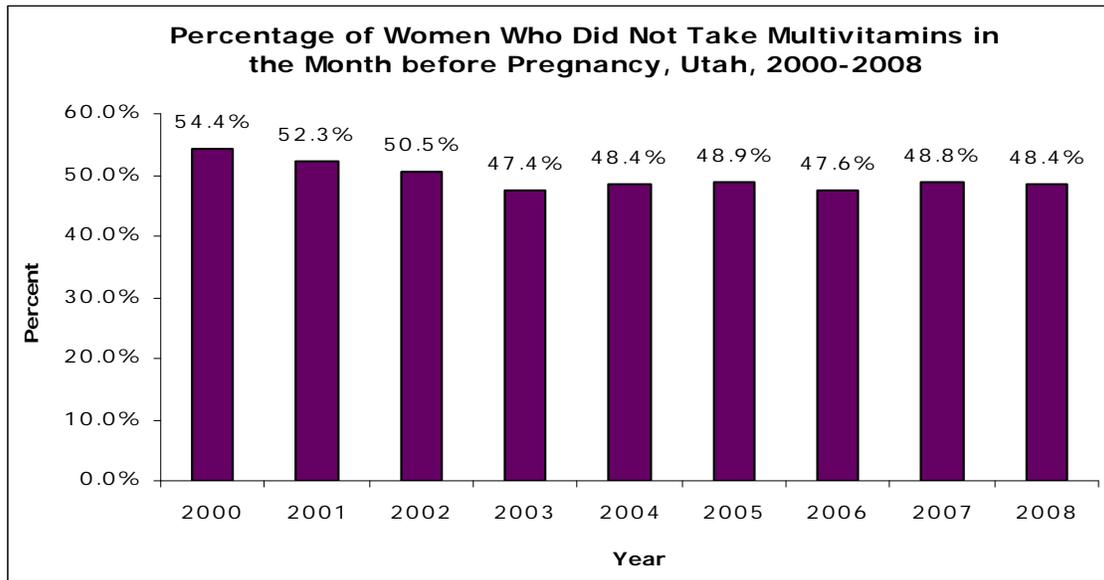
Data Sources

Utah Birth Certificate Database, Office of Vital Records and Statistics, Utah Department of Health

Multivitamin Use

PRAMS 2006 data show that 47.6% of women who had a live birth reported taking no multivitamin in the month before they became pregnant. In 2008 a slight increase to 48.4% was noted. However, the rates for no multivitamins are higher for Hispanic and non-White women at more than 65% for both. This finding is concerning because the women who report the lowest use of multivitamins also report the highest percentages of unintended pregnancy. Figure 11 illustrates the trend of multivitamin use in Utah since 2000.

Figure 11



Data Sources

Utah Pregnancy Risk Assessment Monitoring System (PRAMS), Utah Department of Health

Tobacco Use in Pregnancy

According to the 2004 Surgeon General's Report, *The Health Consequences of Smoking*, cigarette smoking during pregnancy increases the risk for: preterm, premature rupture of membranes; abruption placentae; placenta previa; stillbirth; neonatal mortality; low birth weight; fetal growth restriction/small for gestational age; and Sudden Infant Death Syndrome (SIDS). Additionally, women who smoke are less likely to initiate and continue breastfeeding their infants.

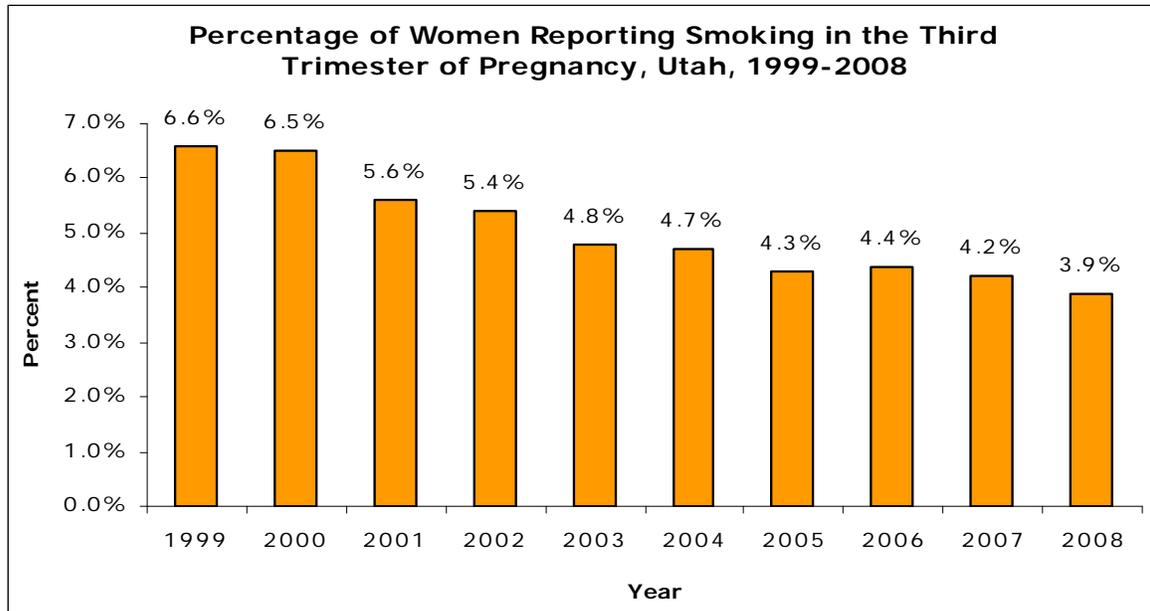
Some unfavorable pregnancy outcomes may be reduced or eliminated through smoking cessation, especially if cessation occurs early in pregnancy. For example, birth weight decreases as the number of cigarettes smoked increases. Smoking cessation by the third trimester of pregnancy can eliminate much of the fetal weight reduction risk incurred through maternal smoking. It has been estimated that the occurrence of LBW could be reduced by as much as 20% and fetal growth restriction by 30% if all women were nonsmokers during pregnancy.

According to Utah Vital Records, during 2008, 3.9% or 2,166 Utah women experiencing a live birth reported smoking during the third trimester of pregnancy. This figure represents a slight decrease from 4.2% in 2007. There are currently no published national data on smoking in the third trimester of pregnancy. Figure 12 illustrates the steady decline in the percentage of Utah women who reported smoking during the third trimester of pregnancy over the past decade.

According to 2008 BRFSS data, 8.9% of reproductive aged women reported current smoking. Smoking rates varied by age with 8.6% of 18-34 year olds and 9.3% for 35-49

year olds reporting current use. Figure 13 illustrates the overall decline in the percentage of reproductive age women who currently smoking since 2001.

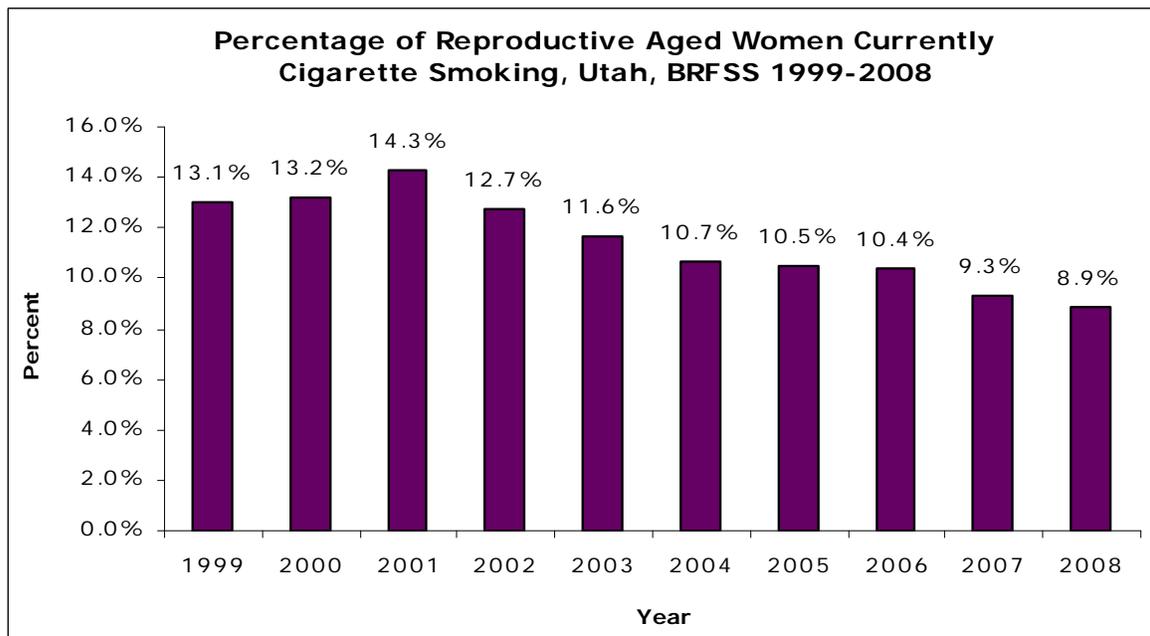
Figure 12



Data Sources

Utah Birth Certificate Database, Office of Vital Records and Statistics, Utah Department of Health

Figure 13



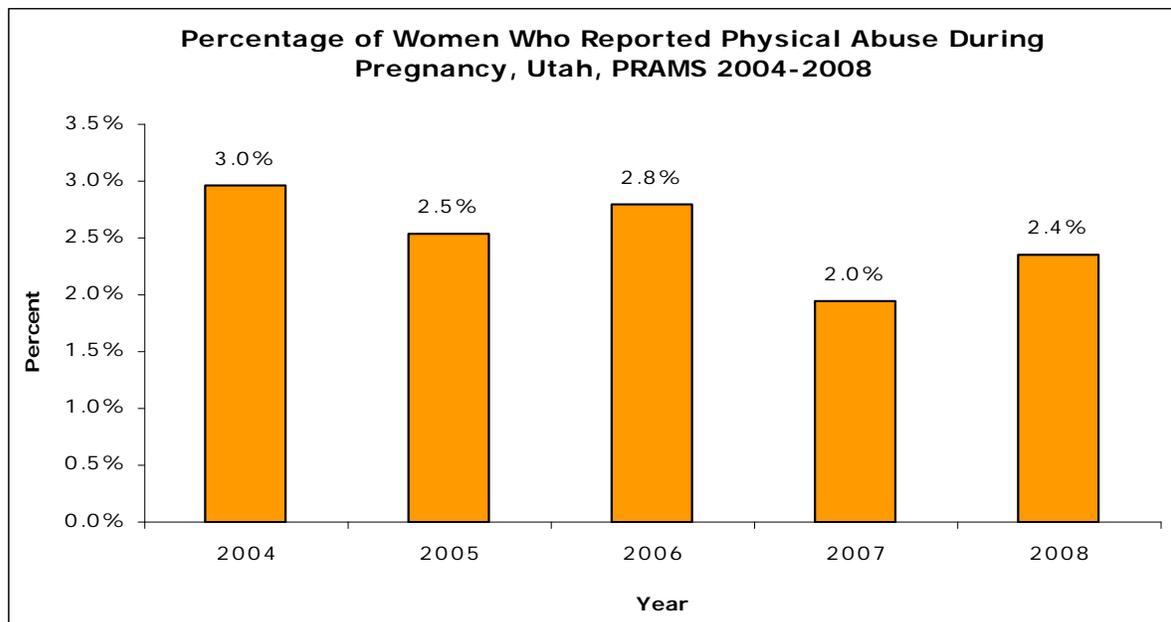
Data Sources

Utah Behavioral Risk Factor Surveillance System, Office of Public Health Assessment, Utah Department of Health

Physical Abuse during Pregnancy

Intimate partner violence during the perinatal time period is concerning because research indicates that women who are abused are more likely to have poorer birth outcomes such as low birth weight infants, preterm labor, and fetal death. In addition, they are more likely to be involved with high-risk behavior, such as smoking, drinking, and delaying prenatal care. An analysis of 2004 – 2008 Utah PRAMS data found that 2.4% of pregnant women reported physical abuse during their pregnancy, a decrease from 3.0% in 2004. According to Utah BRFSS 2008, the rates of intimate partner violence were significantly higher for women who were divorced or separated, who did not have a high school degree, and whose annual income was less than \$20,000. Figure 14 illustrates the trend of reported physical abuse during pregnancy in Utah since 2004.

Figure 14



Data Sources

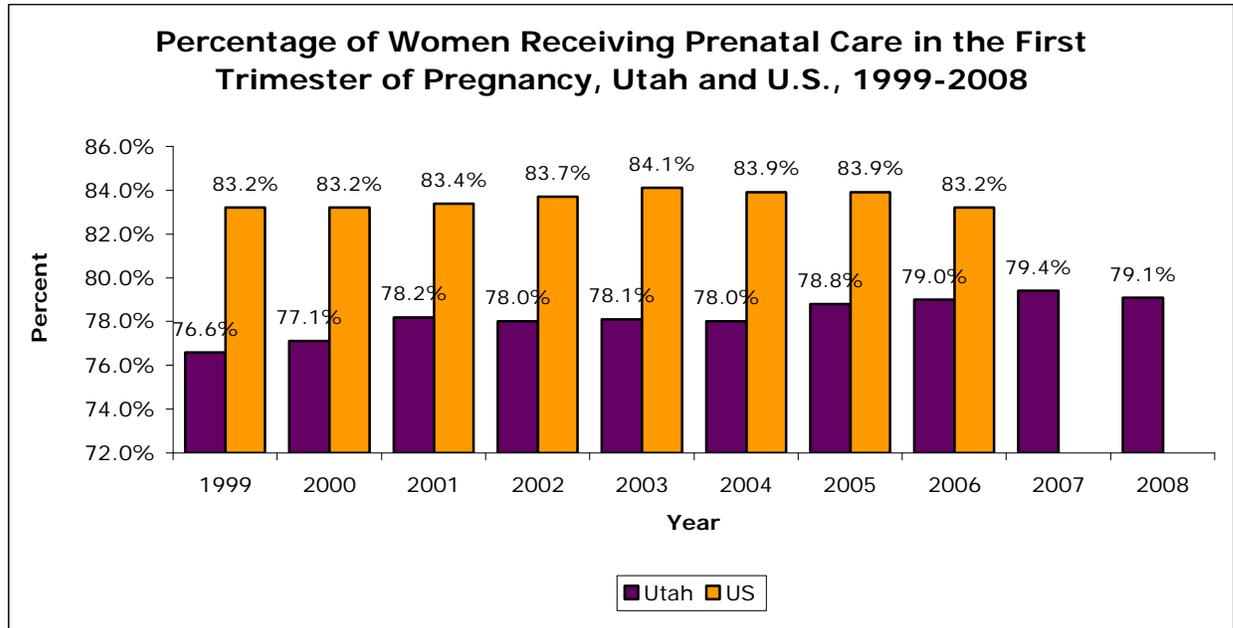
Utah Pregnancy Risk Assessment Monitoring System (PRAMS), Utah Department of Health

Prenatal Care

Women who receive early and consistent prenatal care (PNC) enhance their likelihood of giving birth to a healthy child. Health care providers recommend that women begin prenatal care in the first trimester of their pregnancy. The percentage of Utah mothers receiving prenatal care in the first trimester had been on a decline since 1995 (83.8%). In 2005 a small increase in first trimester prenatal care was noted. The Utah rate in 2006 (79.0%) was below that of the nation (83.2% - NCHS data: 32 states reporting). PRAMS data have provided more in-depth information on prenatal care than we have had in the past, such as barriers to care and perception of adequacy of care. As Utah works toward the Health People 2010 Target of 90%, these data have enabled us to target interventions to populations at risk for inadequate prenatal care especially women who get into care

late in their pregnancies or not at all. Figure 15 illustrates a slightly increasing trend of early entry into prenatal care among Utah women over the past decade. This also illustrates the lower rate of early entry into prenatal care in Utah compared to the U.S.

Figure 15



Data Sources

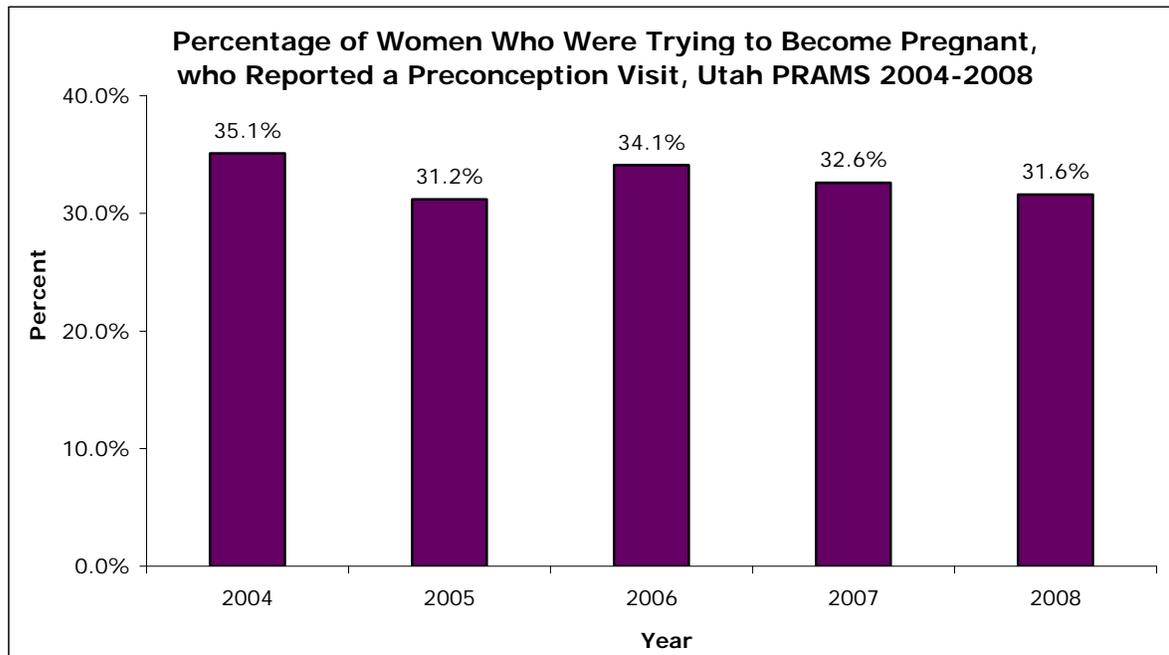
Utah Birth Certificate Database, Office of Vital Records and Statistics, Utah Department of Health

Preconception Health

Recently, the CDC published 10 recommendations to improve women's health before conception that may contribute to healthier birth outcomes. One recommendation is to incorporate a prepregnancy checkup for women who are planning on becoming pregnant. The purpose of this checkup is to ensure that women are in optimal health for pregnancy and do not enter pregnancy with unmanaged health conditions, such as diabetes or hypertension, or unhealthy behaviors like tobacco use.

Risks of having a poor pregnancy outcome can be reviewed and addressed in a preconception visit with a health care provider to reduce possible impact during pregnancy. In 2004-2007, only 25.7% of women reported visiting with their health care provider to prepare for a healthy pregnancy. Looking at 2004 data from five PRAMS states (Louisiana, Maine, New Jersey, Utah, and Vermont), the CDC found that 30.3% of women reported visiting with their health care provider to prepare for a healthy pregnancy. The range among these states was 24.1% (Louisiana) to 34.8% (Maine). Figure 16 illustrates Utah's rate in 2004 was 35.1, which has remained relatively constant since that time.

Figure 16



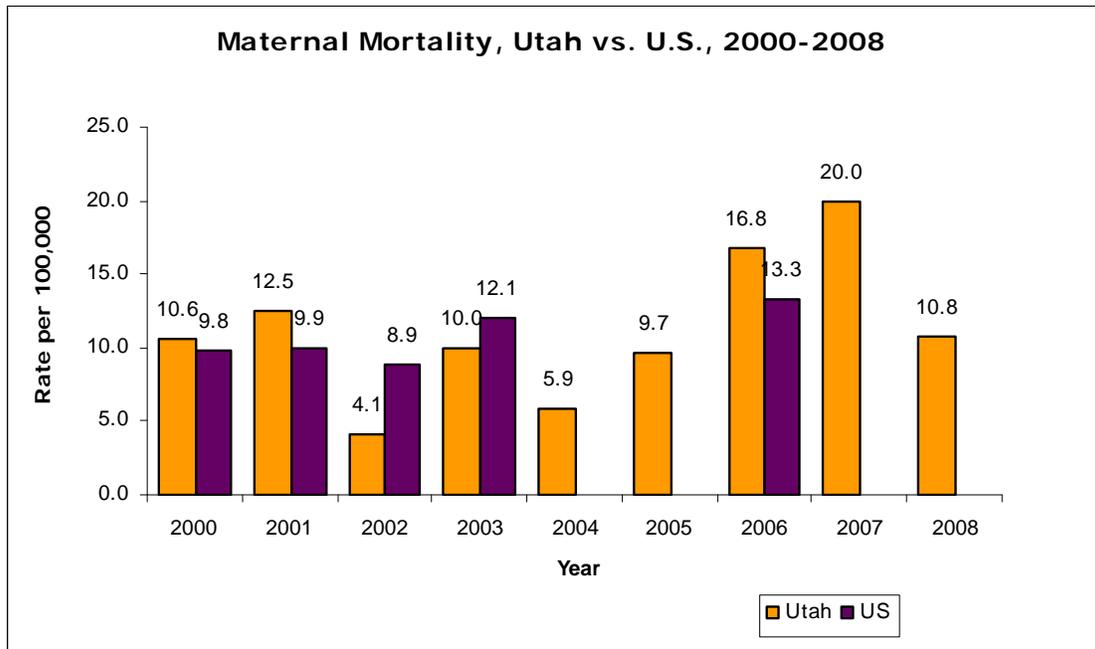
Data Sources

Utah Pregnancy Risk Assessment Monitoring System (PRAMS), Utah Department of Health

Maternal Mortality

Utah's maternal mortality has decreased from 36 deaths per year in 1940 to a range of 2-10 deaths per year between 1999 and 2007. Maternal mortality is defined as the number of deaths to a woman while pregnant or within 42 days of termination of pregnancy, irrespective of the duration and site of the pregnancy, from any cause related to or aggravated by the pregnancy or its management but not from accidental or incidental causes per 100,000 live births. To facilitate the identification of maternal deaths in circumstances in which cause of death attribution is inadequate, a new category has been introduced: Pregnancy-related death is defined as the death of a woman while pregnant or within 42 days of termination of pregnancy, irrespective of the cause of death. Figure 17 reflects this definition for both Utah and the U.S.. The state of Utah uses an expanded definition for surveillance purposes which is the number of women who have died within 12 months of completion of a pregnancy whose cause of death is due to pregnancy or pregnancy-related causes per 100,000 live births. This expanded definition allows the Utah Department of Health's Perinatal Mortality Review Program to more thoroughly examine all pregnancy-related deaths among Utah women to identify factors that might prevent future deaths.

Figure 17



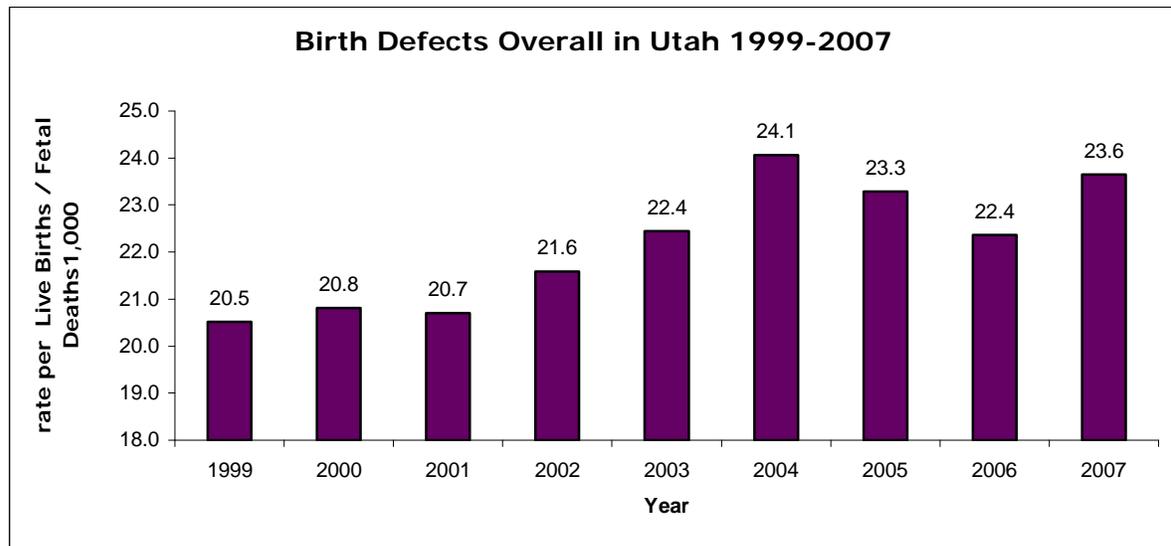
Data Sources

National Vital Statistics System, National Center for Health Statistics, U.S. Centers for Disease Control and Prevention; Office of Vital Records and Statistics, Utah Department of Health

Birth Defects

Major birth defects are associated with many adverse outcomes, from pregnancy through adult life. Major birth defects are those that require medical, surgical, or rehabilitative services, and have an impact on the person's health and development. Affected newborns and children are at an increased risk of premature death, chronic illness, or long term disability. In the United States and other developed countries, birth defects are the leading cause of infant mortality, and are a major contributor to pediatric hospitalizations, chronic childhood illness, and developmental disabilities. Because it has the highest birth rate in the nation, birth defects are a crucial public health issue in Utah. Approximately 3% of live born infants in Utah have a medically significant structural birth defect. Birth defects in Utah are the leading cause of infant mortality, and are specifically responsible for one in four deaths in infants less than one year of age. Birth defects also disproportionately contribute to prematurity. In 2003, 20% of babies born with birth defects in Utah were premature, compared to 9% of all babies born. The overall rate of birth defects in Utah is generally in line with what is expected based on national and international experience. In 2007, the overall birth defect rate in Utah was 23.6 per 1,000 live births (see Figure 18).

Figure 18



Data Sources

Utah Birth Defect Network; rate includes births, stillbirths, and terminations

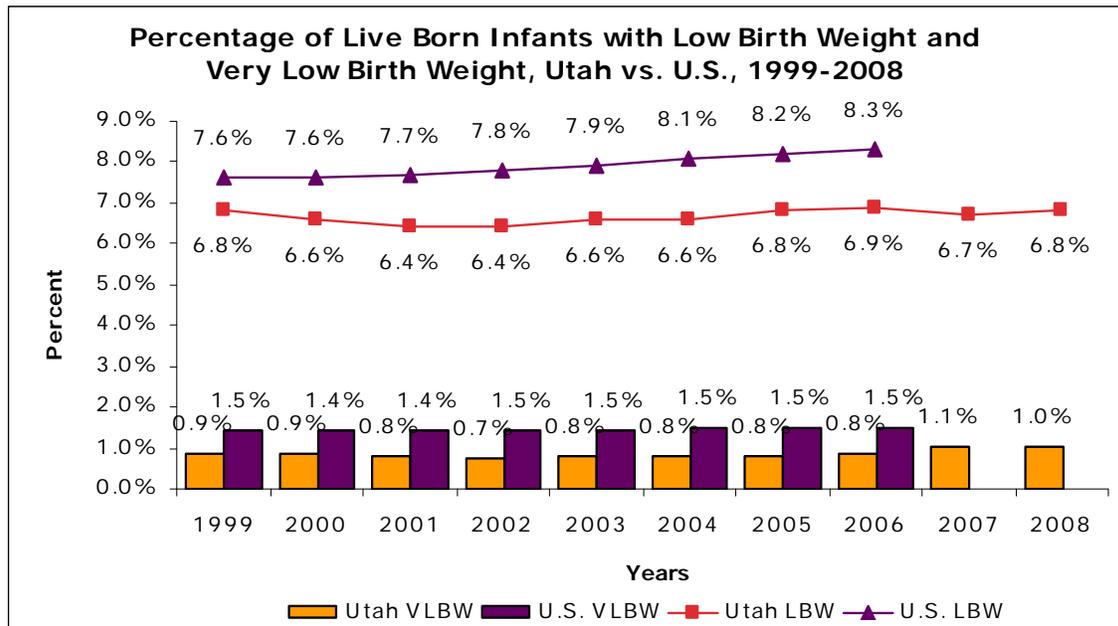
Low Birth Weight

Low birth weight infants are those weighing less than 2,500 grams (about 5.5 pounds). Low birth weight increases the risk for infant mortality and morbidity. Low birth weight infants who survive often require intensive care at birth, may develop chronic illnesses, and later may require special education services. Health care costs and length of hospital stay are higher for low birth weight infants. Utah's low birth weight percentage increased from 5.7% in 1990 to 6.8% in 2008, moving away from the Healthy People 2010 Objective of 5.0%. Utah data indicate that for infants weighing between 1,500 and 2,499 grams costs are 6 times higher and almost 85 times higher for newborns with a birth weight less than 1,500 grams.

Very Low Birth Weight

An infant is considered to have a very low birth weight if they are less than 1,500 grams or about 3.3 pounds at birth. Babies born before 37 completed weeks of pregnancy are called premature. In 2005, 1.5% of live births in the U.S. and 1.0% in Utah were very low birth weight (see Figure 19). Neither the U.S. nor Utah has met the Healthy People 2010 objective for very low birth weight of no more than 0.9% of live births. Very low birth weight babies have an extremely high risk for health and developmental problems. Advances in newborn medical care have greatly reduced the number of deaths among low and very low birth weight. However, a small percentage of survivors develop mental retardation, learning problems, cerebral palsy, and vision and hearing loss. Figure 20 illustrates the trend in Very Low Birth Weight infants born in tertiary hospitals. The trend in Very Low Birth Weight infants born in tertiary hospitals (facilities for high-risk deliveries) has remained within a 7-point range for the past decade, with an increase from 79.9% to 81.3% in the past year.

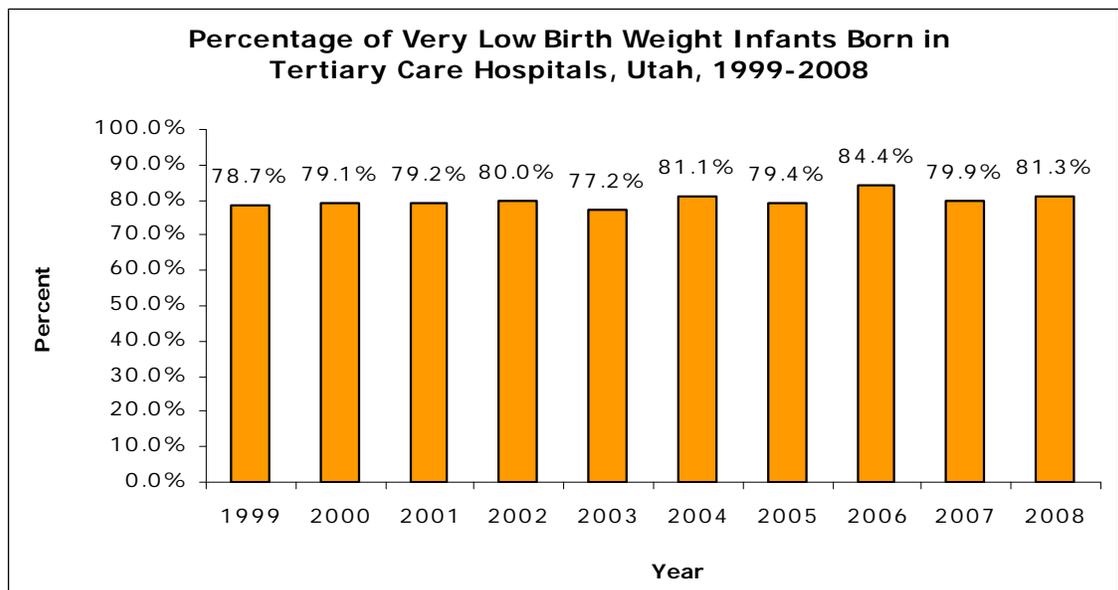
Figure 19



Data Sources

Utah Birth Certificate Database, Office of Vital Records and Statistics, Utah Department of Health; National Vital Statistics System, National Center for Health Statistics, U.S. Centers for Disease Control and Prevention

Figure 20



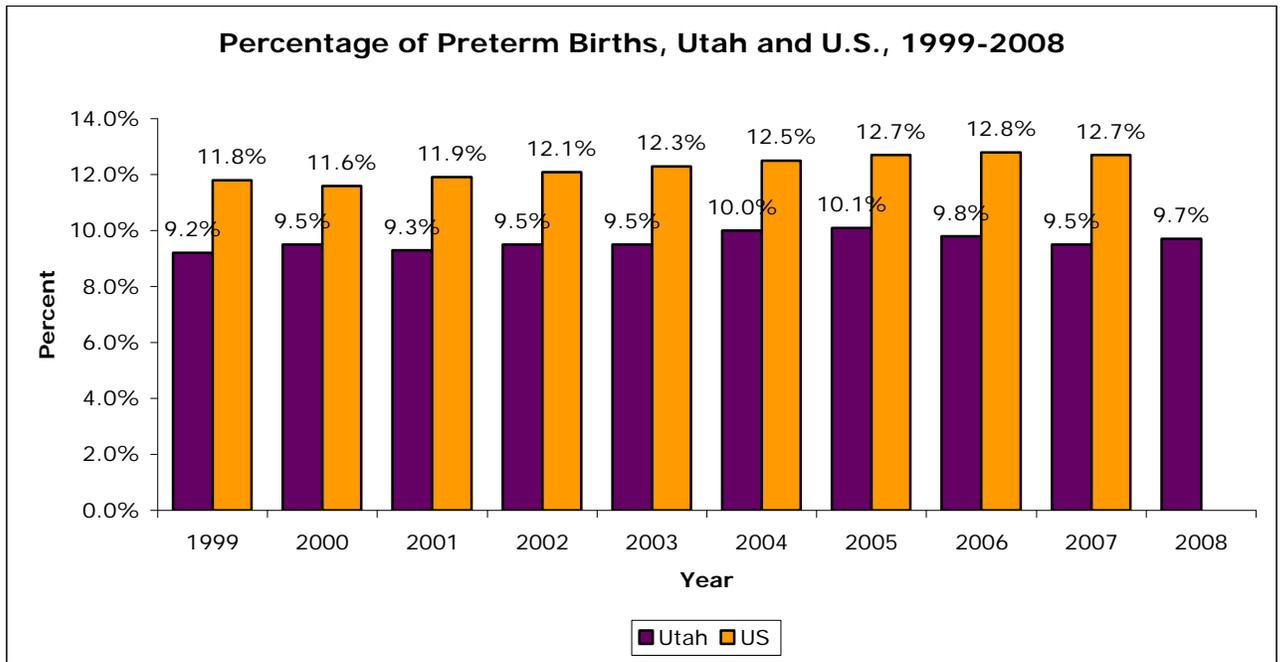
Data Sources

Office of Vital Records and Statistics, Utah Department of Health

Preterm Birth Rate

Preterm birth infants are those born less than 37 weeks' gestation. Preterm birth is the leading cause of perinatal death in otherwise normal newborns. Babies born preterm also have increased risks for long term morbidities and often require intensive care after birth. The March of Dimes estimates that each preterm birth carries an annual societal cost of \$51,600 for medical care, early intervention services, and special education. Following national trends Utah's preterm birth percentage increased from 8.8% in 1990 to 9.7% in 2008, moving away from the Healthy People 2010 Objective of 7.6% (see Figure 21).

Figure 21



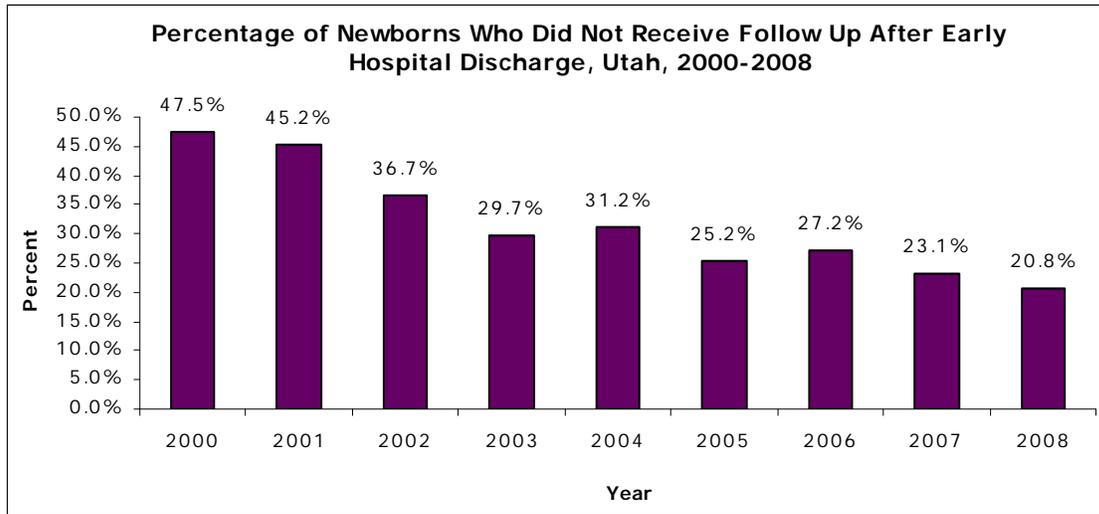
Data Sources

Utah Birth Certificate Database, Office of Vital Records and Statistics, Utah Department of Health

Newborn Follow Up After Early Hospital Discharge

A recent analysis of PRAMS data from nineteen states, conducted by CDC, found that Utah had one of the highest rates of early infant discharge coupled with the lowest rate of infant follow up within the first week of discharge. The American Academy of Pediatrics recommends that infants discharged before 48 hours for vaginal or 96 hours for cesarean section deliveries be seen by a pediatrician within two days of discharge. Utah data from 2008 show that 20.8% of infants with early discharge were not seen within a week of leaving the hospital (see Figure 22), a marked improvement from 2000 when 47.5% of infants were not seen. Higher rates of no follow up were noted among Hispanic and non-White women.

Figure 22



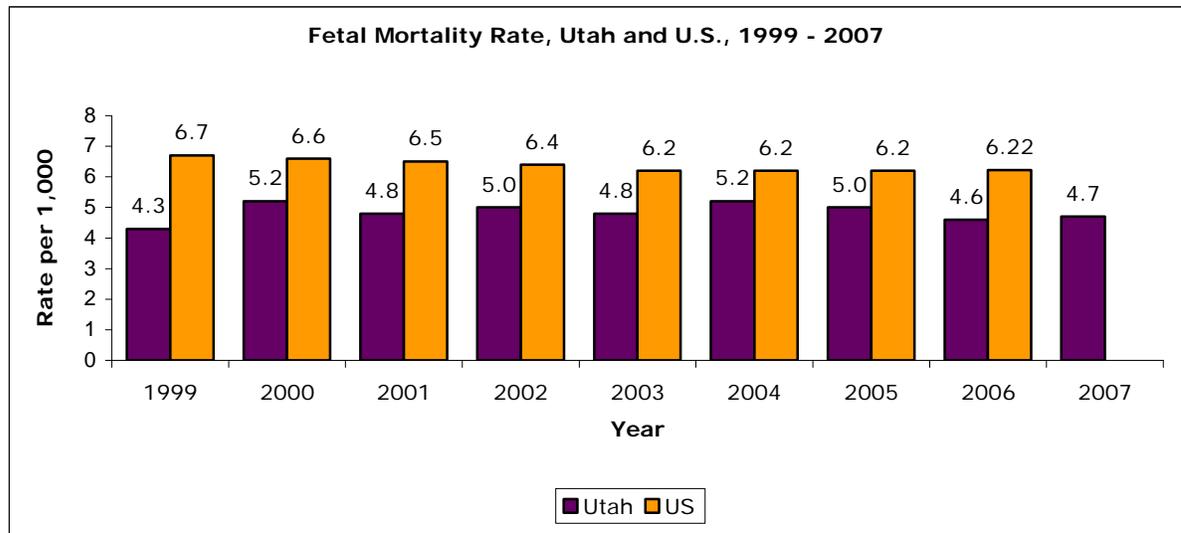
Data Sources

Utah Pregnancy Risk Assessment Monitoring System (PRAMS), Utah Department of Health

Fetal Mortality

Fetal death is one of the important indicators of a society's perinatal health. Fetal deaths at 20 or more weeks' gestation account for 49% of all deaths that occur within 1 year of life. Utah's fetal death rate in 2007 was 4.7 per 1,000 live births and fetal deaths. Although this rate has remained relatively stable for the past decade and is considerably lower than the U.S. rate (6.2 per 1,000 in 2004), it falls short of the Healthy People 2010 Target of 4.1/1,000 live births and fetal deaths (see Figure 23).

Figure 23



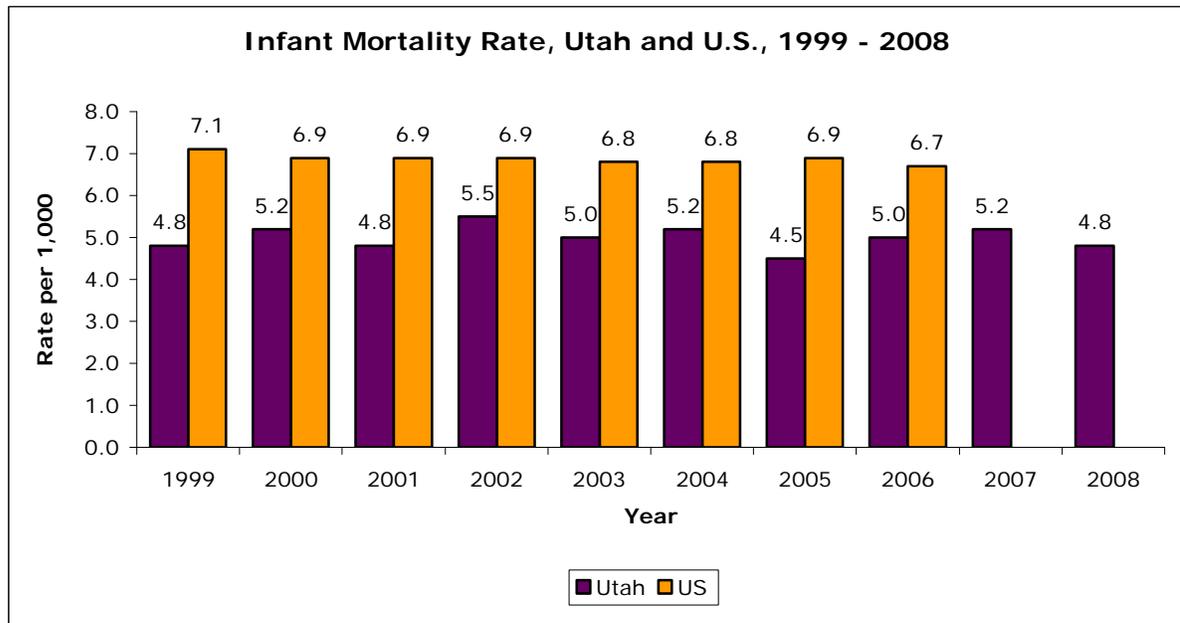
Data Sources

Utah Death Certificate Database, Office of Vital Records and Statistics, Utah Department of Health; National Vital Statistics System, National Center for Health Statistics, U.S. Centers for Disease Control and Prevention

Infant Mortality

The infant death rate is an important measure of a nation's health and a worldwide indicator of health status and social well-being. It is a critical indicator of the health of a population. The infant mortality rate has been declining throughout the past 20 years both locally and nationally. The state's infant mortality rate has declined since 1989 from 8 per 1,000 live births to 4.8 per 1,000 live births in 2008 (see Figure 24). Historically, Utah's rate has been better than the nation's (UT: 5.0 per 1,000; U.S.: 6.7 per 1,000 in 2006). However, Utah continues to work toward the Healthy People 2010 Target of 4.5/1,000 live births.

Figure 24



Data Sources

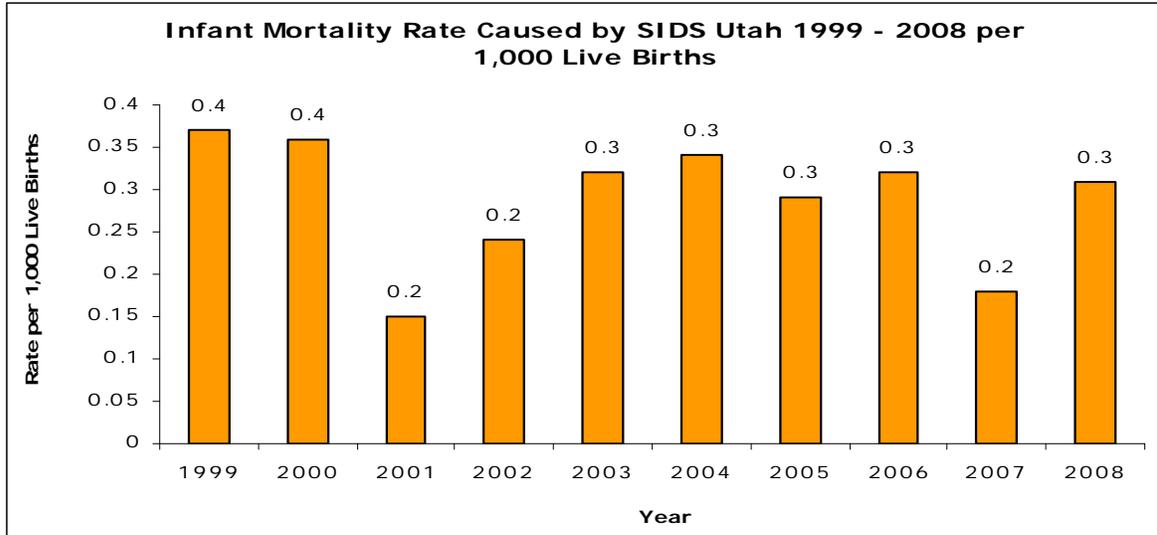
Utah Birth Certificate Database, Office of Vital Records and Statistics, Utah Department of Health; Utah Death Certificate Database, Office of Vital Records and Statistics, Utah Department of Health; National Vital Statistics System, National Center for Health Statistics, U.S. Centers for Disease Control and Prevention

Sudden Infant Death Syndrome

Deaths classified as SIDS have continued to decrease since the beginning of the Back to Sleep Campaign in 1994. In 2008, the Utah rate was 0.31 per 1,000 live births or 17 deaths, which is slightly above the Healthy People 2010 Target of 0.25 deaths per 1,000 live births (see Figure 25). While the total number of SIDS deaths has decreased over time, the number of undetermined deaths (14 deaths, a rate of 0.25) is approximately the same as the number of SIDS deaths. The State Medical Examiner attempts to determine if the infant's sleeping situation, such as other persons or objects in the same bed as the infant, could have caused the infant deaths. Making this determination when infants are found in co-sleeping situations or adult beds is difficult and deaths can be coded as "other ill-defined and unspecified causes of mortality." The SIDS Program provided outreach

material to promote the message of safe sleeping for all infants before CY2007 when funding shortfalls forced the discontinuation of the program.

Figure 25

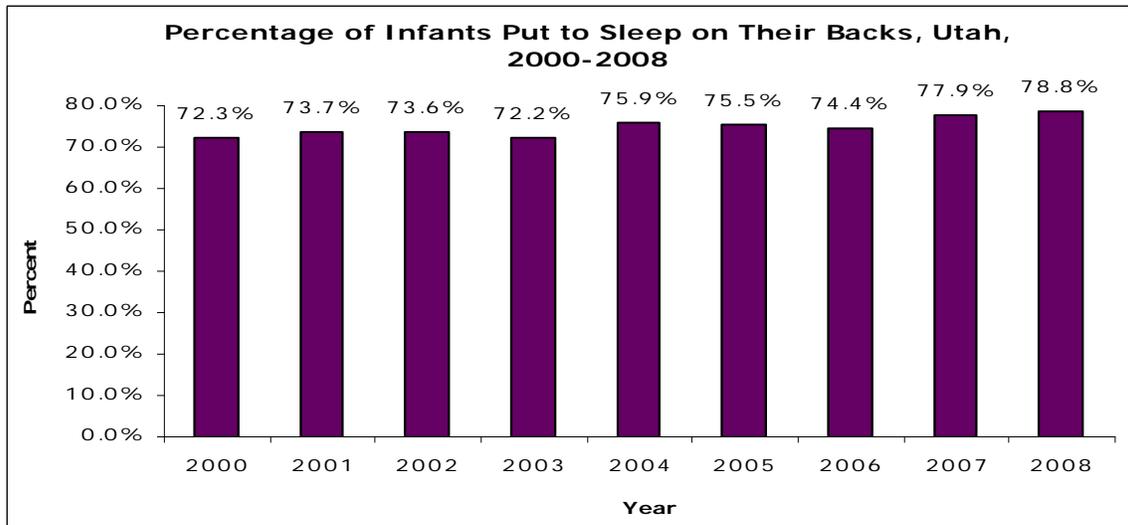


Data Sources

Utah Death Certificate Database, Office of Vital Records and Statistics, Utah Department of Health; Population Estimates: Governor's Office of Planning and Budget, 2008 Baseline Economic and Demographic Projections

The Healthy People 2010 Target is 70% for healthy full-term infants who are put down to sleep on their backs. Utah has met this target for the past decade with a reported 78.8% of infants sleeping on their backs in 2008 (see Figure 26).

Figure 26



Data Sources

Utah Pregnancy Risk Assessment Monitoring System (PRAMS), Utah Department of Health

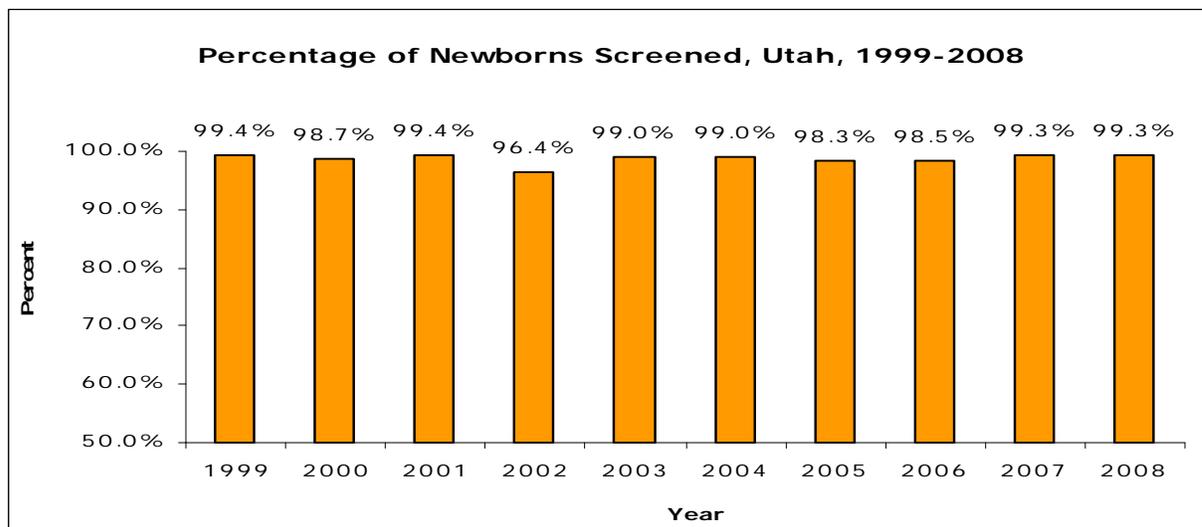
Newborn Screening

Screening of newborns for genetic disorders and disabling conditions facilitates early entry into comprehensive care programs, which can improve quality of life, avoid disability, and save lives. Utah is compliant with the National Recommendations for screening disorders and March of Dimes (37 disorders). For the past two years (2007-2008), 99.3% of newborns were screened in Utah (see Figure 27). While a Healthy People 2020 Target has yet to be determined, these numbers fall just short of the State Target of 100%. The Rule governing Newborn Screening (Rule 398-1) has been updated to include Cystic Fibrosis and clarifies reporting of abnormal results to the Medical Home listed on the screening card. Utah began screening for Cystic Fibrosis in 2009. Figure 28 illustrates the percentage of newborns screening positive and receiving timely follow up to definitive diagnoses and clinical management.

Distribution of newborns who did not receive screening is noted in Figure 29. Utah's largest population of newborns not screened continues to be newborns born at home by lay midwives who deliver in communities who practice polygamy.

Utah offers training and consultation to all midwives, lay or licensed, and continues to provide written instructions for screening. Utah collects a fee for each screening kit from the provider delivering the newborn. This fee is collected by the delivering provider either through third party billing or directly to the family. Families delivering at home often do not have insurance, thus the expense for the kit is incurred by the family. Families and midwives express concern the fee is an additional expense they cannot afford or the family simply does not believe in newborn screening.

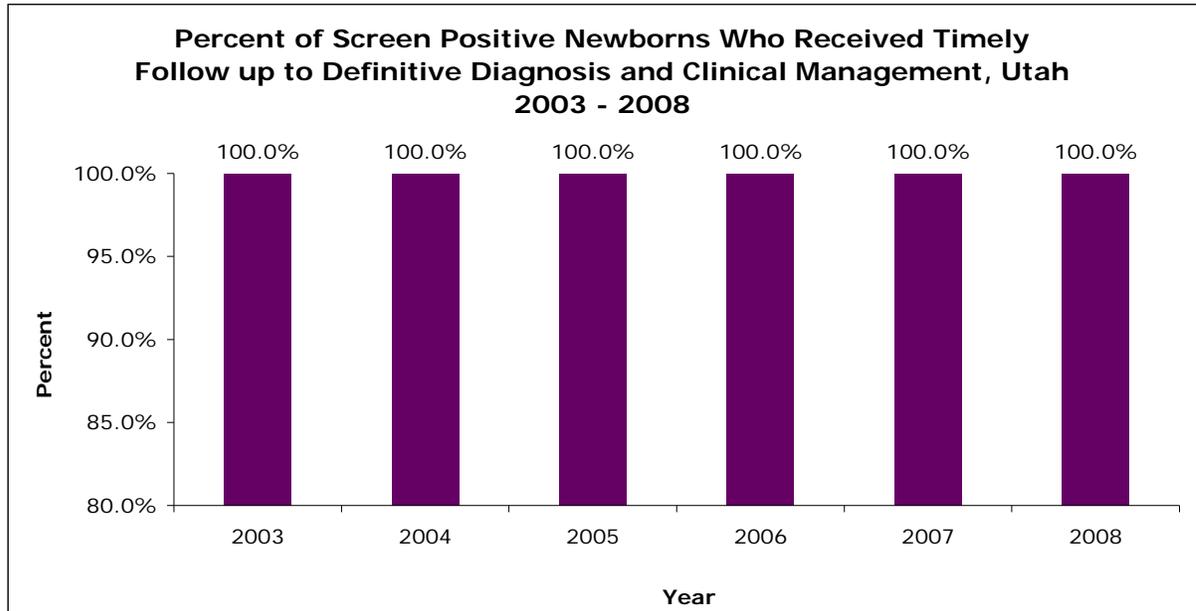
Figure 27



Data Sources

Utah Birth Certificate Database, Office of Vital Records and Statistics, Utah Department of Health; Division of Family Health and Preparedness, Utah Department of Health; Newborn Screening Program Data – LabWare

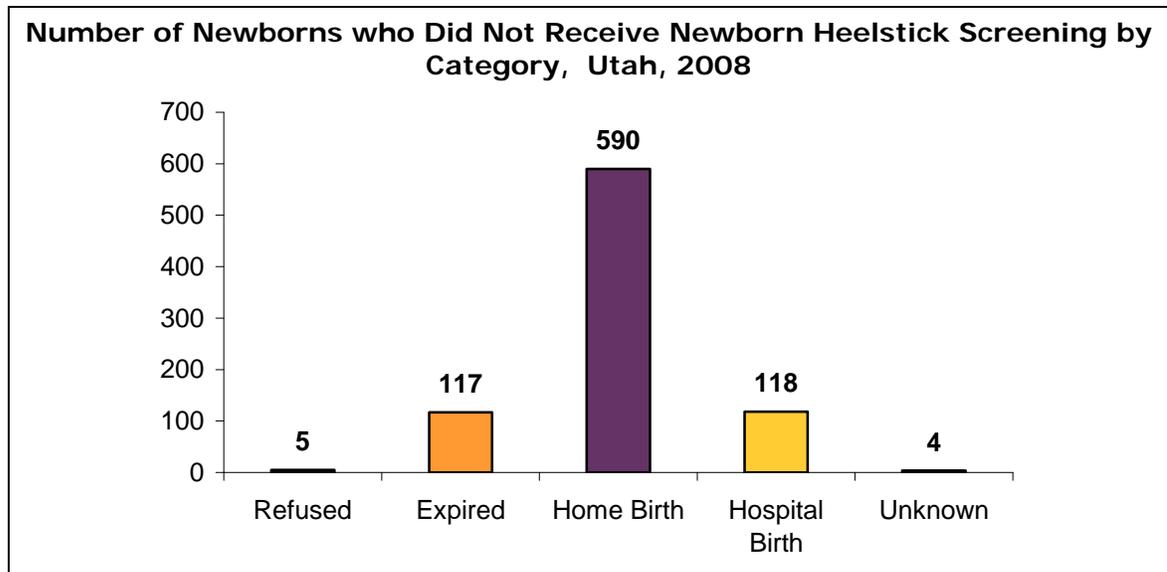
Figure 28



Data Source

Utah Birth Certificate Database, Office of Vital Records and Statistics, Utah Department of Health; Division of Family Health and Preparedness, Utah Department of Health; Newborn Screening Program Data - LabWare

Figure 29



Data Source

Utah State Department of Health, Newborn Metabolic Screening Program, 2008

Follow-up for families identified with a specific disorder can be difficult. Sub-specialists for the disorders are located only in Salt Lake City and families must travel to this location. Travel distance may take as much as 6 hours from the furthest location and may require an overnight stay. A metabolic clinic provider has established a practice in St.

George beginning 2010 which will decrease the travel time in the southern most part of the state.

Diagnostic and follow-up care may not be well covered by third party payers, especially with the increases in out of pocket expenses. Medical foods, enzymes and further genetic testing are often expensive and not well-covered. Utah continues to subsidize medical food and specialty visits for those families who qualify by disorder and income.

Impact of screening on newborns is dependent upon accurate and timely specimens. Utah has developed “safety standards”, for hospitals to meet, improving accuracy and timeliness and is reported monthly to each hospital. The 5 core components are:

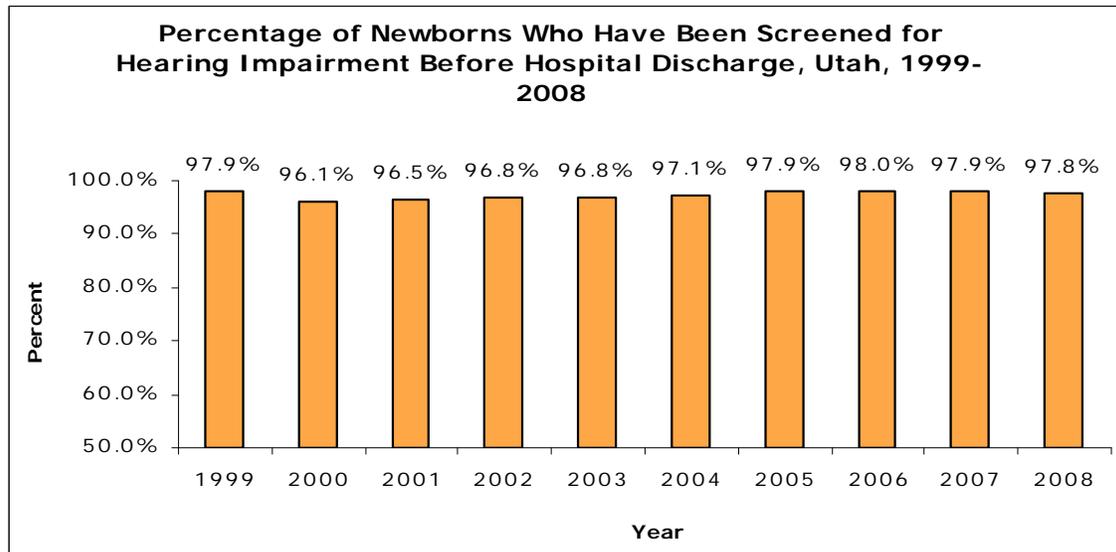
- Unsatisfactory specimens
- Missed first screens
- Missing information from cards
- Transit time
- Batched specimens

Newborn Hearing Screening

It is extremely important for hearing loss to be detected early, so that optimal speech and language development may occur. The most effective method to implement early identification of hearing loss is to screen all babies before they leave the birthing hospital. State legislation requires that ALL newborns, including those born at home, must have their hearing screened by one month of age and the results must be reported to the Utah Department of Health. The UDOH Hearing, Speech and Vision Program oversee Utah newborn hearing screening. Over 99% of Utah newborns are currently screened (as of October 8, 2009), thus exceeding the Healthy People 2010 target of 90%. The percentage of 2007 U.S. total births that received hearing screening as newborns was 94% (as published 8/17/2009). Utah ranks as one of the top newborn hearing screening programs nationally (Data source: CDC EHDI report). Figure 30 illustrates the percentage of newborns screened for hearing impairment prior to hospital discharge.

Although only about three babies per 1,000 actually have hearing loss at birth, it is essential to make certain that babies who do not pass newborn hearing screening receive follow-up testing - and receive it quickly. It is equally important to make certain that ALL babies have an opportunity to have their hearing screened. The Utah Department of Health provides free screening for newborns without access to health insurance or medical coverage.

Figure 30

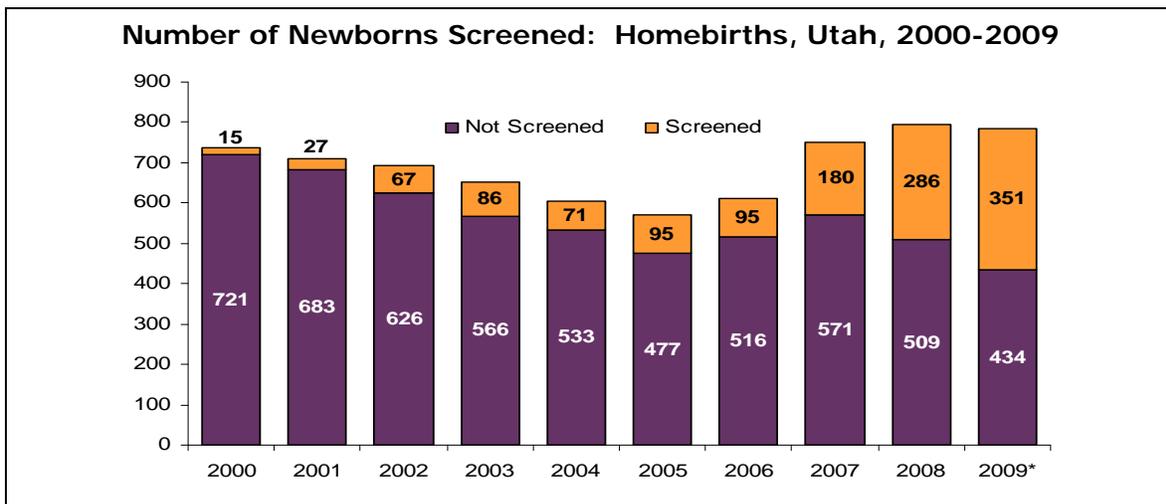


Data Sources

Utah Birth Certificate Database, Office of Vital Records and Statistics, Utah Department of Health; NBHS - HI*TRACK Hearing Screening Tracking and Data Management (C) HI*TRACK, Utah State University

Nearly all (98%) of newborns in Utah are screened for hearing loss with a <5% refer rate at hospital discharge. However, 25-30% of those referred from inpatient screening still do not complete outpatient screening, and diagnostic evaluation results are only documented for 65% of those who were recommended to receive a diagnostic evaluation. Utah’s Homebirth Hearing Project began in February, 2008 with the goal of increasing hearing screening rates for homebirths. Homebirth screening and reporting rates are still under 50%. The HRSA/Utah Loss to Follow-up grant provided funding for nine screening units for lay-mid wives. Participation in this program requires monthly reporting to the State office.

Figure 31

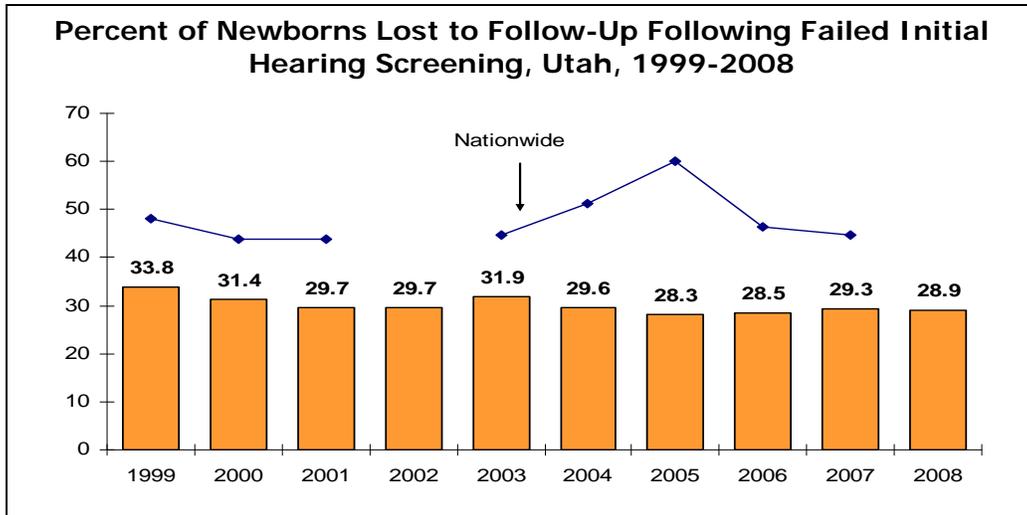


Data Source

Utah State Department Of Health, Newborn Hearing Screening Program, March 2010, *Preliminary Data

Babies lost to follow-up/documentation continue to be an urgent concern; outpatient results are not yet documented for 28.9% of 2008 births not passing initial screening. For infants born in 2008 referred for diagnostic evaluation (429), 61.3% have a completed diagnosis, 30.7% are still in diagnostic process and 7.9% are lost to follow-up/ lost to documentation. There are on-going challenges obtaining information/reports for completed screening and diagnostic evaluations that are completed at private provider offices.

Figure 32



Data Source

Utah State Department Of Health, Newborn Hearing Screening Program, Hi*Track Report.

Gaps and Weaknesses of the System of Care for Pregnant Women, Mothers, and Infants

Family planning services – Access to family planning services is problematic for women without insurance or for whom family planning is not a covered benefit. For several years, legislation for contraceptive equity has been proposed unsuccessfully. PRAMS 2008 data indicated that 33.0% of women reported that their pregnancies were unintended. Rates of unintended pregnancy vary by demographic characteristics of women, e.g. white women reported 31.6% of their pregnancies as unintended while non-white women reported over 52.7% of their pregnancies as unintended.

Variation is seen between Hispanic and non-Hispanic reporting unintended pregnancies, with non-Hispanic women reporting just over 30% of their pregnancies as unintended while Hispanic women reported over 44% as unintended. Another demographic characteristic that reflects differences in unintended pregnancy is mother's income level; women who earn less than \$15,000 per year report higher rates of unintended pregnancies (51.2%) than women who earn \$50,000 or above (18.6%). More family planning services are needed in the state to provide affordable access for women desiring to plan when they become pregnant and space their pregnancies. Low cost services at the community level would assure that low-income women throughout the state could afford to plan their families.

The MCH Bureau has been collaborating with Medicaid for several years to submit an 1115 Research and Demonstration Waiver to extend family planning benefits to women who lose Medicaid coverage 60 days postpartum. The waiver will cover a range of reproductive health care services for eligible women up to two years. We continue to work on the waiver to document the costs savings of the extension for family planning services. However, any Medicaid waiver requires Legislative approval, which may be a difficult barrier to affect the waiver in Utah.

Access to Prenatal Care – Access to prenatal health care varies depending on the geographic area of the state. According to Health Professional Shortage Area surveys conducted between 2000 and 2004, there are areas in Utah with high ratios of women of childbearing age to providers, resulting in limited access to a prenatal provider in their area. Women in rural communities may have to travel many miles to a provider and/or hospital. More than half of the counties (16 out of 29) are without any obstetrician-gynecologist with several counties reporting as few as 1 provider to 10,000 women of childbearing age. There is a need to promote collaboration to assure better access to consultation services for rural providers.

In 2008, 8,900 Utah women (16.7%) who gave birth to a live baby received inadequate prenatal care. Of these, 4,300 (8.2%) received inadequate care due to late entry into care and 4,300 (8.2%) received inadequate care due to an insufficient number of visits. Inadequate care due to late entry was more common among women who were: under the age of 19, not high school graduates, members of racial and Hispanic minority groups, living in households with annual incomes of \$15,000 or less, covered by Medicaid or

uninsured, and cigarette smokers. Among women with inadequate prenatal care, the most commonly reported barriers to obtaining care earlier were: “no money”, “no appointment”, “no Medicaid card”, “health plan / Dr. wouldn’t start earlier”, and “too busy”.

Uninsured women - The percentage of uninsured women of childbearing ages is increasing in Utah. In 2008, almost 15% of women of childbearing ages were without insurance compared to 10.8% in 2001. The 2004 Utah Health Status Survey found that a higher percentage of women under age 35 were uninsured compared with older women. In 2008, 15.4% of Utah women 18-34 years of age had no insurance compared 12.4% of women 35-49 years of age.

Utah Prenatal Medicaid income eligibility is at or below 133% of the FPL, which prevents many women classified as “working-poor” from qualifying. In addition, Utah is one of only a few states that require an asset test for prenatal Medicaid eligibility. Utah PRAMS 2008 data indicate that approximately 15,340 pregnant women (28.3%) had neither insurance or Medicaid prior to pregnancy.

Eligibility for Utah’s Prenatal Medicaid Program remains unchanged at 133% of the federal poverty level and continues to require an asset test for enrollment. As a result, many women do not qualify and find it difficult to access prenatal services. The state initiated the Primary Care Network (PCN) to provide preventive health services to an additional 25,000 Utahns, however PCN does not cover prenatal care and undocumented women are not eligible for enrollment.

Approximately 9,000 women who qualify for Prenatal Medicaid each year lose eligibility two months after delivery, leaving them without a third party payer for family planning services. Without access to long-term family planning, adequate spacing of pregnancies for optimal maternal and child outcomes becomes very difficult. Although clinics offer family planning services on a sliding scale basis, they are limited in their ability meet the high demand for the services. Utah does not allocate any state dollars to family planning services other than the state match for Medicaid.

Preconceptional planning, that is preparing for a pregnancy, can result in better birth outcomes and healthier mothers and infants by identifying potential risks for poor pregnancy outcomes before conception and working to reduce these risks. Risks may include pre-existing medical conditions, medication, and lifestyle practices such as diet or use of tobacco or alcohol, or inadequate intake of folic acid before conception. Women of reproductive age need to utilize health care visits before pregnancy. In addition, third party payers need to reimburse these visits to promote healthy pregnancy outcomes. Utah PRAMS data for 2008 show that only 31.6% of women planning a pregnancy had a preconception visit with a health care provider.

With the influx of Spanish-speaking immigrants many are without documentation and insurance putting a stress on the health care system. From 1999 to 2008, births to Hispanic women rose from 11.8% to 17.1% of live births. According to the Utah Health

Status Survey of 2008, 36.5% of Hispanics had no health insurance compared to 7.0% of non-Hispanic residents who were uninsured. The uninsured rate among Hispanics increased over 40% between 2001 and 2008.

A relatively small amount of Title V funding is contracted to two agencies in Salt Lake City to assist with the provision of prenatal care services for uninsured pregnant women. The Maternal and Infant Health Program (MIHP) has contracts with the Salt Lake Community Health Centers, a network of four community health clinics in Salt Lake City. These clinics provide specialized prenatal care services to teens and low-income women, however this obviously only meets a very small portion of the need

Geographic disparities - Utah suffers from a shortage of certain types of health care Providers in different geographic areas, including nurses, neonatologists, perinatologists, dentists, mental health professionals, etc. Provider shortages exist throughout the state. Access to dentists in Utah is a major issue, particularly for Medicaid participants and for individuals living in rural/frontier areas of the state.

Although most of Utah's population resides in the metropolitan Wasatch Front, residents in rural and frontier areas can be very isolated from health care providers and hospitals. Large expanses of Utah's land are sparsely populated, leaving those who live in these areas very little access to health care services, especially specialty services. Some areas of the state are without an obstetrician/gynecologist. PRAMS 2008 data show that women residing in rural areas have higher rates of inadequate prenatal care although the difference is not statistically significant.

Large, vast areas in Utah have high ratios of women of childbearing age to providers, resulting in limited access to a reproductive health care provider in these areas. More than half of Utah's counties are without any obstetrician/gynecologist for the management of high-risk pregnancies. One rural county has no prenatal care or family planning provider of any kind. Women in this county must travel many miles to see a provider for reproductive health services or to deliver their infants.

Family planning services – Currently some local health departments in the state are no longer able to receive 340B discounted oral contraceptives or Depo Provera. In fact, at this point, most local health departments are unable to purchase discounted oral contraceptives or Depo Provera. Despite development of informal purchasing collaborative among some of the local health departments, several are in danger of losing their ability to subsidize oral contraceptives or Depo Provera at reasonable cost to low-income women. The greatest impact of the loss would be in rural areas without community health centers or Planned Parenthood clinics. The Primary Care Network cannot completely fill this void as the enrollment fee has proved a barrier for some women and non-citizens are not eligible. Due to state laws, local health departments must obtain written parental consent to provide family planning information or services to unmarried minors. The greater impact of this law is seen in rural areas without community health centers or Planned Parenthood clinics. Emergency contraception (EC)

information or services is not permitted by at least one local district's health board and it has been reported that some pharmacies in the state will not fill prescriptions for EC.

Mental health services - Another health service gap for women of reproductive age in Utah is lack of coverage for mental health care services and accessible mental health services. Although data on availability of mental health care services for women of reproductive ages have not yet been compiled, anecdotal evidence indicates that this is a problem. In 2008, 12.3% of women responding to the PRAMS survey reported symptoms of postpartum depression. Of these women, only 32.0% reported seeking help for depression.

Needs of Minority Racial and Ethnic Populations

Studies have shown that despite the steady improvements in the overall health of the United States, racial and ethnic minorities experience a lower quality of health services and are less likely to receive routine medical procedures and have higher rates of morbidity and mortality than non-minorities. Disparities in health care exist even when controlling for gender, condition, age and socio-economic status.

Our current health system was developed based on the needs and perspectives of the White/Anglo-American Utah culture. As a result, Utahns of other cultures often experience barriers to receiving culturally sensitive and appropriate health care. Because of this and other social factors (e.g., proportion of workers in "blue collar" jobs without health benefits, lack of trust in the health care system), the health status of non-white ethnic groups is often poorer than that of the mainstream population. Reducing racial and ethnically-based health disparities is an overarching goal of the U.S. Public Health Service's Healthy People 2010 initiative.

Disparate health outcomes - Health outcomes for some racial minority and ethnic populations are poorer than those for the population as a whole. For example, the percentage of low birth weight for Black infants for the combined three years of data (2006-2008) was 11.4% compared to 6.7% of White infants. The infant mortality rate for infants born to Black Utah women during the same time period was 9.2/1,000 live births compared to 4.6/1000 for infants born to White women. The infant mortality rate for infants born to Hispanic Utah women was 5.1/1000 live births compared to 4.6/1000 for infants born to non-Hispanic women (see Table 11). Hispanic females had a significantly higher teen birth rate compared to other ethnic groups.

Better strategies that address the special needs of minority racial and ethnic populations need to be developed to improve access to services to achieve healthy outcomes. A growing population of undocumented individuals ineligible for most public programs, such as presumptive eligibility for prenatal care, Medicaid (other than Emergency Medicaid), CHIP or the Primary Care Network, has stretched community health centers and local health departments to their limits to provide severely discounted services or unfunded care for this segment of the Utah population.

Table 11 Health Disparities, Utah 2006-2008

	African American Blacks	American Indian	Asian	Hispanic/ Latino	Pacific Islander	Non- Hispanic White	All Utahns
Inadequate Prenatal Care	40.1%	42.0%	20.3%	31.4%	48.9%	13.9%	16.9%
Low Birth Weight	11.4%	7.8%	9.5%	7.4%	6.3%	6.7%	6.8%
Preterm Birth	13.7%	10.7%	10.8%	9.7%	10.7%	9.7%	9.7%
Overall Cesarean Section	27.9	26.2	25.7	22.6	27.3	22.0	22.7
Infant Death/1,000 live births	9.2	2.8	7.4	5.1	6.7	4.6	4.7
Births to Adolescents/1,000 females 15 – 19	44.9	56.2	22.5	112.0	61.7	24.9	34.3

Data Sources

Utah Death Certificate Database, Office of Vital Records and Statistics, Utah Department of Health; Population Estimates: Governor's Office of Planning and Budget, 2006-2008 Baseline Economic and Demographic Projections

In addition to improving accessible health care for this population, improved access to translation services, more ethnic health care providers and sensitivity to the unique needs of culturally diverse populations are needed to facilitate better health care. Local health departments have increased staff that is bilingual in order to meet the needs of the growing Spanish-speaking populations they serve.

More materials and resources have been translated and made available for the Spanish-speaking populations, e.g., the Maternal and Infant Health Program website includes a Spanish section so that Spanish speaking individuals can access the same information that English-speaking individuals can. Other programs have also developed websites for the Spanish-speaking populations. The 2005 Legislature passed a bill that restricts Utah driver's licenses to Utah residents with documentation. Undocumented individuals now will be issued a driving permit that cannot be used by any government entity in the state (regardless of funding source, i.e., WIC) as identification.

Strengths of the System of Care for Pregnant Women, Mothers, and Infants

Utah is generally a very healthy state, ranked second healthiest in 2009 by the United Health Foundation. For mothers, and children we have generally very good outcomes, often reflecting the national trends, but usually with better than average rates. Besides a relatively healthy population in general, the Utah Department of Health has many excellent programs that contribute to the health of mothers and children in the state. We collaborate with state and local agencies, community-based organizations, advocacy groups, health professional organizations, schools, hospitals and university faculty.

Utah's population is growing and changing, with significant increases in the Hispanic and minority populations. The Department's Center for Multi-Cultural Health has provided excellent support to Department programs and local health departments to enhance cultural awareness. The Center provides inservices, print materials, language services and consultation directly to programs in the Department.

Utah has a strong tertiary care system for perinatal and neonatal health care. Referrals are received from the entire Intermountain west region. These tertiary care centers are all situated in a relatively central geographic location around Salt Lake City. In reviewing the data on the percent of very low birth weight infants born in tertiary centers, the trend is improving, with more very low birth weight infants being born in tertiary level hospitals. Collaborative relationships need to be fostered to continue to encourage consultation and referral of high-risk pregnant women as appropriate to tertiary centers. Case review data from the Perinatal Mortality Review Program indicate that prenatal care providers need to be encouraged to refer their high-risk pregnant women with chronic health problems to specialist care as well as support services (e.g. dietitians, tobacco cessation programs and substance abuse treatment) to promote optimal outcomes. Data also illustrate the need for promotion of adequate prenatal risk assessment for all pregnant women, such as screening for tobacco, alcohol and substance use, HIV status, history of previous low birth weight and/or fetal-infant deaths and psychosocial issues.

The 2010 Needs Assessment has provided the state with important information about needs, gaps, and accomplishments. In the past five years, we have noted a great deal of progress in accomplishing our goals to improve the health of mothers and children, including those with special health care needs, and enhancing infrastructure. As we examined the data on the performance measures, outcome measures, health indicators, survey input from the public, survey input from families with children or youth with special health care needs, and key informant interviews, many of the health issues that we consider as high priorities for mothers and children in the state were validated through the public input we sought.

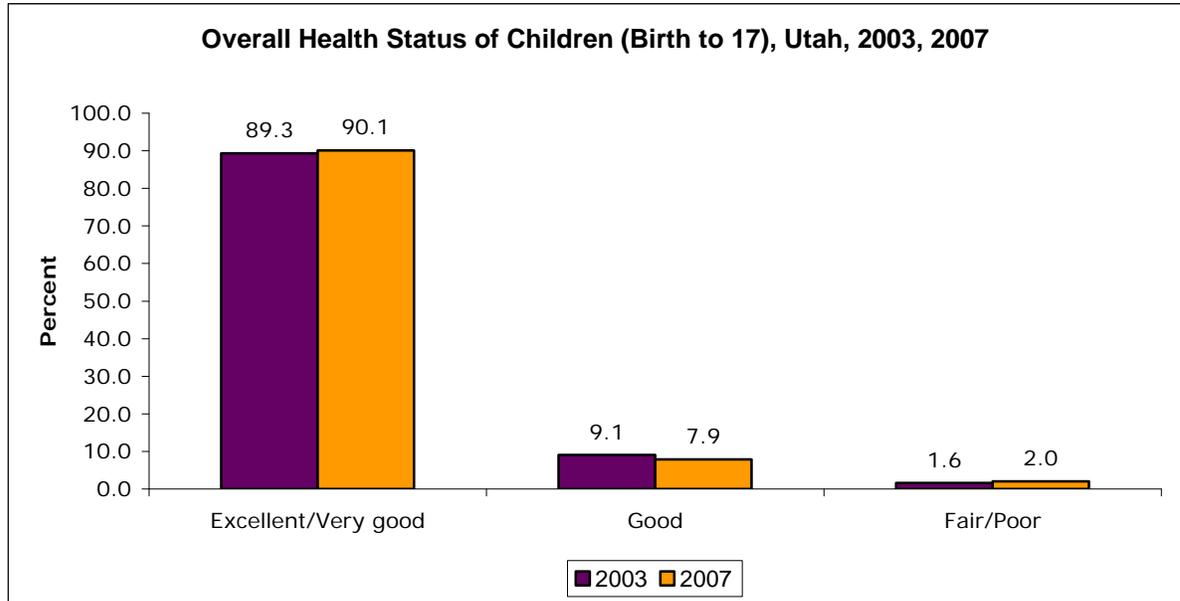
Health Status of Children and Youth

Overall Status of Children's Health

More than 878,000 (878,349) children birth to age 17 live in Utah as estimated by the Utah Population Estimates Committee (UPEC) and the Governor's Office of Planning and Budget (GOPB), 2008 Baseline Economic and Demographic Projections (Revised on 7-23-2008). Utah children generally fare better than children across the nation. With Utah's highest proportion of children to adults, funding needed health, education, and social support services is difficult because of a reduced tax base contributing to public programs. Legislators are always challenged in allocation of general funds given the needs in the state. The impact of funding challenges includes a lower income eligibility level for Medicaid and CHIP eligibility than in many other states. Lower income eligibility levels are compounded by a required asset test for children and pregnant women applying for Medicaid benefits. The 2010 Legislature proposed lowering the

allowable asset level from \$5000 to \$3000 which obviously would reduce the numbers eligible for Medicaid.

Figure 33



Data Sources

National Survey of Children's Health 2003/2007. Data Resource Center for Child and Adolescent Health website.

Below is a summary of different measures of the health of children in Utah compared to the U.S. as reported for the National Survey of Children's Health, 2007. These data indicate that Utah children fare much better than children across the nation, except in the following areas: childhood injuries requiring medical attention, children with insurance, children receiving a preventive medical visit, and children watching TV or videos more than an hour during a weekday.

Table 12. Health Indicators for Utah Children, National Survey of Children's Health, 2007

Measure	US	Utah	Difference
Health status – excellent to very good	84.4	90.1	+5.7
Oral Health Status – excellent to very good	70.7	76.2	+5.5
Childhood injury (birth-5) requiring medical attention	10.4	14.3	-3.9
Breastfeeding of infants birth to age 5 ever	75.5	89.3	+15.8
Children 4 mo – 5 yrs with moderate or high risk for developmental or behavioral problems	26.4	21.9	+5.5
Children age 6 – 17 with 2 or more positive social skills	93.6	94.6	+1.0
Children 6 – 17 who missed 11 or more days of school in past year	5.8	4.7	+1.1
Children with current insurance	90.9	87.7	-3.2
Children with preventive medical visit	88.5	80.2	-7.7
Children with preventive dental visit	78.4	79.1	+0.7
Children 10 mo – 5 yrs with standardized developmental or behavioral screening	19.5	20.6	+1.1
Children 2 – 17 with mental health problems and received care	60.0	66.8	+6.8

Children receiving care in medical home	57.5	63.0	+5.5
Children 6 – 17 repeating at least one grade	10.6	1.8	+8.6
Children 6 – 17 who participate in activities outside of school	80.7	85.8	+5.1
Children 1 – 5 who watched more than one hour of TV or video during a week day	54.4	54.7	-0.3
Children birth to 5 whose families read to them everyday	47.8	48.4	+0.7
Mother’s physical and emotional health excellent or very good	56.9	64.6	+7.7
Father’s physical and emotional health excellent or very good	62.7	71.2	+8.5
Children living in household where someone smokes	26.2	10.8	+15.4
Children who live in neighborhoods with park, sidewalks, library and a community center	48.2	65.1	+6.9
Children who live in neighborhoods with poorly kept or dilapidated housing	14.6	11.3	+3.3
Children living in neighborhoods that are supportive	83.2	92.9	+9.7
Children living in neighborhoods that are usually or always safe	86.1	92.2	+6.1

Data Source

National Survey of Children’s Health website

*All (+) ratings indicate that Utah’s children are better than children nationally and all (-) indicate that Utah children are worse than children nationally.

Children Living in Poverty

Fewer Utah children live in poverty compared to their national counterparts. Table 13 shows the percent of Utah’s population living at different levels of the federal poverty level.

Utah children living in poverty is highest in the Southeastern Health District, a very rural and frontier district with a rate that exceeds the national average. Summit County, just outside Salt Lake City, has the lowest percentage of children living in poverty.

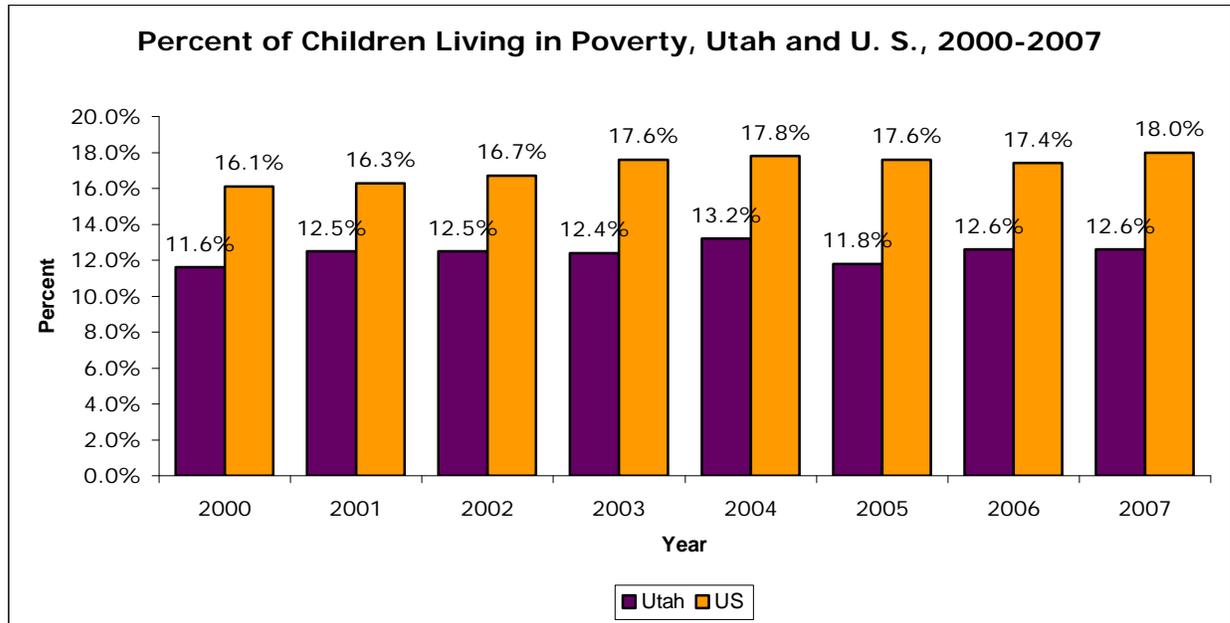
Table 13 Children Living in Poverty, Utah and US, 2000 – 2007

Year	Poverty				
	0-100%	101-200%	201-300%	301% or more	Total
2008	11.8%	26.5%	35.0%	26.6%	100.0%

Data Sources

Utah Healthcare Access Survey, Office of Public Health Assessment, Utah Department of Health

Figure 34



Data Sources

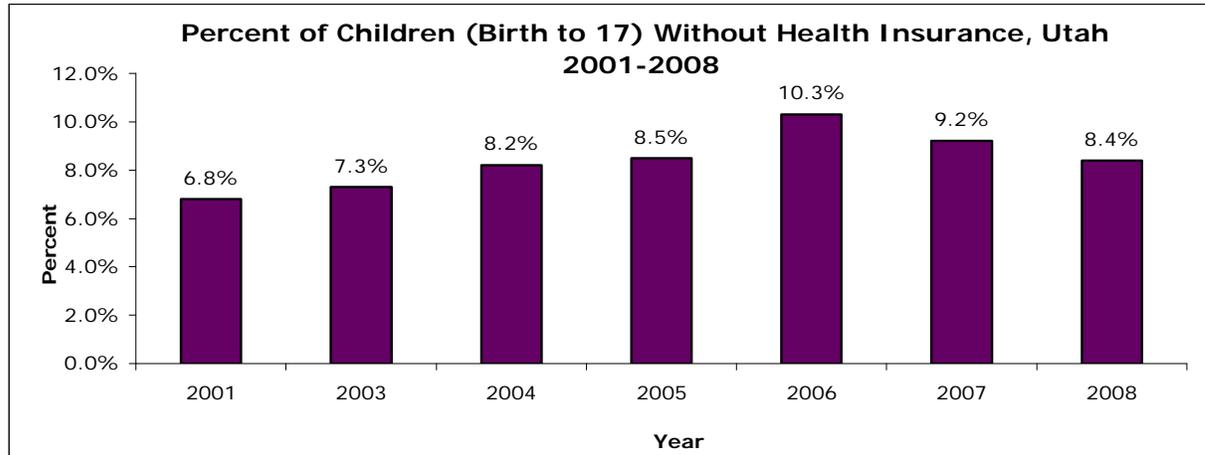
Utah Department of Health, IBIS; U.S. Current Population Survey

Health Insurance Coverage

Approximately one in ten children (8.4%) compared to 10.3% in 2006, was uninsured in the state of Utah in 2008 (see Figure 35). Children with health insurance were more likely than children without health insurance to have a regular source of primary health care. They also are more likely to have routine preventive care than children without insurance coverage. Parents of uninsured children often delay seeking needed care and find services difficult to afford. According to 2008 Utah Health Access Survey data, the most frequent reasons cited for children 17 and under not having insurance were as follows: unable to afford: 45.7%; lost eligibility: 32.4%; lost job: 23.6%; employer not offering insurance: 23.2%; and not needing/wanting insurance: 11.2%.

According to 2007 National Survey of Children’s Health, 11.7% of Utah children were uninsured. Children who are not insured by private or employer-provided plans have an opportunity to be covered by Medicaid (133% of poverty ages 0-5, 100% of poverty ages 6-18) for or the Children’s Health Insurance Program (CHIP) if they are age birth-18 and live in households with incomes below 200% of federal poverty level (see Figure 36).

Figure 35



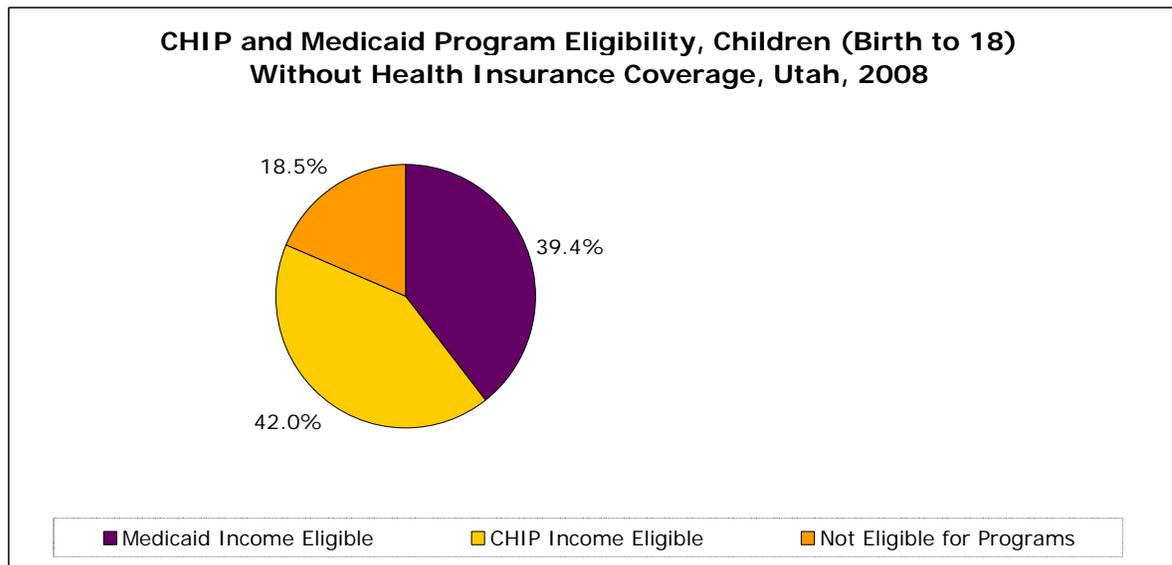
Data Sources

Utah Healthcare Access Survey, Office of Public Health Assessment, Utah Department of Health

Childhood Immunizations

CDC's recommends that all children should have received 4 doses of diphtheria-tetanus-pertussis (DTP), 3 doses of polio, 1 dose of measles-mumps-rubella (MMR), 3 doses of Hepatitis B, 3 doses of Haemophilis influenza, type b (Hib), and 1 dose of Varicella vaccine by two years of age. This recommendation is referred to in shorthand as "4:3:1:3:3:1".

Figure 36



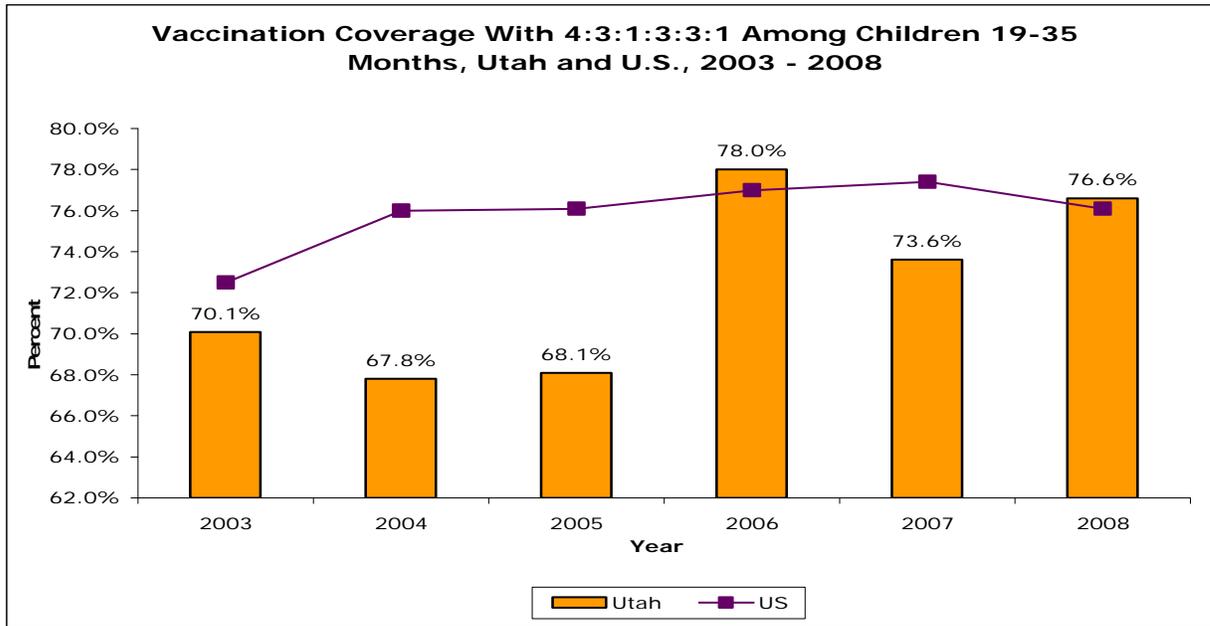
Data Sources

Utah Healthcare Access Survey (formerly Utah Health Status Survey), Office of Public Health Assessment, Utah Department of Health

Utah's coverage levels increased from 73.6% in 2007 to 76.6% of 2-year-old children fully immunized in 2008 (see Figure 37).

Utah's rate of fully immunized is slightly higher than the U.S. percentage (76.1%) and is close to the Healthy People 2010 objective of 80%. Utah's 4:3:1:3:3:1 immunization ranking (among the 50 states) was 19th in 2008.

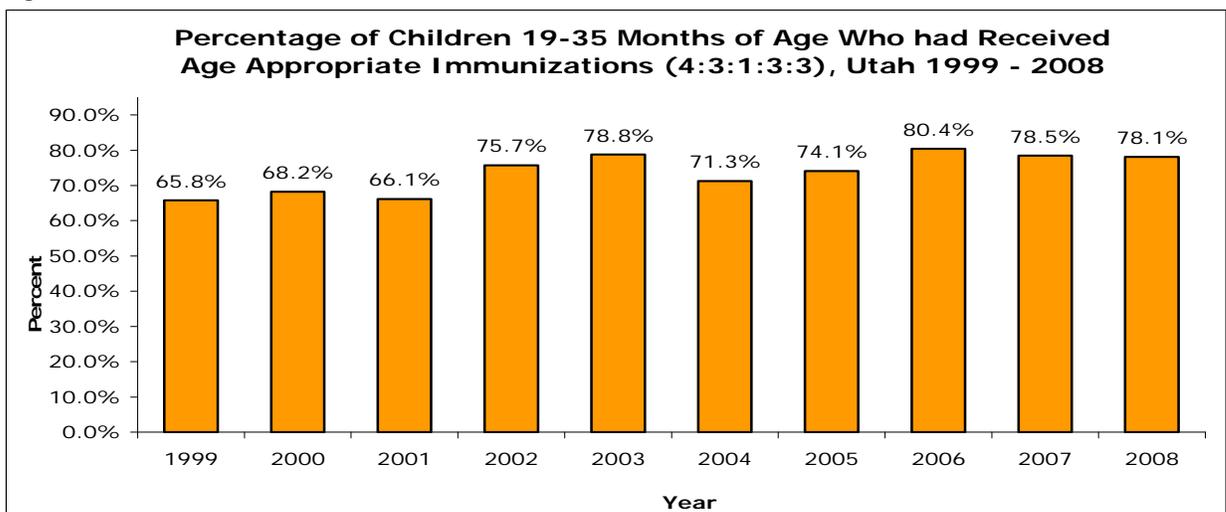
Figure 37



Data Sources

National Immunization Survey, National Center for Health Statistics, U.S. Centers for Disease Control and Prevention

Figure 38



Data Source

National Immunization Survey, National Center for Health Statistics, U.S. Centers for Disease Control and Prevention

Childhood Asthma

Asthma is a serious chronic illness among Utah children. The state prevalence of asthma increased from 8.0% in 2004 to 8.9% in 2006 (see Table 15). Children living in the Utah County Health District had the lowest reported rate of asthma (6.6%), while children residing in Summit County Health District had the highest rate (10.2%) based on combined data (2003-2006). The prevalence of childhood asthma was not statistically different across local health districts or when compared to the state rate (Figure 39).

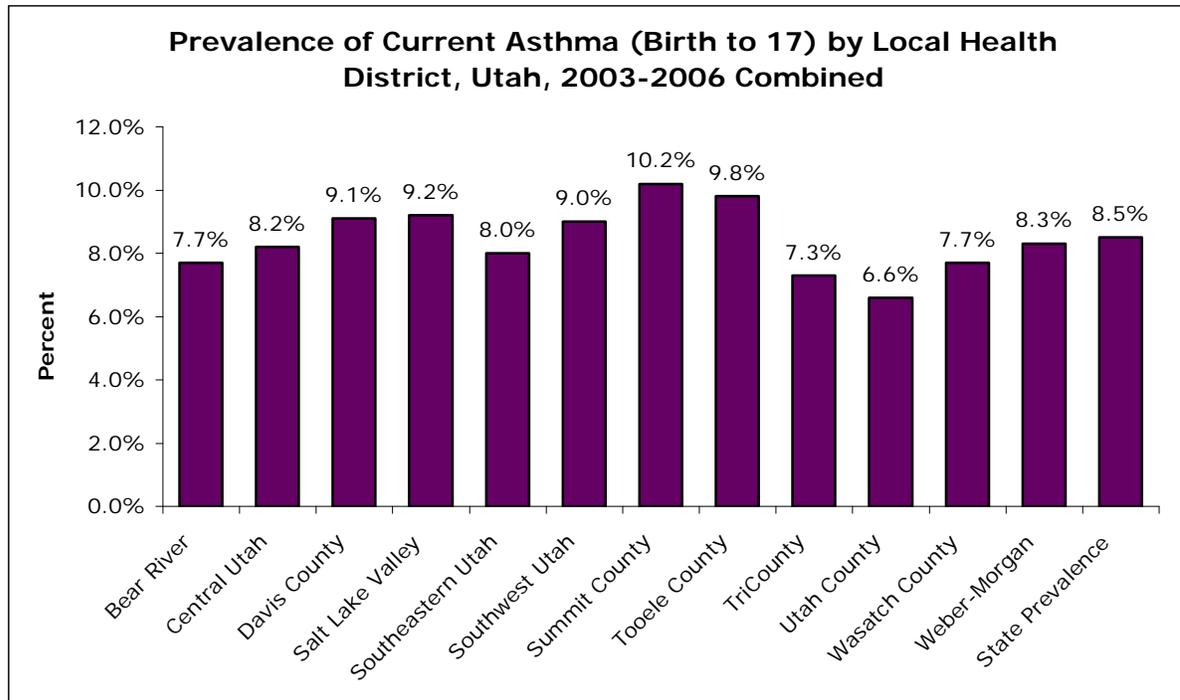
Table 14. Asthma Prevalence, Utah 2003 – 2006

Asthma Prevalence					
Year	2003	2004	2005	2006	Combined
	9.0%	8.0%	8.2%	8.9%	8.5%

Data Sources

Utah Healthcare Access Survey, Office of Public Health Assessment, Utah Department of Health

Figure 39



Data Sources

Utah Health Status Survey 2003-2006

Utah follows the national incidence rates for asthma. Males are more likely to have asthma than females until the child reaches puberty. The prevalence of asthma also increases as the child ages.

Table 15. Percent Lifetime Asthma Prevalence (Ever diagnosed with asthma), Utah, Jan 2007- Dec 2008

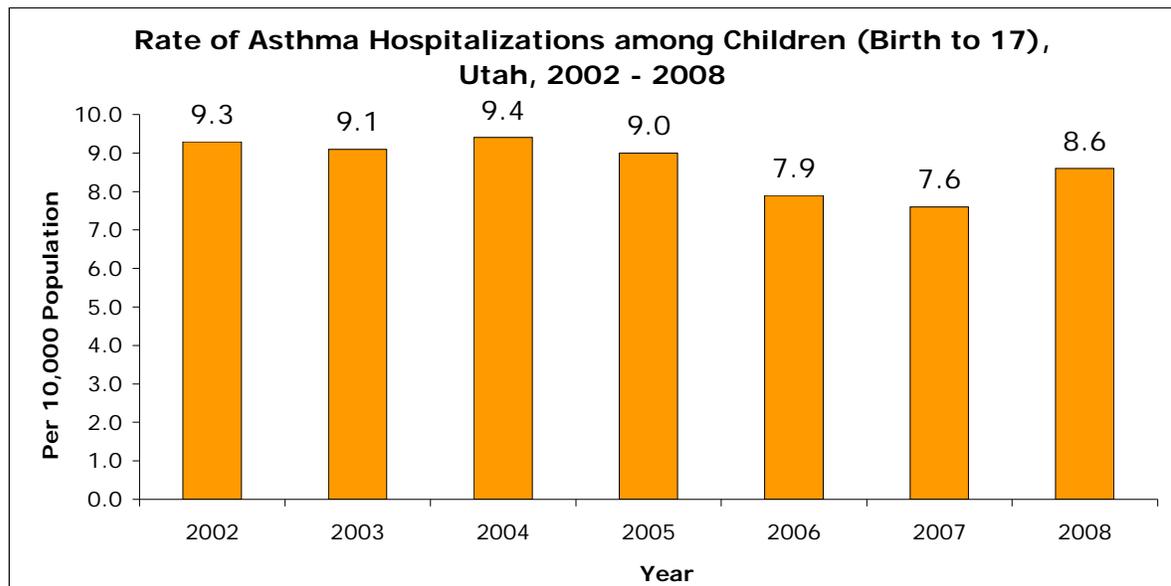
Age Group	Males	Females	Total
1-17	12.1	9.3	10.7
1-4	9.0	4.6	6.9
5-9	11.9	10.7	11.3
10-14	14.0	11.2	12.7
15-17	15.5	13.2	14.4

Data Sources

Utah Data from BRFSS

Asthma can usually be managed in an outpatient setting, reducing the need for inpatient hospitalization. However, an asthma attack can require hospitalization and can be initiated by a variety of triggers. The majority of problems associated with asthma, including hospitalization, may be preventable if asthma is managed according to established guidelines. The Utah asthma hospitalization rate for children remained constant from 2002 to 2005. The 2006 asthma hospitalization rate of 7.9 hospitalizations per 10,000 children aged birth-17 years is significantly lower than the 2002 rate of 9.3 hospitalizations (see Figure 40).

Figure 40



Data Sources

Population Estimates: Utah Governor's Office of Planning and Budget; Utah Inpatient Hospital Discharge Data, Office of Health Care Statistics, Utah Department of Health

Oral Health

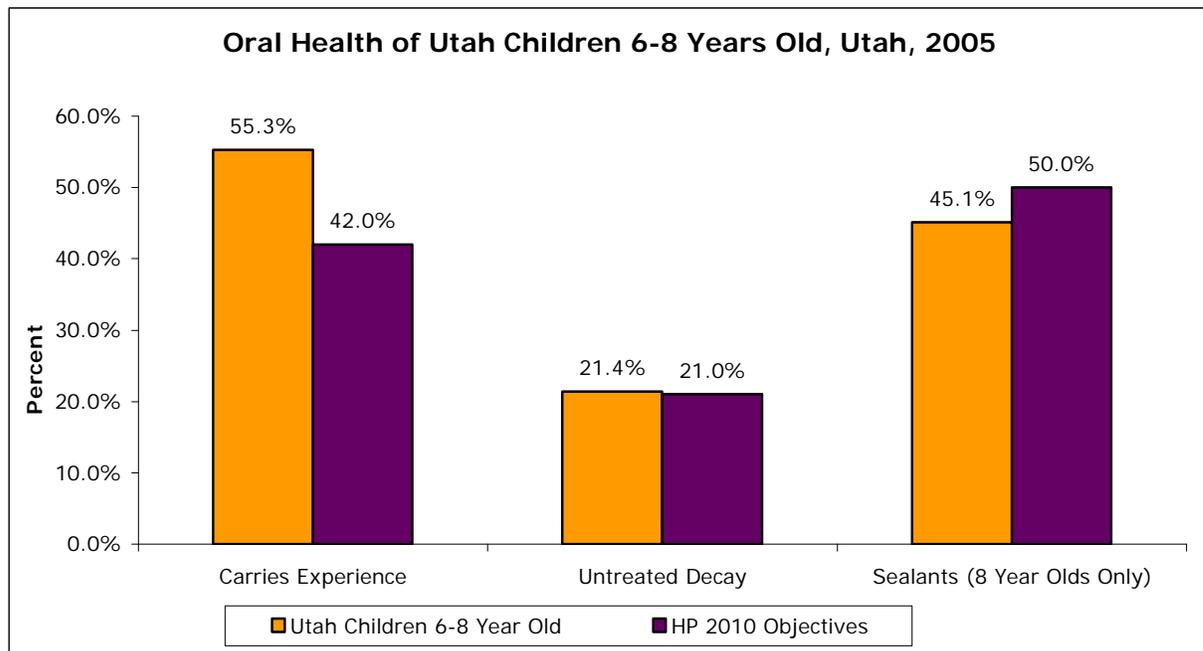
Dental Caries: Dental caries (tooth decay) is one of the most common health problems in the United States and the most common chronic childhood disease. It is five times as common as asthma in children. It is also one of the most preventable diseases. Oral

health affects a person's overall general health. In a recent survey of parents of first through third grade children, one in four did not have insurance for dental care. In 2005, one in ten children required dental care during the past year but were unable to obtain needed dental treatment. In the 2005 oral health survey, 55.3% of Utah children aged 6-8 were found to have had dental caries (see Figure 41). The 2007 National Survey for Children's Health indicates that parents report that 76.2% of children have teeth that are in excellent or very good condition, 16.2% reported teeth in good condition and 7.6% reported their children's teeth as being in poor condition. About 73% of parents reported no problems with their child's teeth. Almost 80% of parents reported that their child had received at least one preventive dental visit during the previous year.

Untreated Decay in Children age 6-8 in Utah: Among school-aged children, 45% have caries in their permanent teeth. Among adults, 94% show evidence of past or current dental caries. Untreated dental caries is an important indicator of adequate and timely access to dental care.

In a 2005 oral health survey of parents of 3rd grade children, one in ten reported that their child needed dental care during the past twelve months but could not get it. In 2005, 21.4% of Utah children aged 6-8 were found to have untreated dental caries, which nears the Healthy People 2010 objective of 21%, however there were counties within the state that had much higher rates.

Figure 41



Data Sources

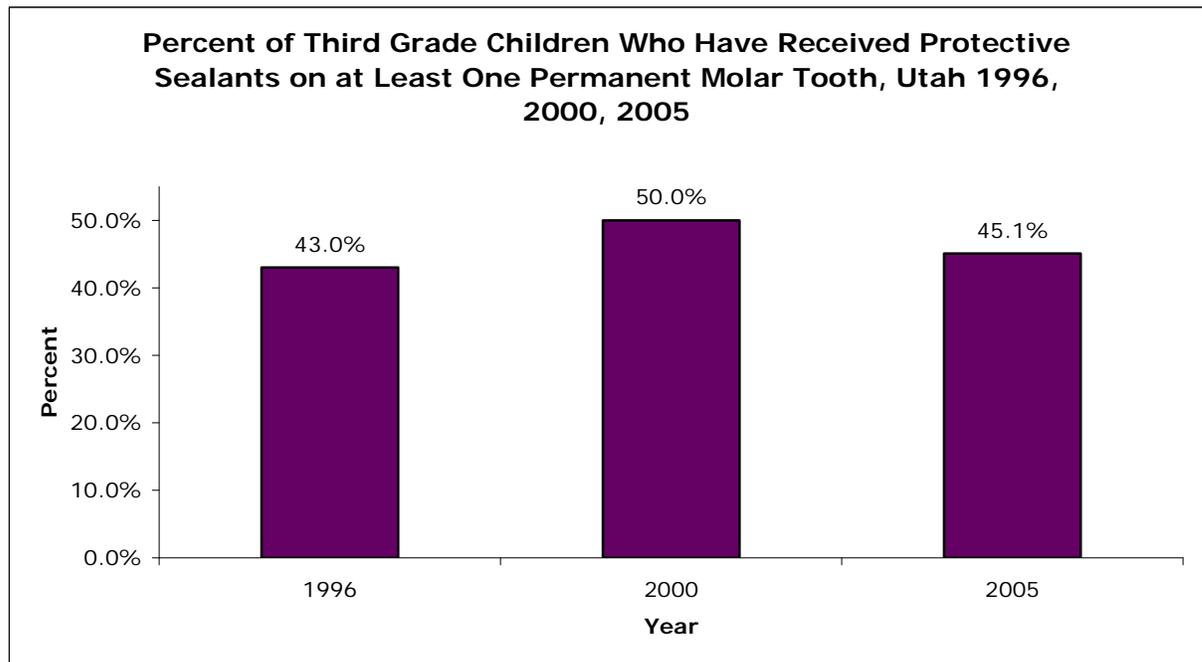
“Make Your Smile Count,” Utah Oral Health Survey 2005. Utah Department of Health, Oral Health Program

Dental Sealants: Children Age 8: Eighty percent of a child's dental decay is found on the occlusal or biting surface of the tooth. Occlusal sealants form a barrier to protect this

part of the tooth. The occlusal surface of teeth with deep pits and fissures are difficult to clean and therefore this part of the tooth is more susceptible to decay. In the 2005 oral health survey, 45.1% of Utah eight year olds were found to have sealants, which is lower than the Healthy People 2010 objective of 50% (see Figure 42).

The U.S. Centers for Disease Control and Prevention has recognized the fluoridation of drinking water as one of ten great public health achievements of the twentieth century. Water fluoridation has helped improve the quality of life in the United States by reducing pain and suffering related to tooth decay, time lost from school and work, and money spent to restore, remove, or replace decayed teeth. An economic analysis has determined that in most communities, every \$1 invested in fluoridation saves \$38 or more in treatment costs. As noted in *Oral Health in America: A Report of the Surgeon General*, community water fluoridation continues to be the most cost-effective, equitable and safe means to provide protection from tooth decay in a community. Utah community water supplies already contain some fluoride but at suboptimal levels. Only 54.3% of Utah residents have drinking water with fluoride levels that are adequate to prevent cavities. While this is progress, much is yet to be done. Policymakers, community leaders, private industry, health professionals, the media, and the public should affirm that oral health is essential to general health and well being and take action to make our families and our communities healthier.

Figure 42



Data Source

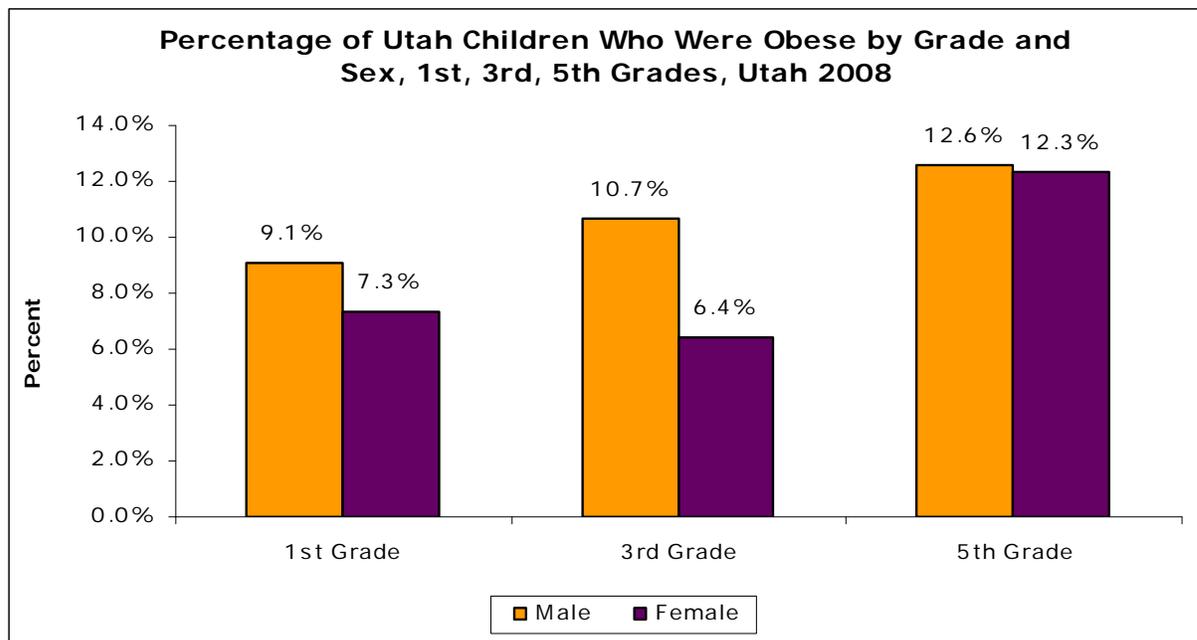
“Make Your Smile Count,” Utah Oral Health Survey 2005. Utah Department of Health, Division of family Health and Preparedness, Oral Health Program

Overweight and Obesity

The percentage of obese children in Utah has increased dramatically over the past decade. From 1994 to 2008 the percent of obese third grade boys increased by 78%, from 6.0% in 1994 to 10.7% in 2008 where as the percentage of obese third grade girls increased by only 5% over the same time period. In 2008, 6.4% of third grade girls were obese compared to 6.0% in 1994 (see Figure 43).

According to the National Pediatric Nutrition Surveillance System (PedNSS) 2002 baseline report, 14% of children aged 2 to 5 years enrolled in federally funded maternal and child health programs (survey population consisted of 83% of WIC children) were overweight. In Utah, according to the 2005 PedNSS report, 21.8% of all children ages 2 to 5 years exhibited a BMI at or greater than the 85th percentile. The increasing prevalence of childhood obesity has been especially pervasive among different minority groups. The highest rates in Utah, according to the 2005 PedNSS report, are among the Black, non-Hispanic and American Indian/Alaskan Native populations at 22% and 36%, respectively. This same report indicated that the rate for the non-Hispanic White children was 16.9%, lower than the overall rate.

Figure 43

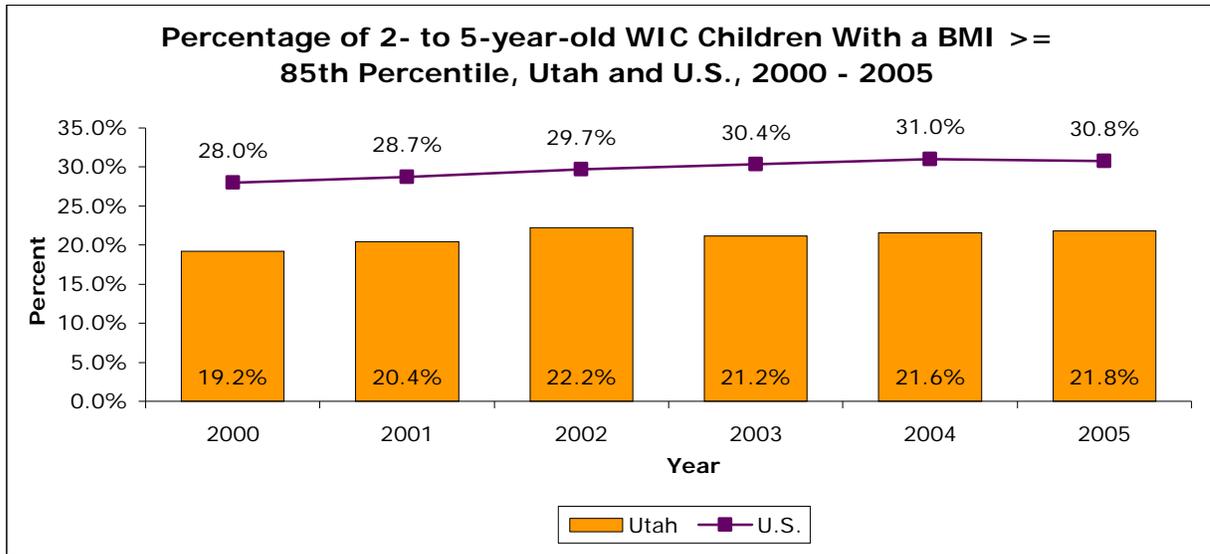


Data Sources

Heart Disease and Stroke Prevention Program. (2008) Height/Weight Measurement, Utah Department of Health, Bureau of Health Promotion

Among high school students obesity rates increased from 5.4% in 1999 to 8.7% in 2007. The rate dropped to 6.4% in 2009 (see Figure 45). Close to one in four (23.8%) of Utah students described themselves as slightly or very overweight. In 2009, 6.4% of students reported vomiting or taking laxatives to lose weight.

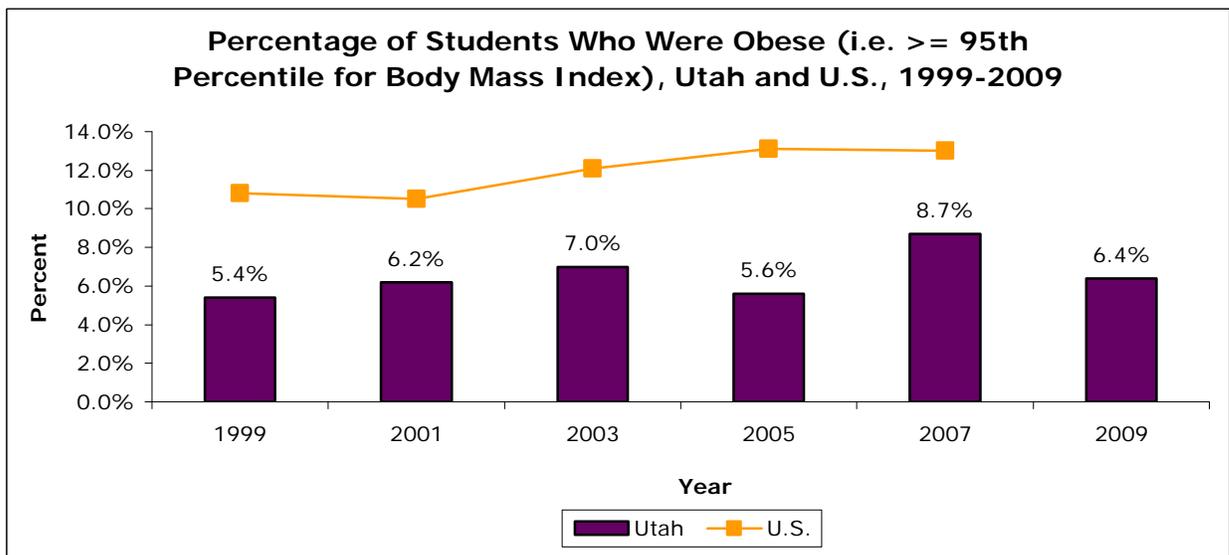
Figure 44



Data Sources

CDC Pediatric Nutrition Surveillance System (PedNSS)

Figure 45



Data Sources

Utah Youth Risk Behavior Surveillance System, Utah Department of Health; Youth Risk Behavior Surveillance System National Center for Chronic Disease Prevention and Health Promotion

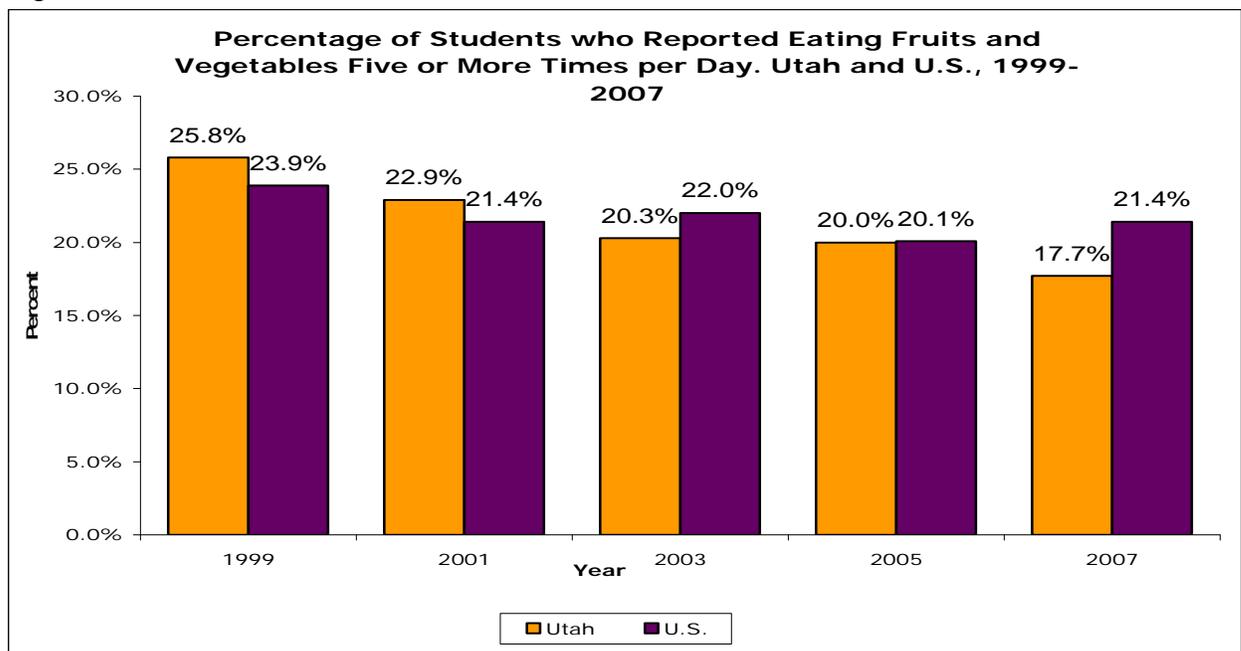
Nutrition

Fruits and vegetables contain essential vitamins, minerals, fiber and other compounds that may help prevent many chronic diseases. Compared with people who consume a diet with only small amounts of fruits and vegetables, those who eat more generous amounts as part of a healthy diet are likely to have reduced risk of chronic diseases including stroke and perhaps other cardiovascular diseases and certain cancers. Fruits

and vegetables also help people to achieve and maintain a healthy weight because they are relatively low in energy density. To promote health and prevent chronic diseases the 2005 Dietary Guidelines for Americans recommend 2 cups of fruit per day for a standard 2,000 calorie diet with recommendations based on an individual's age, gender, and activity level. Utah had a higher percentage of students reporting to consume more fruits and vegetable compared to the national percentage as noted in Figure 46.

Milk provides the body with calcium and vitamin D, which are necessary nutrients and building blocks for the human body. The Utah percentage of students who drank three or more glasses of milk per day is consistently higher than the National percentage (see Figure 47).

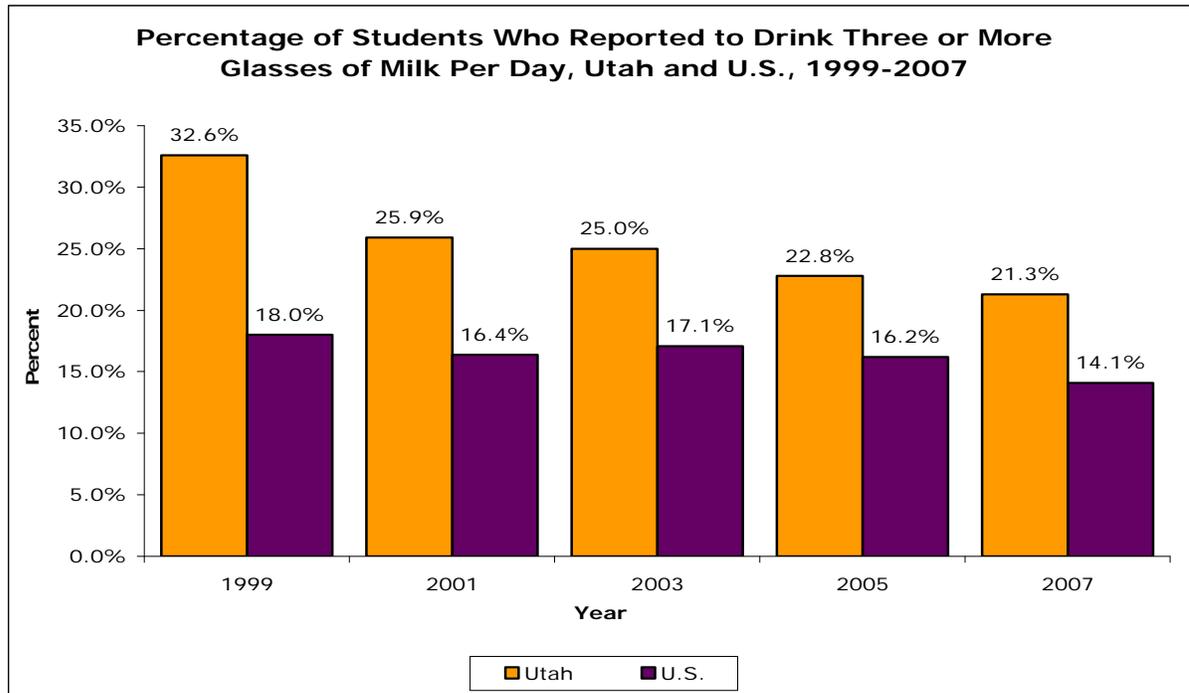
Figure 46



Data Sources

Utah Youth Risk Behavior Surveillance System, Utah Department of Health; Youth Risk Behavior Surveillance System, National Center for Chronic Disease Prevention and Health Promotion

Figure 47



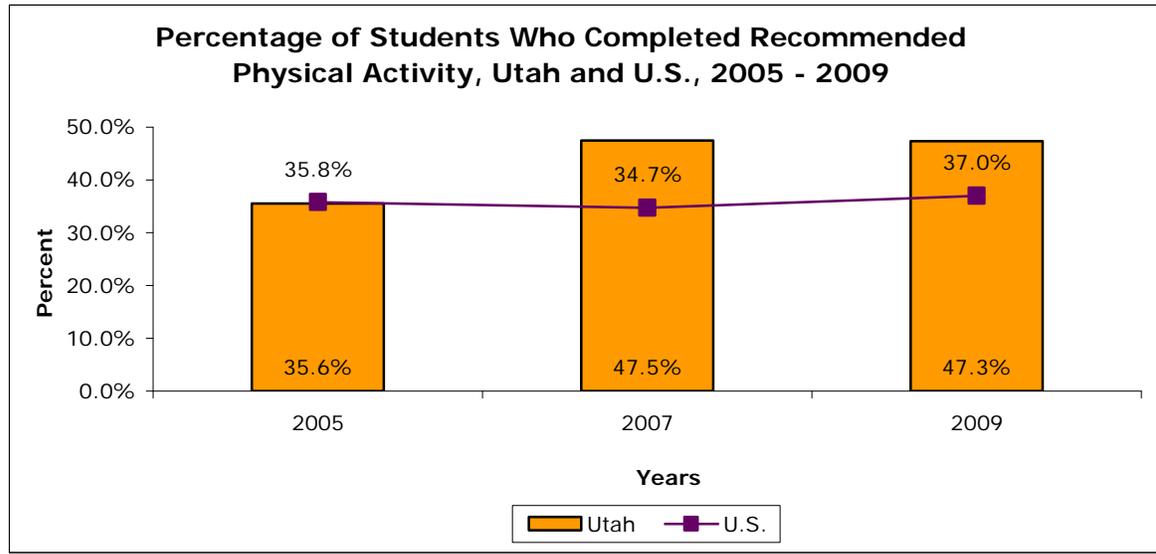
Data Sources

Utah Youth Risk Behavior Surveillance System, Utah Department of Health; Youth Risk Behavior Surveillance System, National Center for Chronic Disease Prevention and Health Promotion

Physical Activity

In 2009, 39.2% of girls and 55.2% of boys in Utah high schools reported getting at least 60 minutes of physical activity at least 5 days per week. These percentages are similar to the 2007 estimates of 37.8% of girls and 56.3% of boys. Utah high school students reported higher rates of recommended physical activity in 2007 and 2009, 47.5% and 47.3% respectively, compared to the national average (34.7% and 37.0% respectively, see Figure 48). Almost thirty percent (29.9%) of students reported taking physical education classes 5 days in an average week when they were in school. This percentage is comparable to the national average of 30.3% in 2007.

Figure 48



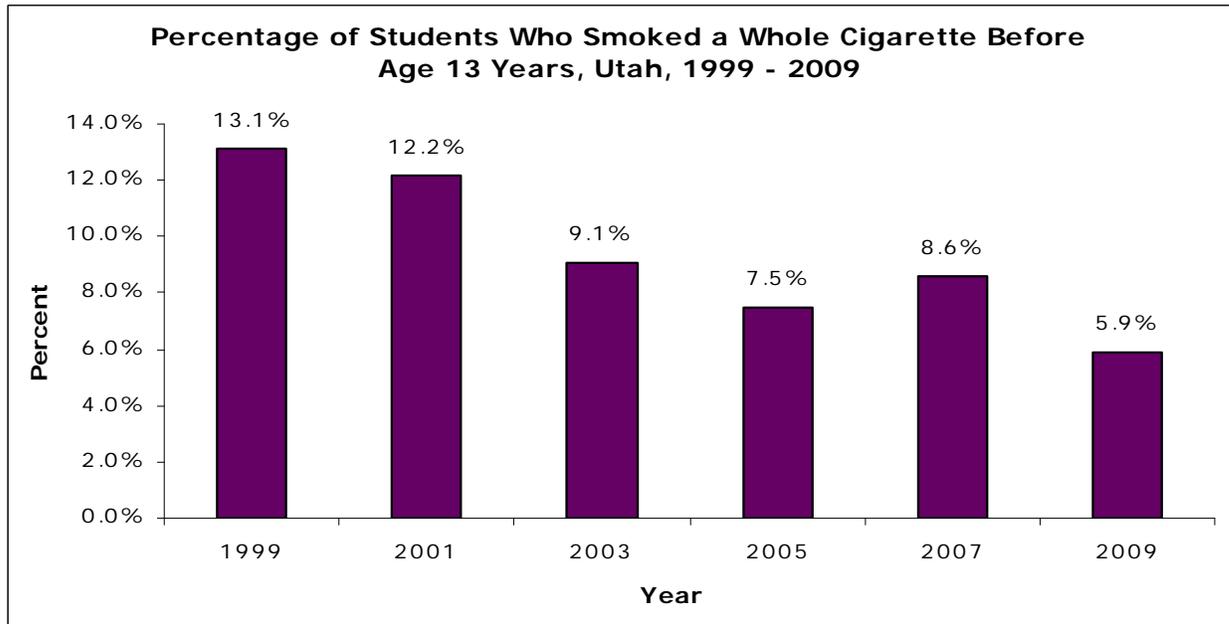
Data Sources

Utah Youth Risk Behavior Surveillance System, Utah Department of Health; Youth Risk Behavior Surveillance System, National Center for Chronic Disease Prevention and Health Promotion

Tobacco Use

Tobacco use remains the leading cause of preventable disease and death in the United States. Children and adolescents who smoke are at increased risk for developing respiratory illnesses, impaired lung growth, cancer, heart disease, and weakened immune systems and one third of those who continue to use tobacco will die from tobacco-related diseases. In addition, youth smokers are less physically fit and less likely to be committed to their education than their nonsmoking peers. Since nearly all adult smokers began smoking during adolescence, preventing youth from starting to use tobacco products is expected to result in a substantial decrease in tobacco-related disease and death, in later years. Since the mid-90s teen smoking rates declined from 17% to 8.5% mainly between 1997 and 2001. Teen smoking has been stable since 2001. However, smoking experimentation significantly increased between 7th and 8th grade and continued to increase throughout most of high school (Utah Youth Tobacco Survey 2005). According to 2009 YRBS data, 5.9% of Utah students smoked a whole cigarette for the first time before age 13 (see Figure 49). Utah's current cigarette use for students in 2009 was 8.5%, well below the Healthy People 2010 Target of 16% (see Figure 50). Utah's current tobacco use (those who smoked cigarettes, cigars, or used chewing tobacco, snuff, or dip) among students was 8.5% with a higher rate for male students over female students. Utah middle and high school students reported cigar smoking as the second most prevalent form of tobacco use.

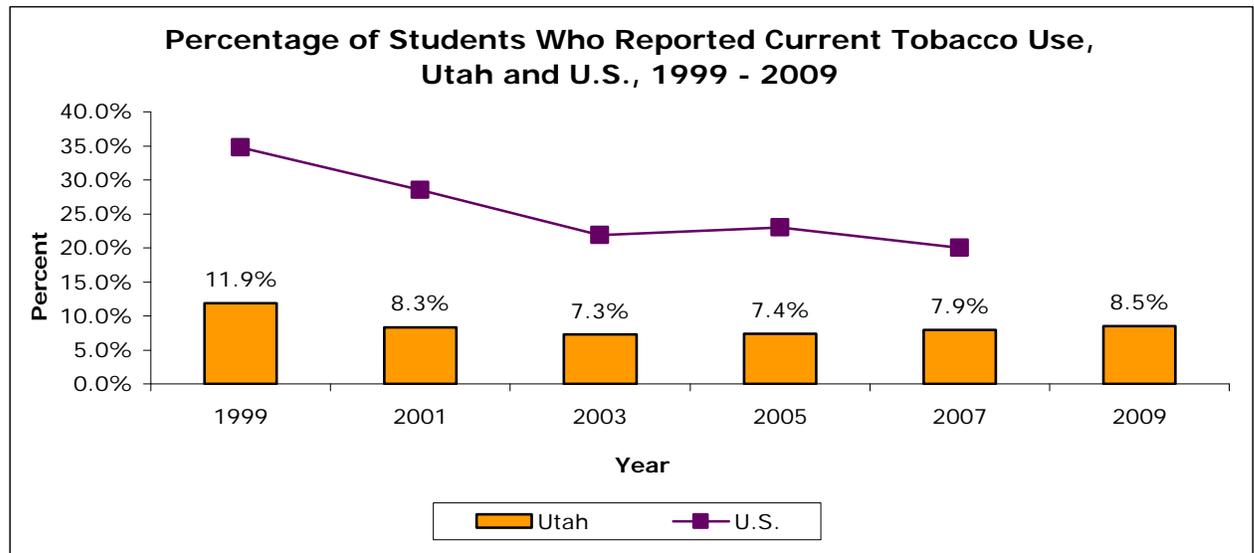
Figure 49



Data Sources

Utah Youth Risk Behavior Surveillance System, Utah State Office of Education

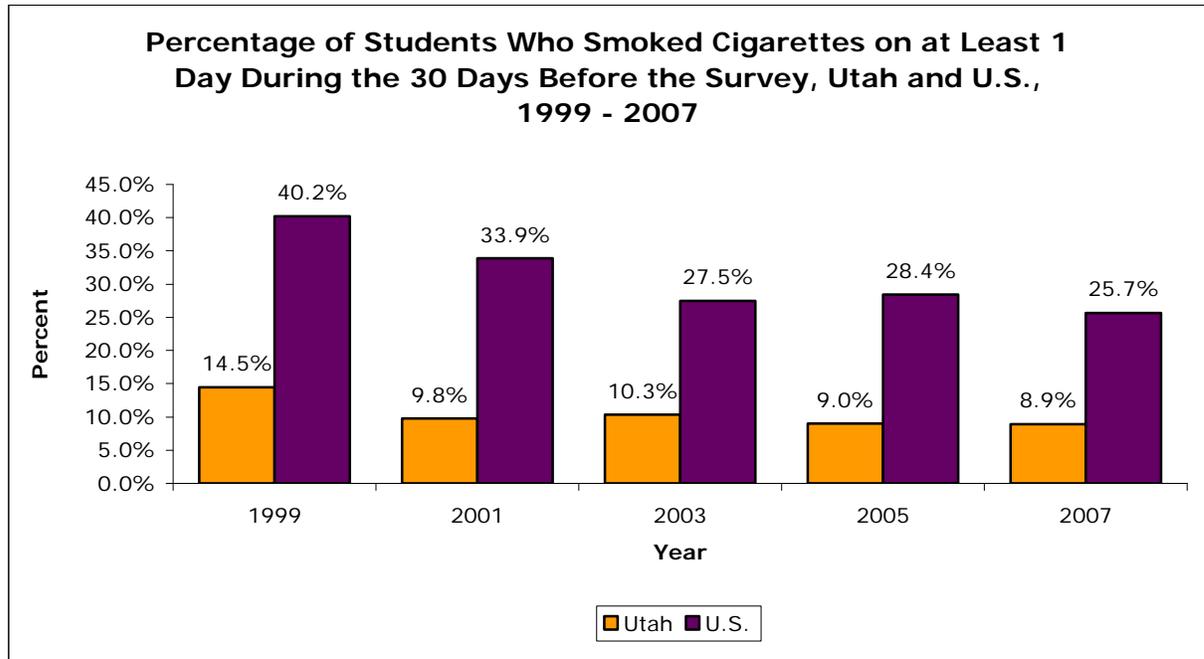
Figure 50



Data Sources

Utah Youth Risk Behavior Surveillance System, Utah Department of Health; Youth Risk Behavior Surveillance System, National Center for Chronic Disease Prevention and Health Promotion

Figure 51



Data Sources

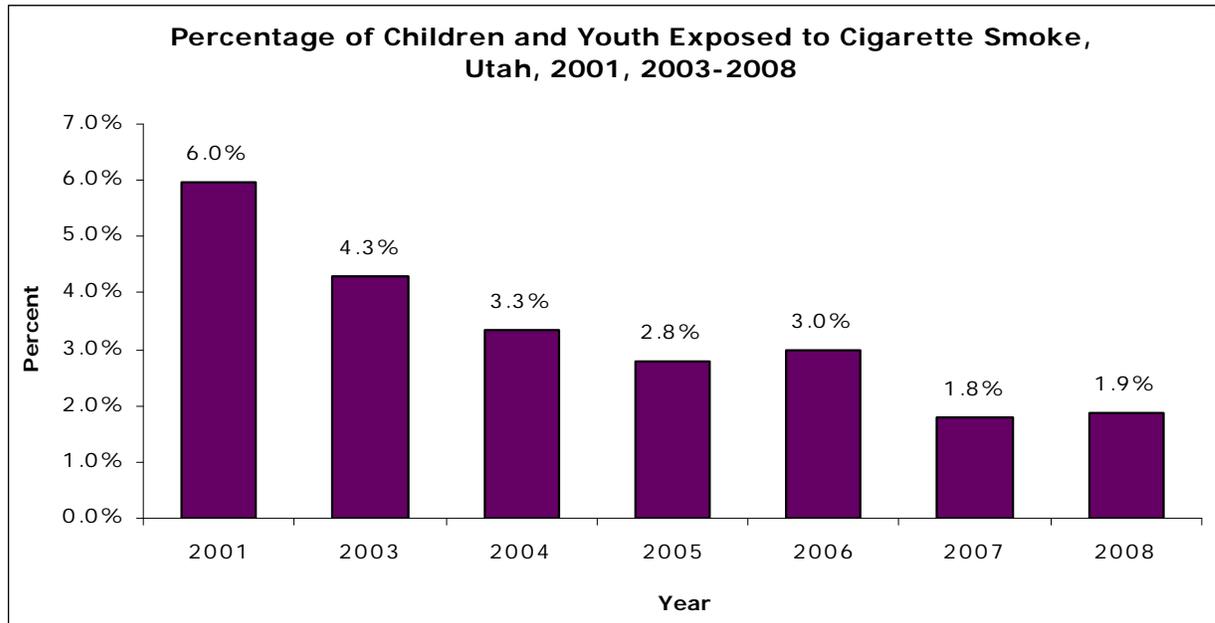
Utah Youth Risk Behavior Surveillance System, Utah Department of Health; Youth Risk Behavior Surveillance System, National Center for Chronic Disease Prevention and Health Promotion

Secondhand Smoke

Data from the 2008 Utah Healthcare Access Survey show that 1.9% of Utah children (approximately 15,000 children) were exposed to secondhand smoke inside the home during the past month (see Figure 52). Since 2001, child exposure to secondhand smoke in homes declined by 68%. This number is well below the Healthy People 2010 target of 6% of children (ages 6 years and under) exposed to tobacco smoke at home. The 2006 Surgeon General’s Report "The Health Consequences of Involuntary Exposure to Tobacco Smoke" concludes that there is no safe level of secondhand smoke exposure.

Children and youth exposed to secondhand smoke are at increased risk for sudden infant death syndrome, acute respiratory infections, ear problems, and more severe asthma. Educational interventions and public policy to prevent exposure to tobacco smoke lead to improved health and substantial savings in societal and health care costs.

Figure 52



Data Sources

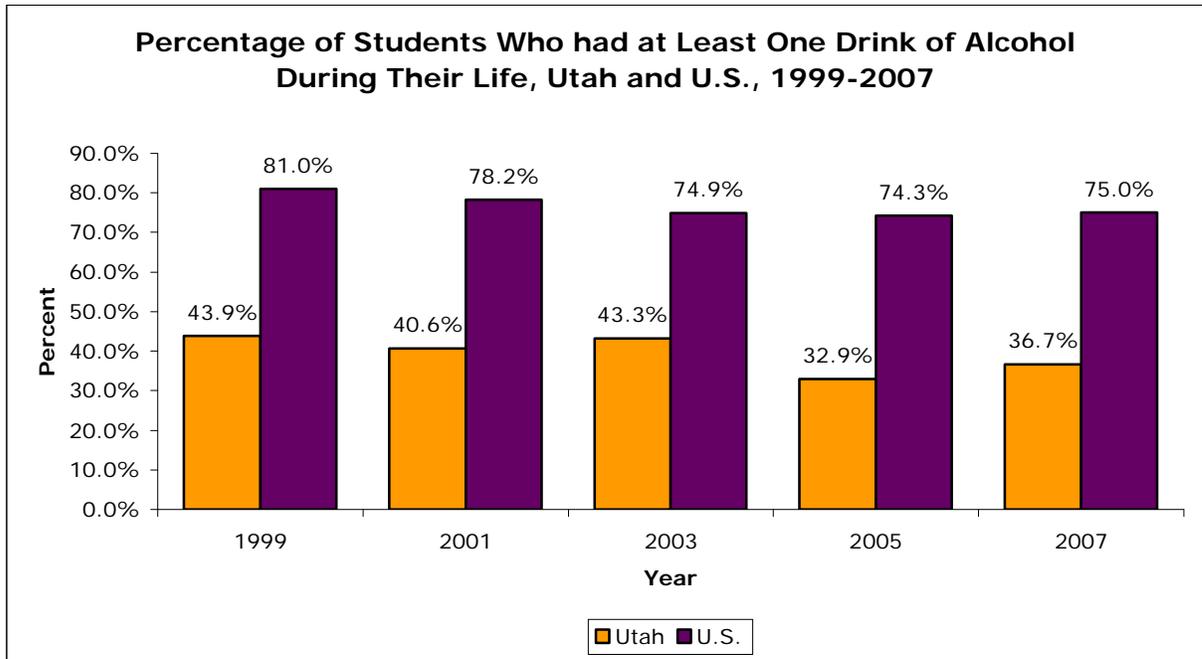
Utah Healthcare Access Survey, Office of Public Health Assessment, Utah Department of Health

Substance Abuse

The most commonly abused substance among Utah high school students in 2009 was alcohol (18.2%), followed by marijuana (10.0%), and cocaine (2.8%). According to CDC, the use of alcohol and other drugs has been linked to unintentional injuries, physical fights, academic and occupational problems, and illegal behavior among youth. Long-term alcohol misuse is associated with liver disease, cancer, cardiovascular disease, and neurological damage as well as psychiatric problems such as depression, anxiety, and antisocial personality disorder. Of Utah students, 36.7% report that they have had at least one drink of alcohol at least once during their lifetime. Current alcohol use was reported as 18.2%. (Figures 53 and 54).

Marijuana is the most commonly used illicit drug among youth in the United States. Current marijuana use in U.S. decreased from 26.7% in 1999 to 19.7% in 2007 (see Figure 55). One in ten Utah students reported current marijuana use, an increase from 2005 (7.6%). Students who smoke marijuana tend to get lower grades and are less likely to graduate from high school, compared with their nonsmoking peers. According to National Institute on Drug Abuse research, marijuana use has the potential to cause problems in daily life or make a person's existing problems worse.

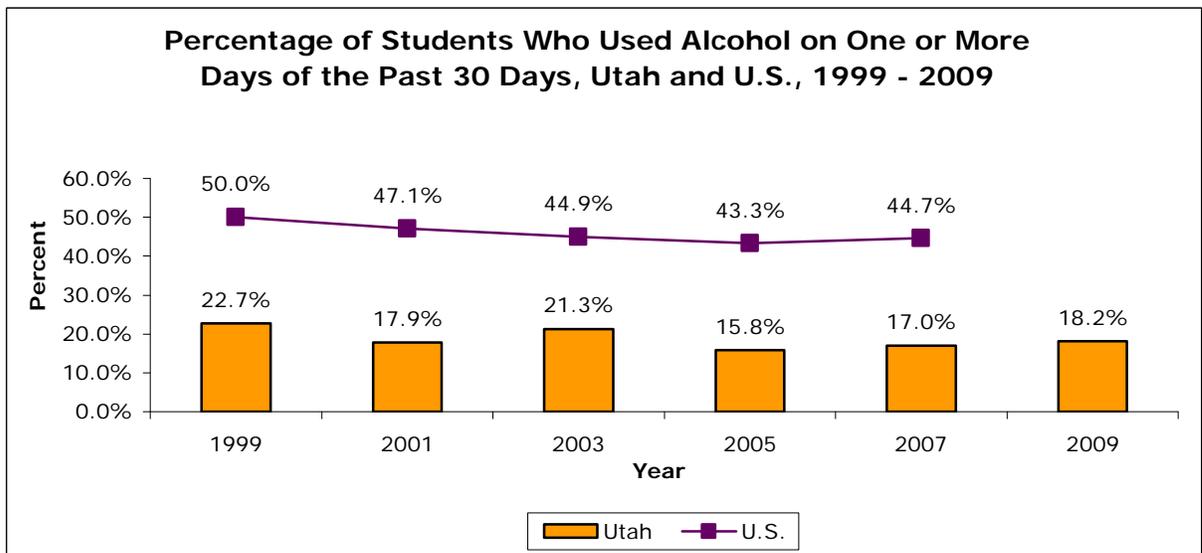
Figure 53



Data Sources

Utah Youth Risk Behavior Surveillance System, Utah Department of Health; Youth Risk Behavior Surveillance System, National Center for Chronic Disease Prevention and Health Promotion

Figure 54

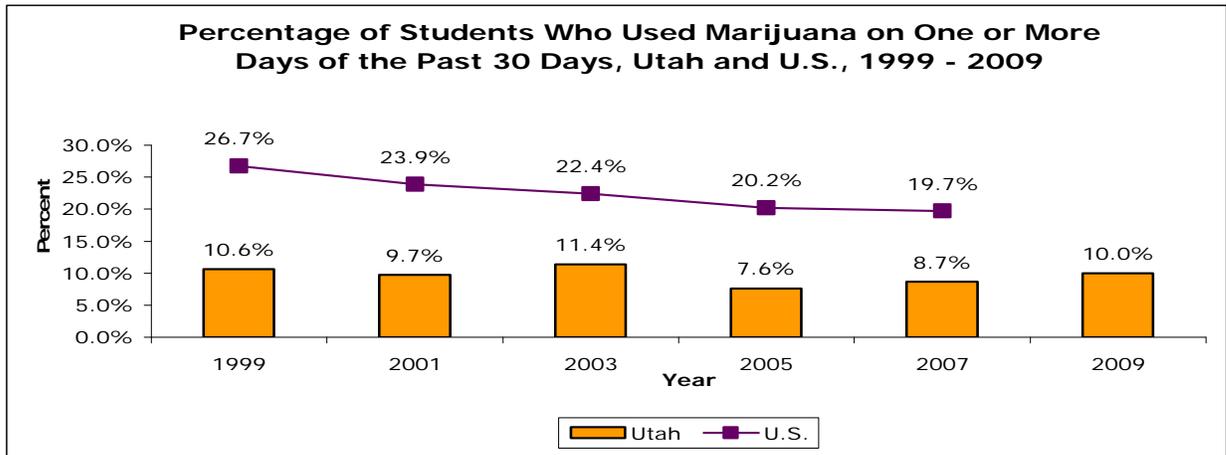


Data Sources

Utah Youth Risk Behavior Surveillance System, Utah Department of Health; Youth Risk Behavior Surveillance System, National Center for Chronic Disease Prevention and Health Promotion

Because marijuana compromises the ability to learn and remember information, the more a person uses marijuana the more he or she is likely to fall behind in accumulating intellectual, job, or social skills. The Drug Abuse Warning Network (DAWN), a system for monitoring the health impact of drugs, estimated that, in 2002, marijuana was a contributing factor in over 119,000 emergency department visits in the United States, with about 15 percent of the patients between the ages of 12 and 17.

Figure 55

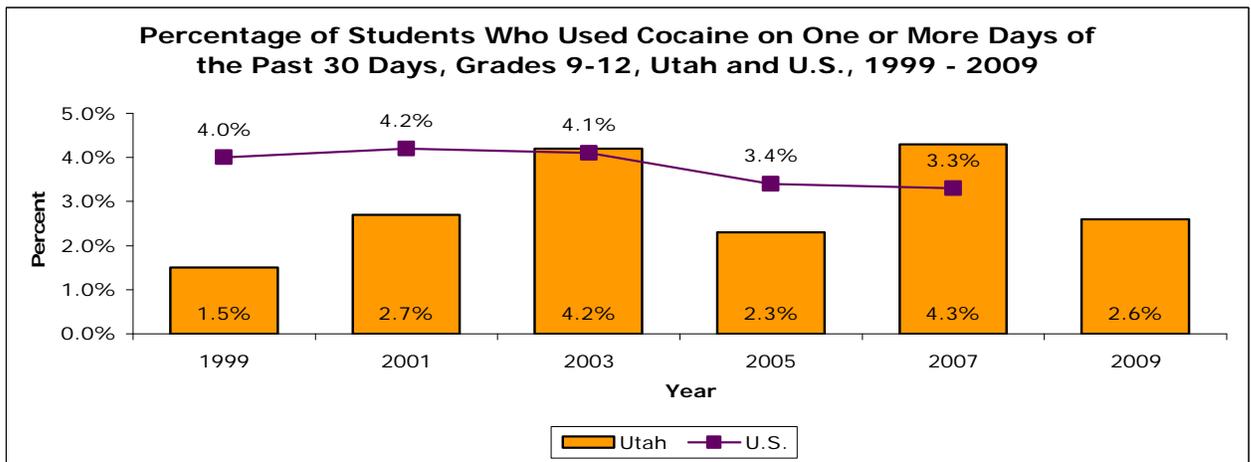


Data Sources

Utah Youth Risk Behavior Surveillance System, Utah Department of Health; Youth Risk Behavior Surveillance System, National Center for Chronic Disease Prevention and Health Promotion

While most categories of alcohol and marijuana use among students in Utah are generally below the national average, Utah has similar rates as national (based on 2007 YRBS) for life time use of cocaine (6.8% vs. 7.2%), heroin (5.5% vs. 2.3%), methamphetamine (6.6% vs. 4.4%), and steroids (5.5% vs. 3.9%).

Figure 56



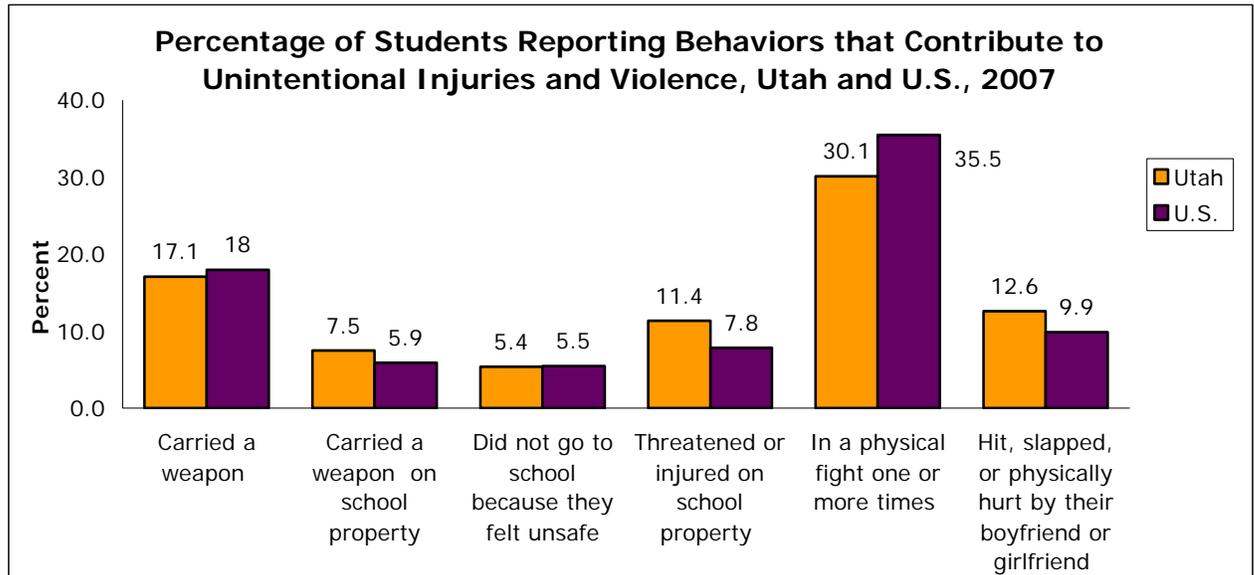
Data Sources

Utah Youth Risk Behavior Surveillance System, Utah Department of Health; Youth Risk Behavior Surveillance System, National Center for Chronic Disease Prevention and Health Promotion

Violence and Injury

According to the National Adolescent Health Information Center, unintentional injuries accounted for the greatest number of adolescent and young adult deaths in 2004. The Youth Risk Behavior Surveillance System asks questions about behaviors that may lead to unintentional injury. In 2007, the percentage of students in Utah who carried a gun or other weapon (17.1%) at least one day in the previous month was no different than the U.S. rate (18.0%) and the percentage of Utah students who did not go to school because of safety concerns was not different from the U.S. (5.4% vs. 5.5%). Utah students reported higher rates of being threatened or injured with a weapon than the U.S. (11.4% vs. 7.8%). The percentage of Utah students who had been in a physical fight one or more times (30.1%) was much lower than the U.S. rate of 35.5% (see Figure 57). However, Utah's rate of being physically hurt on purpose by their boyfriend or girlfriend was significantly higher than the U.S. rate (12.6% vs. 9.9%).

Figure 57



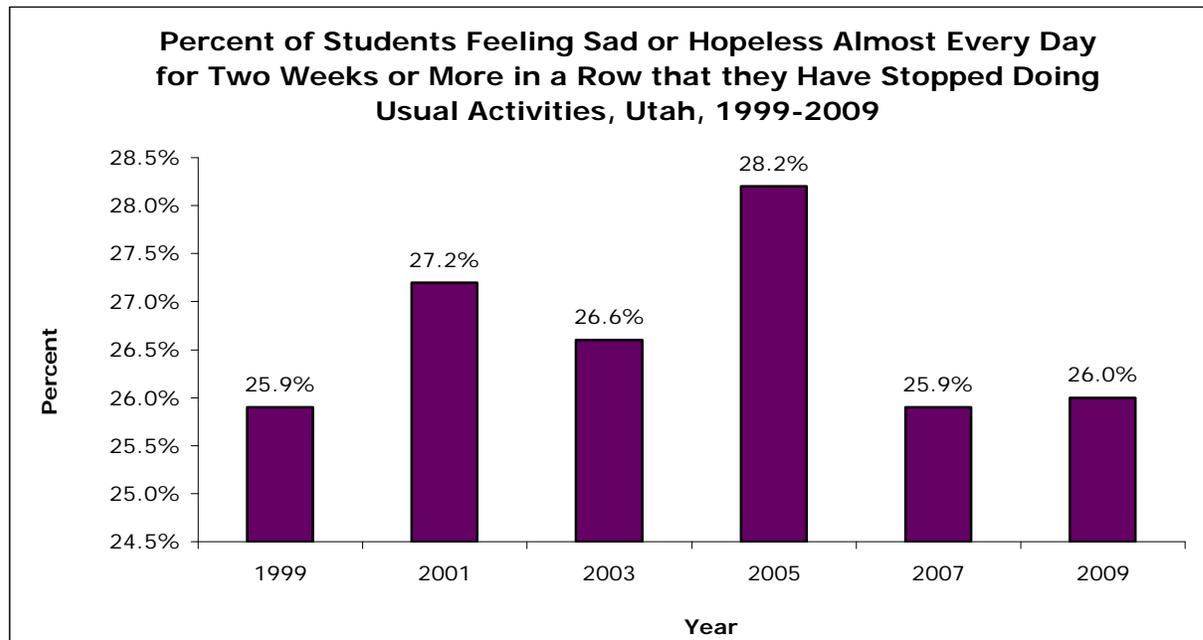
Data Sources

Utah Youth Risk Behavior Surveillance System, Utah Department of Health; Youth Risk Behavior Surveillance System, National Center for Chronic Disease Prevention and Health Promotion

Suicide

According to 2009 YRBS, 26% of Utah students reported to feel sad or hopeless almost every day for two weeks or more (see Figure 58). This percentage has remained stable since 1999. Higher percentage of female students reporting feeling sad compared to male students (32.8% vs. 19.4%). More than fifteen percent (15.4%) of students had seriously considered attempting suicide.

Figure 58



Data Sources

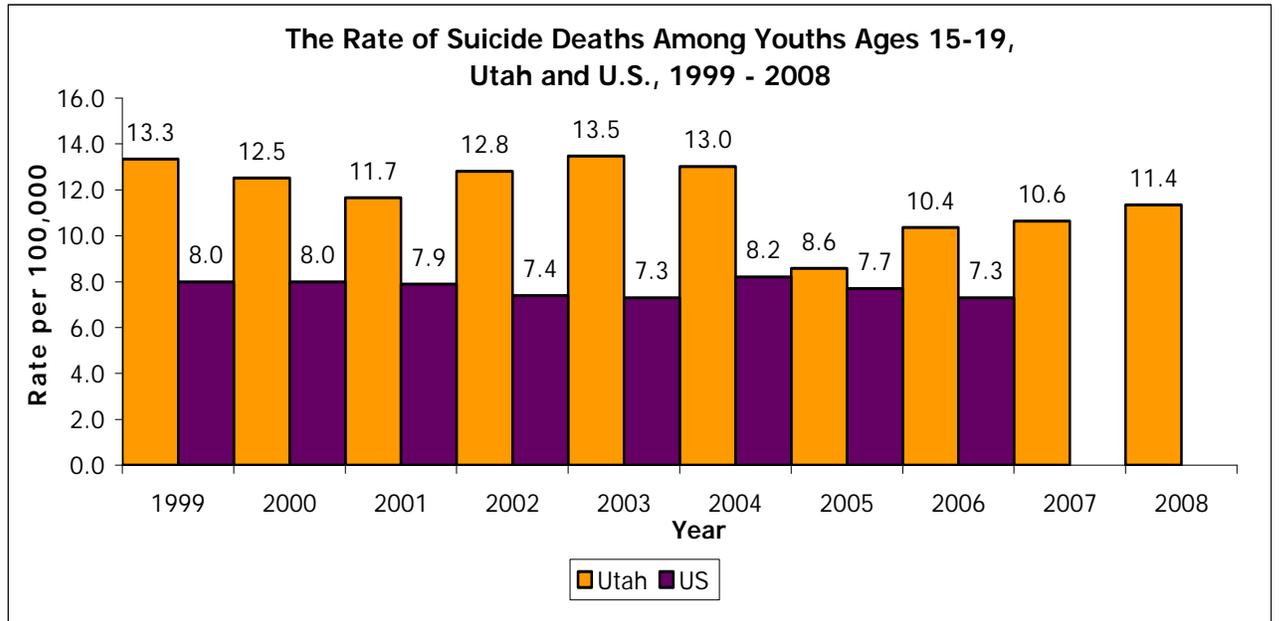
Utah Youth Risk Behavior Surveillance System, Utah Department of Health

Suicide continues to be the second leading cause of death among Utah residents 15-19 years; the rate in Utah is much higher than the national average (see Figure 59). From 2004 to 2008, suicide accounted for 26% of all deaths among Utah teens aged 15-19 years. Males accounted for 79% of these. Children ages 10 to 14 years old had the lowest suicide rates among males and females. The Utah baseline was 21.1 per 100,000 in 1997 (see Figure 60). Recent data show a decrease to 18.3 per 100,000 in 2008. Utah's goal is to reduce suicide deaths among adolescent males' ages 15-19 years to 10 per 100,000 by 2010.

In 2007, close to one in ten students (9.6%) reported attempting suicide one or more times during the past year. This rate was significantly higher than the U.S. rate of 6.9%. Suicidal ideation is defined as having thoughts of suicide or of taking action to end one's own life, with or without a suicide plan. YRBS data for 2007 also reveal that almost twelve percent (11.9%) of students reported having made a suicide plan during the past 12 months, more common among female students (14.1%) compared to male students (9.8%). The national rate for the same time frame was 11.3%.

Although teen suicide deaths are significantly higher for males, females were more likely to be treated in the hospital or emergency department for self-inflicted injuries than males. More people are hospitalized or treated in an emergency room for suicide attempts than are fatally injured. According to the 2009 Youth Risk Behavior Survey, during the past 12 months before the survey, 7.2% of Utah high school students report attempting suicide one or more times and 3.2% of these students suffered an injury, poisoning, or an overdose that had to be treated by a doctor or nurse (see Figure 61).

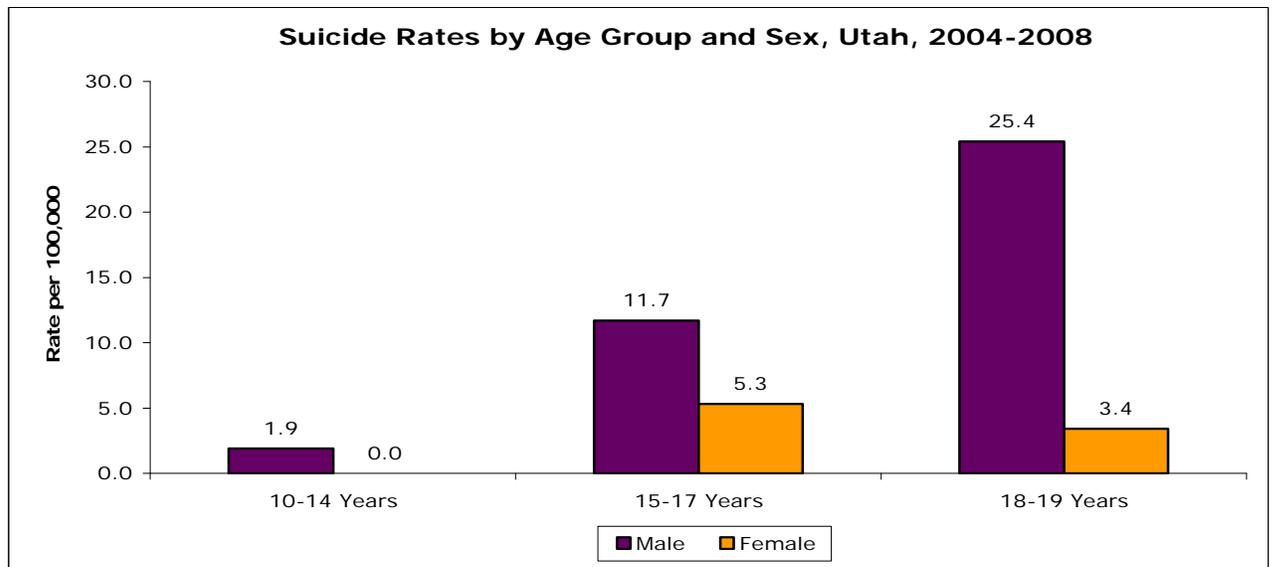
Figure 59



Data Sources

Office of Vital Records and Statistics, Utah Department of Health (Utah Death Certificate Database),
Population Estimates: Utah Governor's Office of Planning and Budget

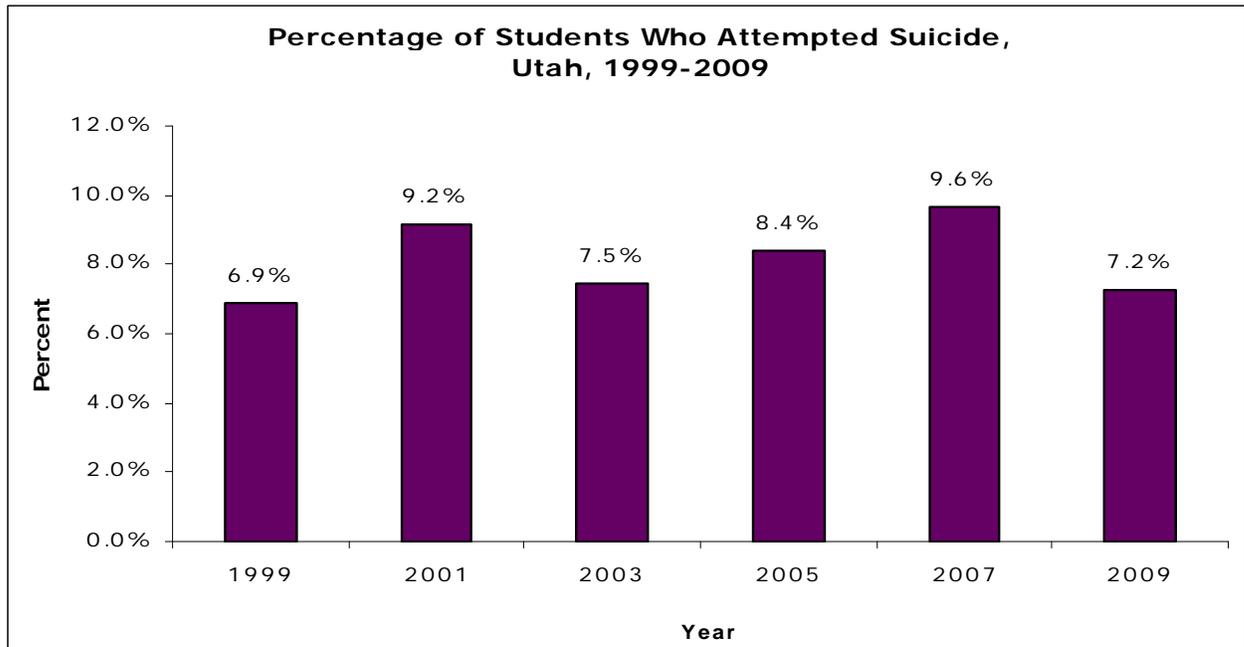
Figure 60



Data Sources

Office of Vital Records and Statistics, Utah Department of Health (Utah Death Certificate Database),
Population Estimates: Utah Governor's Office of Planning and Budget

Figure 61



Data Sources

Utah Youth Risk Behavior Surveillance System, Utah State Office of Education

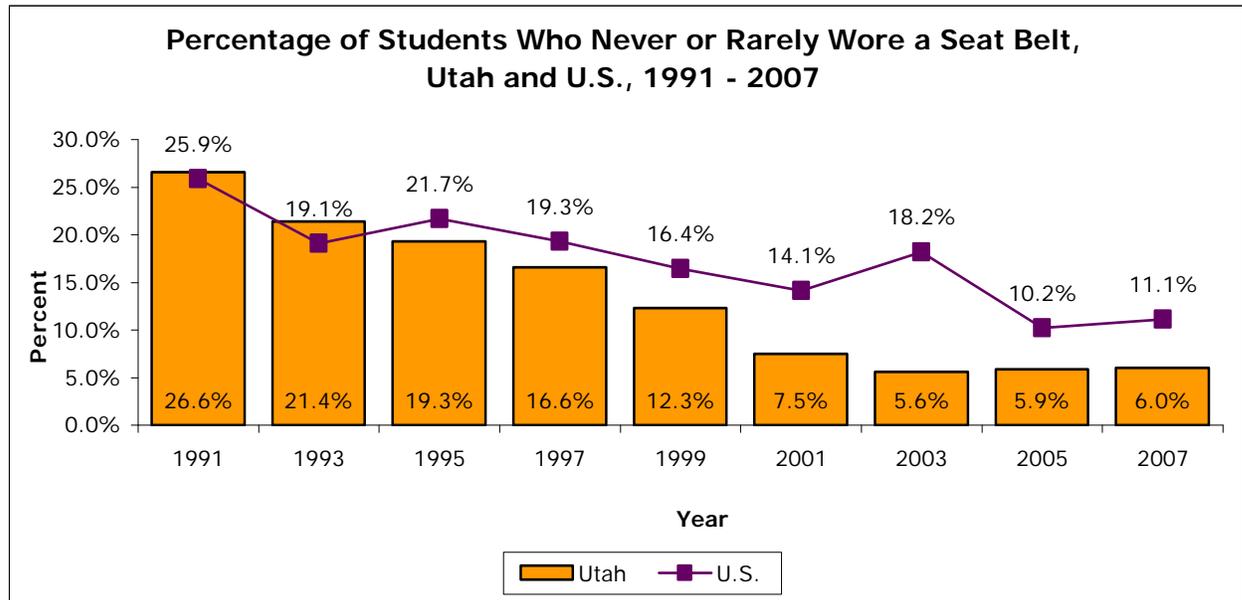
Safety Restraints

According to the National Highway Traffic Safety Administration (NHTSA) deaths and serious injuries caused by motor vehicle crashes could be reduced by approximately 50% with proper and consistent use of safety belts. NHTSA also found that the average inpatient cost for crash victims who were not wearing safety belts was 55% higher than for those who were restrained. In Utah, unbelted crash occupants were 20 times more likely to die in a crash than those wearing seat belts.

As part of the Youth Risk Behavioral Survey, high school students are asked about their seat belt use when riding in a car driven by someone else. In Utah, teen seat belt nonuse has remained steady ranging between 7.5% in 2001 to 6.0% in 2007 (See Figure 62). Utah's rate of infrequent seat belt use has been lower than the U.S. rate since 1995 and meets the Healthy People 2010 goal of 92% using seat belts in this age group.

Utah has not met the Healthy People 2010 target of 100% for child restraint use for children ages 4 and younger. The Utah Legislature has passed laws to increase the use of safety restraints and in 2000 they upgraded the law to make child safety seat use mandatory for children through age four. This legislation was an important step in improving the state's child passenger law since all safety experts recommend that children ride in an appropriate safety seat until they are approximately 80 pounds or 8 years of age.

Figure 62



Data Sources

Utah Youth Risk Behavior Surveillance System, Utah Department of Health; Youth Risk Behavior Surveillance System, National Center for Chronic Disease Prevention and Health Promotion

Adolescent Births

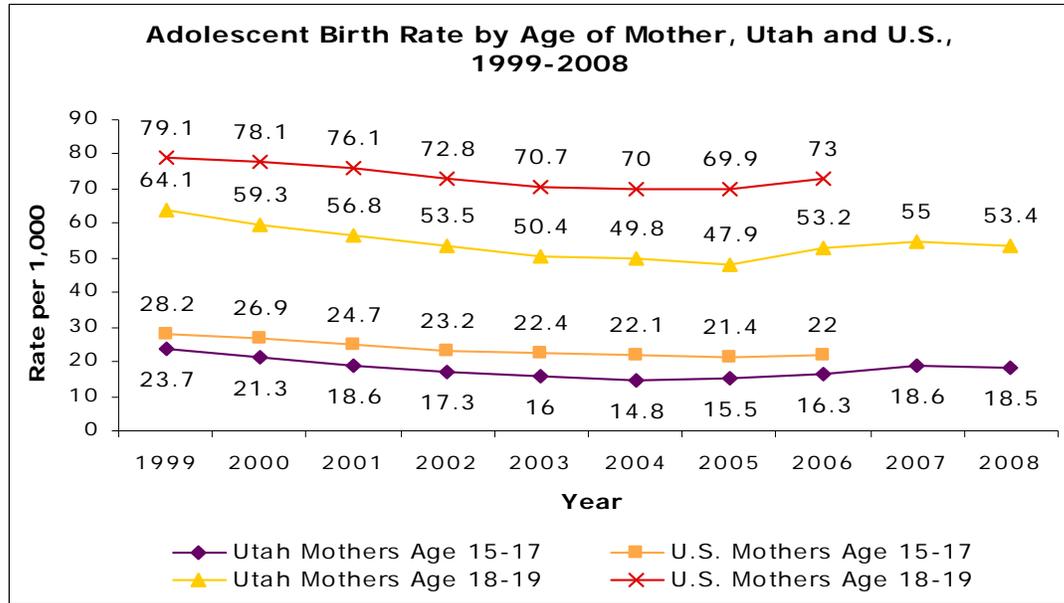
Research indicates that bearing a child during adolescence is associated with long-term difficulties for the mother, her child, and society. These consequences are often attributable to poverty and other adverse socioeconomic circumstances that frequently accompany early childbearing. For the mothers, giving birth during adolescence is associated with limited educational attainment which can reduce future employment prospects and earning potential. Compared to babies born to older mothers, babies born to adolescent mothers, particularly young adolescent mothers, are at higher risk of low birth weight and infant mortality. These babies are more likely to grow up in homes that offer lower levels of emotional support and cognitive stimulation, and they are less likely to earn a high school diploma.

In 2008, Utah’s teen birth rate was 33.8 per 1,000 females 15-19 compared to a national rate of 42.5 (see Figure 63). Utah's adolescent birth rate has been lower than the United States' overall rate over the past decade, but is higher than several other states.

Furthermore, there are 18 areas in Utah where adolescent birth rates exceed national rates. In the 2008 PRAMS, 80.8% of Utah women aged 15-17 and 62.5% of Utah women aged 18-19 reported their pregnancy as unintended. When broken down by race and ethnicity, the highest teen birth rates continue to occur among Hispanic/Latina girls between the ages of 15-19. In 2008, the Utah rate for Hispanic/Latina teens was 113.4 per 1,000 females aged 15-19.

Utah is an abstinence-based education state and does not allow the collection of sexuality information on the Youth Risk Behavior Survey leaving Utah with no formal statistics on adolescent sexual behavior other than birth date.

Figure 63



Data Sources

Utah Birth Certificate Database, Office of Vital Records and Statistics, Utah Department of Health; Population Estimates: Utah Governor's Office of Planning and Budget; National Vital Statistics System, National Center for Health Statistics, U.S. Centers for Disease Control and Prevention

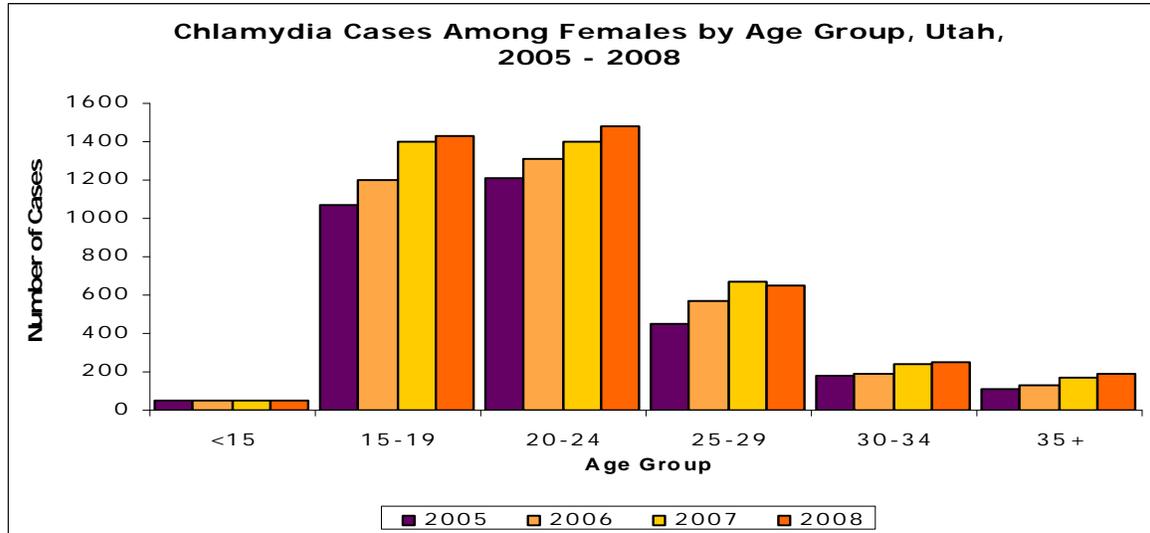
Sexually Transmitted Infections

Infection caused by the bacterium *Chlamydia trachomatis* is the most frequently reported notifiable disease in the U.S., with 1,108,374 cases reported in 2007. Nearly 71% of reported Chlamydia infections in the U.S. were among those 15 to 24 years of age. This is evident in Utah as well with 66% of Chlamydia cases being among same age group in 2008. Chlamydia infections in both men and women are commonly asymptomatic, yet screenings occurring mostly among females produce higher rates of reported infections. Females with Chlamydia infection are at risk for developing pelvic inflammatory disease (PID) both men and women may become infertile as a result of untreated Chlamydia infections, because they can damage the reproductive systems of both males and females. Susceptibility to more serious infections such as HIV also increases when an individual is infected with Chlamydia. In addition, pregnant women with Chlamydia can pass the infection to their infant during delivery, potentially resulting in pneumonia or neonatal ophthalmia.

Chlamydia rates in Utah have increased since 1992. In 2008, Utah had 6,147 reported cases of Chlamydia, a 6% increase from 2007 (5,821 cases) additionally, the number of cases has increased across all age groups except the less than 15 group (see Figure 64). Since 2004 rates have increased from 10.1% to 13.4% among women ages 15-19 (see

Figure 65). Ethnic minorities comprise 18% of Utah’s population yet made up 33% of those newly diagnosed with Chlamydia in 2008. This increase in rates can be attributed to improved screening efforts, use of increasingly sensitive diagnostic testing, efforts to increase reporting by providers and laboratories, and improved information systems for reporting. Such increased rates can be interpreted as progress in Chlamydia infection control as more infections are identified and treated, providing opportunity to intervene in reducing the spread of infection.

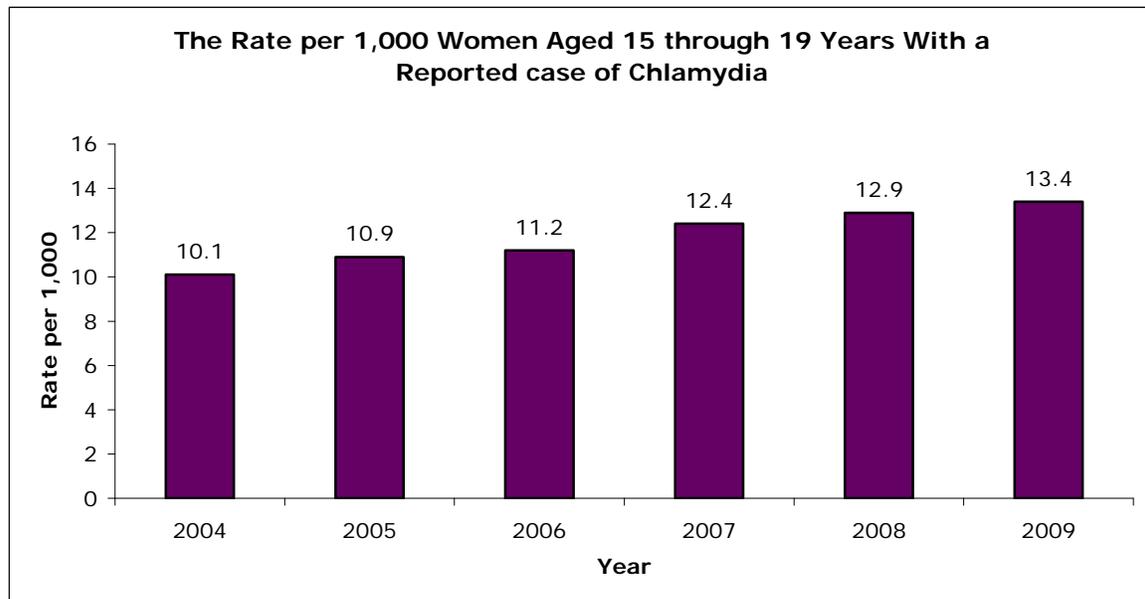
Figure 64



Data Source

Bureau of Epidemiology, STD Surveillance Program, Utah Department of Health

Figure 65



Data Source

Bureau of Epidemiology, STD Surveillance Program, Utah Department of Health

Gaps and Weaknesses of the System of Care for Children and Youth

Access to Health Care - The majority of maternal and child health services are provided through the private sector and managed care organizations. The 10 community health centers and the Wasatch Homeless Clinic provide primary care to underinsured and uninsured MCH populations. Six of these community health centers are located in rural areas of the state. Three migrant farm worker clinics are co-located with Wasatch Front community health centers and a fourth clinic is located in Brigham City. Unfortunately, many of Utah's Hispanic workers, especially along the Wasatch Front, are not engaged in farm work and therefore do not qualify for these services. Eight of the twelve local health departments continue to offer well child services. Whenever necessary, referrals are made to providers and/or clinics within the community for follow-up of identified health concerns, and the local health departments strive to assist families in identifying primary health care providers for their children. The Division has worked with the local health departments through a variety of programs to encourage them to foster medical homes for children and to redirect their resources from direct services to core public health functions. Medicaid's system of health care along the urban areas of the state is managed care or PPO type systems. Medicaid has experienced difficulty in maintaining MCOs willing to continue to contract for service coverage for Medicaid populations in the state due to economic crises that have forced some of the MCOs out of the Medicaid market. MCOs have spread to some rural areas of the state; however, Medicaid participants in rural areas do not have to enroll with a MCO for health care.

The public health system in Utah is hampered in providing services to all in need due to funding shortages, staffing shortages, and other challenges. Utah is faced with a growing population of families without insurance, especially those of undocumented citizenship status, placing a stress on a health care system with limited resources. Local health districts and community health centers in the state have been forced to place limits on the number of individuals seen due to limited resources. Limited resources also prevent hiring additional public health nurses to provide services at needed levels or more in-depth services to the maternal and child populations of the state, such as care coordination, home visiting services, and grief support to families that experience SIDS.

Health Insurance Coverage - Utah Healthcare Access Survey data indicate that the uninsured rate for children under 18 years of age increased from 6.8% in 2001 to 10.3% in 2006. Even though the most recent data show a decline, more than eight percent (8.4%) of children were uninsured in 2008 which is still higher than the 2004 rate of 8.2%. As the lead agency in public health, the Utah Department of Health is committed to reducing the numbers of uninsured children. More than a decade ago, state staff, along with many partners, provided the leadership to implement a state model Children's Health Insurance Program (CHIP) in 1998 to address the problem of uninsured children in Utah. Utah's CHIP is a state-designed program that provides health coverage to low-income children who are not eligible for Medicaid and who have limited or no health insurance. The Utah CHIP eligibility level is 200% FPL for children from birth to 18 years of age.

The 2003 Legislative session provided additional funds for needed programs and projects. Additional funding was appropriated for an increased enrollment of 12,000 children for CHIP, which will allow the program to maintain open enrollment. In 2002 only 29% of children enrolled in CHEC (Utah's EPSDT) had utilized dental services. However, utilization of dental services by children enrolled in CHIP was significantly higher at approximately 70%. We have hypothesized that the increased utilization among children enrolled in CHIP may be due to the fact that CHIP dental reimbursement rates are on the same level as those of the state government plan. Dentists are more willing to see children on CHIP because of the higher reimbursement rates compared to Medicaid's rates. Children on CHIP have greater access to dentists willing to provide care. Enrollment capacity has been increased to approximately 40,000 children with the increase in state funds for the program in 2005. CHIP open enrollment throughout 2009 may have contributed to an increase of 11.6%. As of December 2009 the CHIP enrollment was 41,748.

Utah CHIP provides greater access to affordable health insurance for children from many working families, primarily the working poor (at or under 200% of the federal poverty level). Policy and outreach efforts in Utah have enabled the state to enroll more children in Medicaid and reduce disenrollment in CHIP. The increase in state funds to the CHIP program has increased enrollment capacity to help meet the needs of uninsured children allowing for open enrollment. Strong partnerships, through the Covering Kids and Families Coalition, have explored legislative and agency rule changes that would improve the Medicaid and CHIP systems by dropping the asset test for children.

Increases in dental and prenatal provider reimbursement rates are vying with each other as well as other numerous competing budgetary requests and needs, with little budget relief in sight. Both groups of providers have approached the Medicaid Medical Advisory Committee to provide information on the need for higher compensation for care. The Division will continue to keep a pulse on these two important issues for mothers and children in Utah.

Financial barriers continue to exist for families and children whose condition and/or services are not covered by third party payers (e.g., pre-existing conditions, therapy, mental, orthodontia, dental and surgical exclusions). Limited provider panels offered through managed health care plans reduce accessibility to pediatric specialty care. CHIP has improved basic medical coverage for uninsured children but specialty services are not covered.

The new health reform law will increase access and extend health care coverage. The major feature of the bill is that insurance companies will no longer be able to refuse insurance for children and eventually adults with pre-existing medical conditions. It is expected that the new law will address many of the problems in Utah's health care coverage so that residents will be able to obtain and keep high-quality, affordable coverage that meets their needs. Since this law will be implemented over time and will not be fully in place until 2014, we will be tracking how this affects our uninsured children.

Provider Access - With Utah's large family size and low per capita income, economic constraints in utilizing and paying for health care are inevitable. Given the geographic makeup of the state, access to pediatric services in the rural communities is limited due to the lack of pediatricians. In fact 19 counties out of 29 have no pediatrician in their jurisdictions. Three more have a pediatrician to child population of 1: 5684. This leaves only 7 counties with pediatrician coverage that may or may not be adequate for the population size. In addition, ten counties in the state have a family physician to population ratio of 1:2964. So, access to pediatric care, either by a pediatrician or family physician is very limited in Utah.

Local health districts are short staffed and for rural and frontier districts, it is very difficult to find a nurse, registered dietician, and so forth due to the sparsity of the population in these areas. The health districts in the southeastern and southwestern part of the state encompass such a large geographic area that it is difficult to provide care in other parts of the district.

School nurses are few and far between in Utah with only six of the twelve health districts providing school nurses in their districts. In the past, most school nurses were employees of local health departments, but there has been a shift to school districts employing the nurses. This shift is both good and bad: good in that as an employee of the school district, school nurses have more authority than as employees of the local health department; bad in that the school nurses are not part of a health care agency to support them in their work. With budget cuts to all state agencies, school nurses are concerned that their positions may be eliminated. In the past year a large school district was cut in half leaving one of the districts with a large budget shortfall. This district is threatening to release 500 employees, which probably will include school nurses, from their employment. Residents in this district are protesting and asking the school district to raise taxes rather than lay off some many employees.

Other issues that school nurses face is that they may designate responsibility for certain health services as appropriate under the Nurse Practice Act and accompanying rules but maintain ultimate responsibility for the outcome. School nurses are expected more and more to do so to ensure school aged children get medications and other treatments without benefit of direct nurse oversight. Since Utah's Legislature has passed several bills requiring schools to administer medications, such as glucagon, school nurses are put in a very difficult position due to nurse practice act provisions on delegation of responsibilities. A large gap in the Department's capacity to address school health issues is funding for a school health consultant/school nurse consultant. Due to budget cuts, the position was eliminated several years ago.

The Department has formed a School Health Advisory Committee to assist in development of plans to address the health needs of children and youth in schools. Representatives from various entities were invited to participate on the Advisory Committee.

Mental Health - Mental health services for children may be difficult to access, especially for very young children. Pediatric psychiatrists are limited in the state, making it difficult to access these important providers for children, especially in complex cases of mental disorders. The mental health system in the state is based on community mental health centers located throughout the state, with Medicaid having carved out services to these centers. Perception has been that accessing services through the community mental health centers is very difficult unless the individual has significant complex long-term mental health disorders and is on Medicaid.

Mental health issues have been identified as one of the top priorities in the Stakeholder Survey. The scope of mental health concerns includes a variety of issues for mothers, children and adolescents related to primary prevention and screening. Issues that are included under mental health are positive youth development, self-esteem building, depression prevention, and suicide prevention. Utah continues to have higher suicide rates compared to the nation average. Suicide prevention remains a high priority for the Utah Department of Health which partners with a number of other agencies to develop strategies to address prevention, intervention and treatment.

Mental health screening and early recognition of issues are important services that will be promoted with primary care providers in order to get those in need into appropriate services and treatment if needed. Additionally, the Utah Pediatric Partnership to Improve Healthcare Quality, a joint project with funding from several sources including Title XIX, has engaged in provider training for pediatric practices to assist them in screening for social emotional delays in infants and toddlers.

Mental health providers, especially those specializing in children's mental health, are limited, in part due to the mental health system in the state which is a Medicaid carve-out serving primarily Medicaid chronically mentally ill, but not necessarily those with acute conditions.

Oral health and water fluoridation – The 2005 Utah Oral Health Survey indicated that 55.3% of 6 - 8 year old children in Utah had experienced dental caries compared to 53% nationally. The percentage of untreated dental caries among 6 - 8 year old Utah children, an important measure of access to dental care, was 21.4%, while the national rate is 29%. The survey also indicated that 45.1% of 8 year old children had at least one dental sealant compared to 32% nationally.

In November 2000, Salt Lake and Davis counties voted to fluoridate their water supplies, with implementation completed by October 2003 for most water districts. Water fluoridation in these two counties increased access to fluoridated water from 3% to 52% of the state's residents and 67% of the urban residents. However, only about 1% of Utahns residing in rural areas benefit from community water fluoridation or optimum levels of naturally fluoridated water. Water fluoridation has been hotly contested in the State Legislature with numerous bills approaching the issue from a variety of perspectives to try to undermine this important public health intervention for Utah

populations. Since Utah continues to have this as a contested issue, legislative bills and local ballots will be monitored in the future.

Needs of Minority Racial and Ethnic Populations

Utah led the nation in the proportion of mixed race growth in 2008. Refugee populations in Utah are growing, along with the Hispanic population. The growth in a non-English speaking population impacts the health care system's ability to adequately address the needs of the diverse populations, such as translation services and culturally sensitive health care. Because of this and other social factors (e.g., proportion of workers in "blue collar" jobs without health benefits, lack of trust in the health care system), the health status of ethnic/racial groups is often poorer than that of the white non-Hispanic population.

With the growing populations of children from ethnically diverse families, the health care system is challenged to address their needs. Language barriers, concern about accessing government services by parents who are not documented, even when their children are citizens, continue to be a barrier to health care coverage and access to services.

The Center for Multicultural Health (CMH) is working with state and local programs to address health disparities, improve cultural awareness in the health care community, and to develop strategies to improve health outcomes for the multicultural populations in the state. The CMH sponsors cultural competence training for local and state health staff.

The CMH developed "fact sheets" for each subpopulation, addressing key health needs of a population instead of approaching health issues for minority groups by disease categories. With these fact sheets, staff can focus more on the key health needs of each specific subpopulation. In addition, the Center provided cultural competence training for both state and local public health staff.

The Utah WIC Program has adapted to the cultural needs of the Hispanic population by modifying food packages, to include some individual preferences such as substituting beans for peanut butter when requested. Recipes using substituted beans are also available for participants. Many WIC clinics offer their classes in Spanish and have educational materials in Spanish. The local clinics have access to interpretive services, which allows for improved care to minority populations. WIC participants who speak only Spanish and have no designated primary care provider are referred to a Spanish-speaking provider when available.

Local health departments and community health centers have worked to hire bilingual health professionals to better meet the needs of their changing client population. Since the major ethnic group in Utah is Hispanic, clinics have attempted to address the needs of the Hispanic population through hiring of bilingual staff. However, there are other groups in the state that are growing in numbers that are hard to reach due to language barriers, cultural barriers, and provider acceptability. Much remains to be done in this

arena. Staff needs more training on cultural awareness and it needs to be recognized that cultural sensitivity incorporates more than language, country of origin, or skin color.

Strengths of the System of Care for Children and Youth

Utah children are healthier than their national counterparts in general and exceed national averages in a number of health indicators. With the low rate of tobacco use along with alcohol, children in Utah live by and large in healthy family environments.

Utah is fortunate to have quality health care providers and centers in the Wasatch Front area of the state. We have a number of highly skilled health care providers that are sought after by others outside the state. With surrounding states having little to no capacity to handle high risk infants and children, Utah often cares for these children.

The partnerships that have developed over the years with stakeholders, colleagues, peers have been phenomenal. We work very closely with the University of Utah Pediatrics Division and with Primary Childrens Medical Center. Partnerships with others are described in Section E of the Annual Application and Report document and Section 2 of the Needs Assessment document.

With Medicaid and CHIP as sister Divisions, we have a close working relationship with staff. We support each other in our work and keep Medicaid and CHIP staff apprised of changes in standards of care, etc. as needed.

Other strengths of the system are that the Utah Department of Health is collaborating with several organizations, under the leadership of the Utah Chapter of the American Academy of Pediatrics to improve health care services for children through primary care provider education and quality improvement projects. This project, the Utah Pediatric Partnership to Improve Healthcare Quality, provides an opportunity for practices to improve components of well child visits, developmental screenings, and social-emotional screenings for infants and young children. The process involves an initial learning session followed by conference calls, follow-up calls, chart audits, and technical assistance visits for a group of practices around a specific topic. While results vary across the individual practices, results from the group of practices are demonstrating improvements such as an increase from an initial two out of ten practices to nine practices out of ten using standardized social-emotional screening tools. The downside of this successful collaborative project is that it is dependent on soft funding at this time.

Health Status of Children and Youth with Special Health Care Needs

Prevalence of Children with Special Health Care Needs

The prevalence of children with special health care needs in Utah is between 11% and 14.6% for children birth to-17 years of age, based on the 2005 National CSHCN survey and the 2007 National Survey of Children's Health respectively, see tables 16 below. The National Children Survey shows that 11% of all Utah children have some special

health care need, and nearly 20% of all Utah households have one or more children with a special health care need.

Table 16. Prevalence of Children with Special Health Care Needs, Utah and US, 2001 and 2005/06

	Utah (2005/06)	Utah (2001)	US (2005/06)	US (2001)
% of CSHCN among children birth to 17 years	11.0	11.0	13.9	12.8
Number of CSHCN birth to 17 years	82,502	79,832	10,200,000*	9,400,000*

Data Sources

Child and Adolescent Health Measurement Initiative. *2001, 2005/06 National Survey of Children with Special Health Care Needs*, Data Resource Center for Child and Adolescent Health website.

* Approximate Estimate

Table 17. Prevalence of Children with Special Health Care Needs, Utah and US, 2003 and 2007

	Utah (2007)	Utah (2003)	US (2007)	US (2003)
% of CSHCN among children birth to-17 years	14.6	15.5	19.2	17.6
Number of CSHCN birth to-17 years	118,912	114,290	73,800,000*	72,800,000*

Data Sources

Child and Adolescent Health Measurement Initiative. *2003, 2007 National Survey of Children's Health*, Data Resource Center for Child and Adolescent Health website.

* Approximate Estimate

Prevalence of CSHCN: Demographic Characteristics

The prevalence of Utah CSHCN by demographic characteristics is shown in Table 16. Although Utah's prevalence is lower than the national rate of 13.9%, the differences between the two rates narrows as children get older.

The percentage of Utah families of children and youth with special needs who live at or below 200% of poverty is lower than the National average. Factors for this might include Utah's relatively stronger economy, and lower unemployment rates compared to the national figures.

Utah's general population is predominantly white (97.9%), with Hispanic residents comprising the largest minority population (12.0%). The Utah Hispanic population continues to grow at a faster rate compared to the state's population as a whole (see table 18). Although the CSHCN survey data shows a decrease in the number of Hispanic families, this is probably a limitation of the survey rather than a trend.

Table 18. Prevalence of CSHCN, Utah, U.S. 2001, 2005/06

Prevalence of CSHCN, Utah	Utah % 2005/06	Utah % 2001	US % 2005
Age			
Age birth to 3 years	5.0	4.4	7.2
Age 4 to 7 years	9.8	8.2	13.2
Age 8 to 11 years	12.5	13.2	16.5
Age 12 to 14 years	15.0	14.2	16.7
Age 15 to 17 years	16.9	17.9	16.9
Sex			
Male	12.5	12.0	16.1
Female	9.4	9.9	11.6
Poverty Level			
0-99% FPL	8.7	12.4	14.0
100-199% FPL	10.6	11.7	14.0
200-399% FPL	11.1	10.5	13.5
400% FPL or more	12.3	11.5	14.0
Hispanic Origin and Race			
Non-Hispanic	11.3		15.0
White	11.5	11.5	15.5
Black	11.3*	12.4	15.0
Asian	---	---	6.3
American Indian/ Alaskan Native	---	---	14.3
Native Hawaiian/ Pacific Islander	---	---	11.5
Multiple Races	10.6	14.4	17.9
Other	10.4		8.2
Hispanic	6.7	7.5	8.3
Spanish Language Household	2.7		4.6
English Language Household	12.3		13.1
Primary Language Spoken			
English	96.7		95.1
Any other language	3.3		4.9

Data Sources

Child and Adolescent Health Measurement Initiative. *2005/06 National Survey of Children with Special Health Care Needs*, Data Resource Center for Child and Adolescent Health website.

* Estimates cannot be determined accurately, sample sizes too small to meet standards for reliability or precision.

--- Estimate suppressed as it does not meet the standard for reliability or precision, group does not make up at least 5% of total population of children in the State.

Overall Health Status of Children with Special Health Care Needs

Utah data from the National Survey of Children's Health in Table 19 show that compared with children without special health care needs, CSHCN have significantly poorer health; more moderate or severe health problems; miss more school due to illness or injury; have more concerns regarding learning, development or behavior and have more difficulties with emotions, concentration, behavior and getting along with others.

Table 19. Overall Comparison of Health Status of Children with and without Special Health Care Needs, Utah, 2007

	% Children WITH Special Health Care Needs	% Children WITHOUT Special Health Care Needs
Children whose overall health is excellent or very good	74.3	92.8
Children with health conditions rated as moderate or severe by parents	43.2	2.6*
School age children who missed 11 or more days of school in past year due to illness or injury	9.8	3.6
Parents have one or more concerns about child's physical, behavioral or social development (age 4 months to 5 years)	69.1	34.2
Received BOTH preventive medical and dental care	69.0	34.1

Data Sources

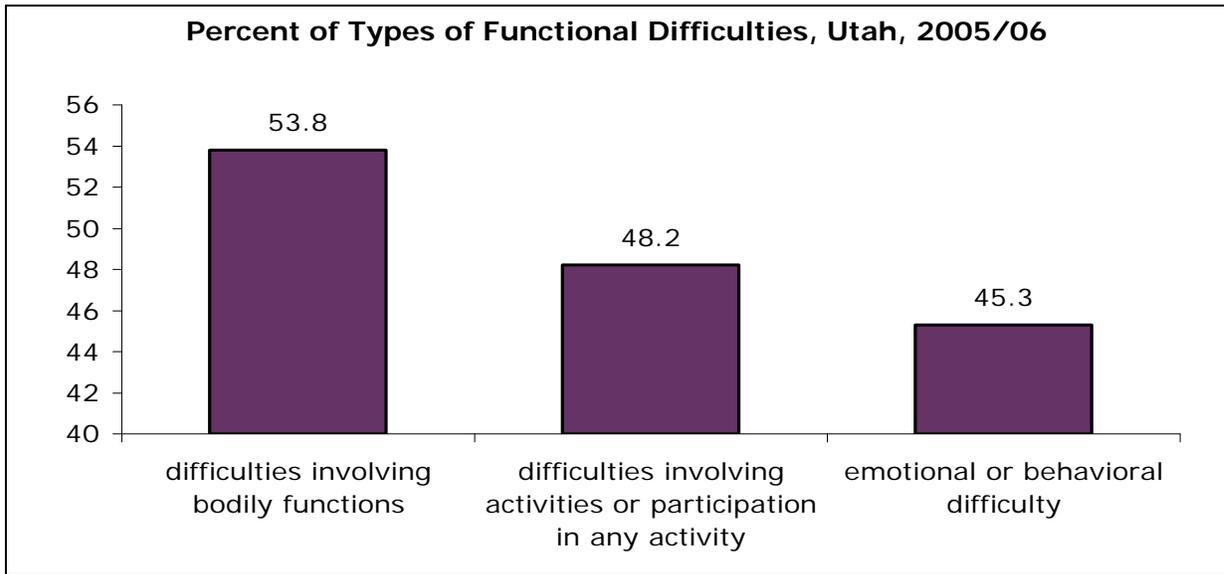
Child and Adolescent Health Measurement Initiative. *2007 National Survey of Children's Health*, Data Resource Center for Child and Adolescent Health website.

* Estimates cannot be determined accurately, sample sizes too small to meet standards for reliability or precision.

Functional Difficulties

The National CSHCN survey captures information on children with special needs by looking at the level and type of impact the conditions have on the child. This information is as important or perhaps more important than looking only at the child's specific condition to evaluate the consequences the child's chronic condition. Even though children and of youth may have widely differing diagnoses, there are many similarities in the impact these conditions have on the individual and family, depending on severity, age at diagnosis, access to treatment, access to health insurance, access to family support and finally having a usual source of health care or Medical Home.

Figure 66



Data Sources

Child and Adolescent Health Measurement Initiative. *2005/06 National Survey of Children with Special Health Care Needs*, Data Resource Center for Child and Adolescent Health website.

Common Health Conditions

The health conditions most frequently reported in the National CSHCN survey are allergies, asthma, depression and anxiety. All conditions reported are equal to or lower than national rates, except depression/anxiety. The National CSHCN survey provides some information on the health conditions of CSHCN, although due to the small Utah sample size, only certain conditions prevalence rates are reported at high enough numbers to be deemed reliable.

Table 20. Percent of CSHCN with Selected Health Conditions, Utah and US, 2005/06

	Utah	US
Allergies (Any Type)	48.4 (est. 39,726)	53.0
Asthma	35.3 (est. 29,042)	38.8
Depression, anxiety, eating disorder or other emotional problem	28.5 (est. 23,377)	21.1
Attention deficit disorder or attention deficit hyperactivity disorder	27.5 (est. 22,322)	29.8
Migraine or frequent headaches	13.6 (est. 11,135)	15.1
Mental retardation or developmental delay	11.9 (est. 9,838)	11.4
Allergies (food only)	9.3 (est. 7,547)	11.0

Data Sources

Child and Adolescent Health Measurement Initiative. *2005/06 National Survey of Children with Special Health Care Needs*, Data Resource Center for Child and Adolescent Health website.

Access and Overall Quality of the System of Care

The overall comparison of system of care indicators between Utah and the nation is shown in Table 21. Utah children had more conditions affecting their activities and missed more school days compared to children across the nation. They also reported having more difficulties in maintaining health insurance throughout the year: 11.4% of children in Utah had no insurance at one point during the year compared to 8.8% of children nationally. Inadequacy of insurance was slightly higher among Utah children at 34.1% versus 33.1% nationally. Utah families reported higher unmet needs for accessing health care and family support services. They reported they spend more out of pocket than their national peers, and that their child's condition causes more financial burden for the family. Conversely, they spend less time caring for their affected child and they report missing less work than the national cohort does.

Table 21. Overall Comparison for Children with Special Health Care Needs, Utah, 2005/06

Indicator	Utah %	National %
Child Health		
CSHCN whose conditions affect their activities usually, always, or a great deal	28.1	24.0
CSHCN with 11 or more days of school absences due to illness	16.4	14.3
Health Insurance Coverage		
CSHCN without insurance at some point in the past year	11.4	8.8
CSHCN without insurance at time of survey	4.2	3.5
Currently insured CSHCN whose insurance is inadequate	34.1	33.1
Access to Care		
CSHCN with any unmet need for specific health care services	20.2	16.1
CSHCN with any unmet need for family support services	8.4	4.9
CSHCN needing a referral who have difficulty getting it	19.0	21.1
CSHCN without a usual source of care when sick (or who rely on the emergency room)	4.0	5.7
CSHCN without any personal doctor or nurse	5.0	6.5
Family-Centered Care		
CSHCN without family-centered care	31.4	34.5
Impact on Family		
CSHCN whose families pay \$1,000 or more out of pocket in medical expenses per year for the child	26.4	20.0
CSHCN whose conditions cause financial problems for the family	22.1	18.1
CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care	7.8	9.7
CSHCN whose conditions cause family members to cut back or stop working	19.9	23.8

Data Sources

Child and Adolescent Health Measurement Initiative. *2005/06 National Survey of Children with Special Health Care Needs*, Data Resource Center for Child and Adolescent Health website.

Birth Defects

Birth defects affect an estimated 1 of every 33 newborns in Utah or 1,500 babies every year. Birth defects are also the leading cause of infant death in Utah a major determinant of pediatric hospitalizations, and a contributor to prematurity rates. Utah shares several birth defects patterns with the rest of the nation, but it is also different. Utah has the highest rate in the U.S. of cleft lip and cleft palate (1 in every 450 births). Several birth defects are increasing in Utah: malformations of the penis (hypospadias) and a specific malformation of the abdomen (gastroschisis). Of particular concern is the increased defects of the brain and spine (such as spina bifida), unlike most of the US where these defects are decreasing.

The medical costs for spina bifida have been estimated at \$50,000 during the first year of life alone and over \$600,000 in lifetime costs per child. In Utah more than half of babies born with birth defects are enrolled in Medicaid during their first year of life. For these reasons, birth defects are considered a high public health priority.

Table 22. Selected Birth Defects Counts and Birth Prevalence, Utah and US, 1999-2006

Defects	Utah [†]		US [‡]	
	Average annual no. of cases	Birth prevalence*	Average annual no. of cases	Birth prevalence*
Central nervous system				
Anencephalus	12	2.32	1,009	2.51
Spina bifida without anencephalus	22	4.40	1,477	3.68
Cardiovascular				
Transposition of great arteries	15	2.87	1,901	4.73
Tetralogy of Fallot	19	3.81	1,574	3.92
Atrioventricular septal defect (also known as endocardial cushion defect)	29	5.62	1,748	4.36
Hypoplastic left heart syndrome	18	3.46	975	2.43
Orofacial				
Cleft lip with and without cleft palate	68	13.31	4,209	10.47
Cleft palate without cleft lip	37	7.31	2,567	6.39
Musculoskeletal				
Upper limb defect	31	6.01	1,521	3.79
Lower limb defect	9	1.85	763	1.90
Gastroschisis	27	5.22	1,497	3.73
Chromosomal				
Down syndrome	78	15.40	5,132	12.78

Data Sources

Utah Birth Defects Program, 2009 per 10,000 live births [†] estimates based on pooled data from birth years 2002-2006 estimates based on pooled data from birth years 1999-2001 Note: Due to variability in the methods used by state birth defects surveillance systems and differences in populations and risk factors, state prevalence estimates may not be directly comparable with national estimates or those of other states.

Autism

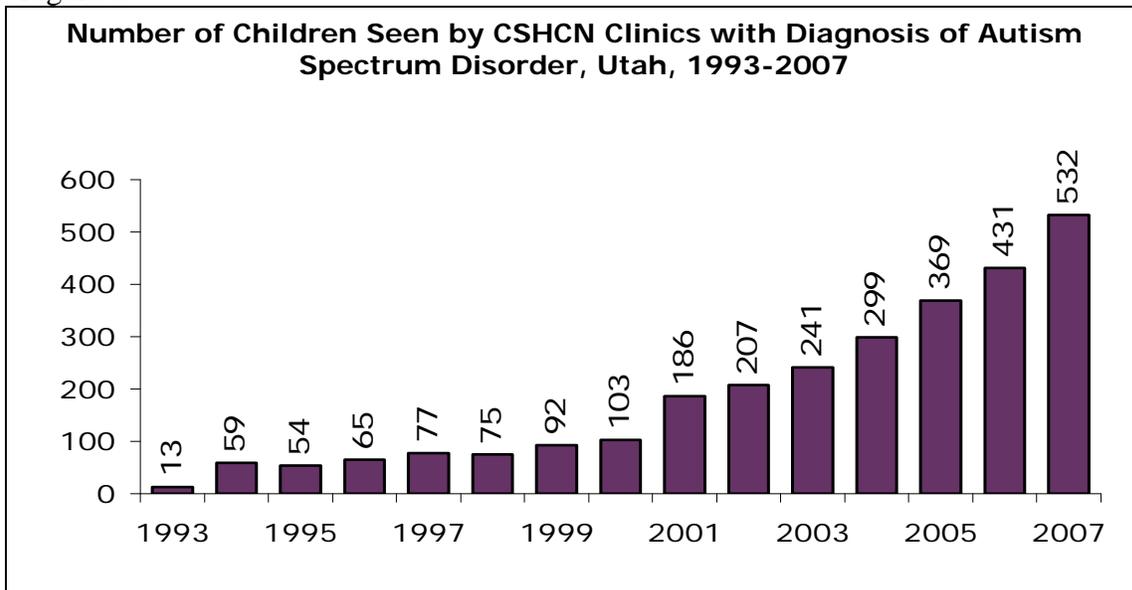
The diagnosis of Autism Spectrum Disorder (ASD) in Utah continues to require increased need for evaluation and therapeutic services. Utah's health code mandates the reporting of ASD cases. The state has the Utah Registry for Autism and Developmental Disabilities (URADD) which conducts ongoing surveillance studies.

The most current program prevalence information available based on 2002 data:

- 1 out of every 133 children in Utah has the diagnosis of an ASD
- A boy is 6 times more likely than a girl to develop an ASD
- Older mothers are 1.6 times more likely to have a child with an ASD
- First born children are 1.2 times more likely to have an ASD

Diagnostic, multi-specialty clinics provided through the CSHCN programs throughout the state have continued to see an increase in the number of children with a diagnosis of an ASD (Figure 67), both in the metropolitan Salt Lake area and outside the Salt Lake area.

Figure 67



Data Sources

Utah CSHCN Bureau Data, Megawest Billing System

Health Conditions of Extremely Premature Infants Utah

The Utah Neonatal Follow up Program (NFP) provides clinical screening and follow-up for all newborn ICU graduates with a birth weight less than 1500 grams. The database for the NFP provides information on the prevalence and types of disability in these very low birth weight babies. Information is shown in Table 23 for the infants seen between

2001 and 2005. Generally, for these infants, the risk for long-term disability increases as gestational age decreases.

Table 23. Condition of Extremely Premature Children Seen by the Neonatal Follow-Up Program, 5 year follow-up, Utah, 2001 thru 2005

		2001-2005 <27 weeks gestation n=221
Average birth weight		732 grams
Average gestational age		25 weeks
Average Newborn Intensive Care Unit (NICU) stay		118 days
Normal mental development		56%
Tested in the MR range		33%
Average mental development score		84
Children anticipated to need special education services		44%
Cerebral palsy		13%
Blind in one or both eyes		4%
Sensor neural hearing loss		4%
Demographics		
Gender	Males	57%
	Females	43%
Race / Ethnicity	White	78%
	Hispanic	18%
	Other	4%
	Black	2%

Data Sources

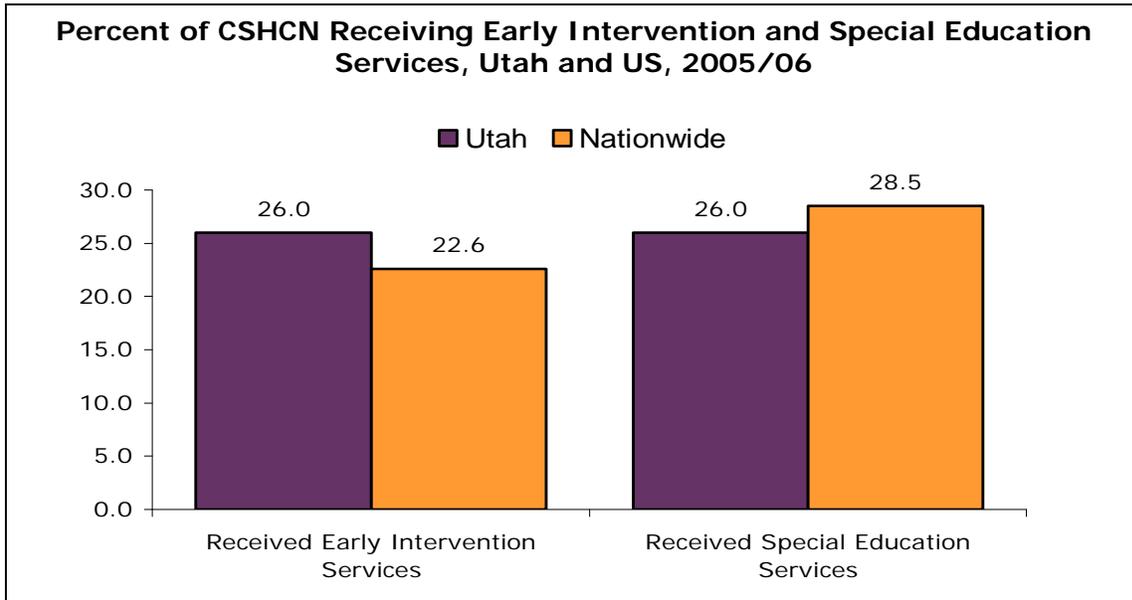
Utah neonatal follow-up program, 2001-2005

Children Age Birth to 3 Years Served Under Part C of IDEA

According to the National Survey of CSHCN, in Utah, 26% of the children birth to 2 years of age received Early Intervention services, a slightly higher rate compared to 23% of children birth to 2 years nationally. Utah children in older age groups conversely received fewer Special Education services (26%) than their national counterpart (29%). This difference probably is due to different eligibility criteria for Part B and Part C programs. Utah Special Education program eligibility requirements are generally more restrictive than those of the BabyWatch Early Intervention Program (BWEIP). Utah's early intervention program for children birth to 3 years, BabyWatch Early Intervention Program (BWEIP) reports conditions of the children they serve in Table 24. The most common conditions in this population are expressive language and motor delays followed by specific medical diagnoses. To be eligible for Utah services, a child must have at least

a moderate delay in one area of development or a diagnosed condition that has a high probability of delay such as: Down syndrome or other chromosomal abnormality, hearing or vision loss, spina bifida, congenital disorders, cerebral palsy or autism spectrum disorder.

Figure 68



Data Sources

Child and Adolescent Health Measurement Initiative. 2005/06 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website.

Table 24. Reason Children Age Birth to-3 Years were Referred for Early Intervention Services, Utah, July 1, 2008 thru June 30, 2009

Area of Delay Concern	Number of Referred Children	% of Referred children
Expressive Language	3348	60
Motor (fine/gross)	1613	29
Medical Concern/Diagnosis	1320	24
Receptive Language	647	12
Adaptive	494	9
Social/Emotional	395	7
Hearing	321	6
Other Concerns	185	3
Cognitive	178	3
Vision	151	3

Data Sources

Utah data from Program BabyWatch Early Intervention Program Report, July 1, 2008 until June 30, 2009

Children and Youth Age 3-21 Served Under Part B of IDEA

Table 25 displays disability categories of children and youth served under Part B of IDEA. For children age 3-5, the most common categories of disability are developmental

delays and speech or language impairments. For youth age 6-21 years, the most common categories are speech and language disabilities followed by speech or language impairment.

Table 25. Disability Categories for Children Receiving Special Education, Part B of IDEA, Utah, 2009

Disability	% Children Served Age 3-5 years	% Population Age 6 – 21 years
Autism	4	5
Deaf-Blindness	0	0
Developmental Delay	46	3
Emotional Disturbance	0	4
Hearing Impairment	1	1
Mental Retardation	1	5
Multiple Disabilities	2	3
Orthopedic Impairment	0	0
Other Health Impairments	1	7
Specific Learning Disability	0	49
Speech or Language Impairments	43	21
Traumatic Brain Injury	0	0
Visual Impairments	0	0

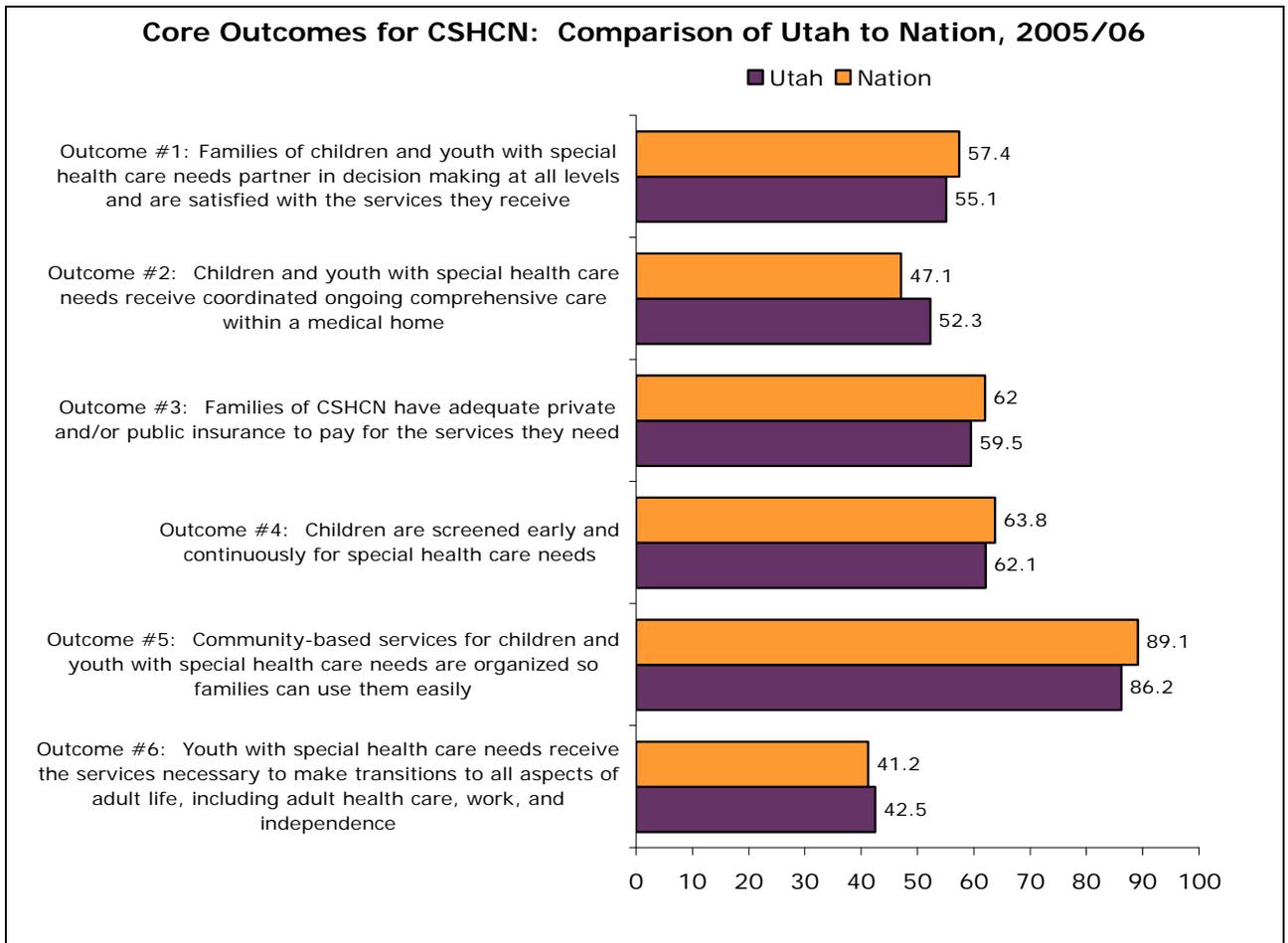
Data Sources

Utah State Office of Special Education, Report of Children Receiving Special Education, www.schools.utah.gov

CSCHN Core Outcomes

The National Survey of CSHCN makes information available on the six core outcomes for CSHCN. Overall, Utah's rates are similar or higher to National rates in all six outcome areas. Utah's Medical Home outcome rate was higher than the National rate, but the rate is not significant. Transition to adult health care in Utah, as in the Nation is relatively low, compared to the other five outcomes. The CSHCN Surveys data from 2001 and 2005/06 are only comparable in two of the six Core Outcomes: Families collaborate in decision-making and are satisfied with the services they receive and families have adequate private or public insurance to pay for the services they need. Questions and data from the two surveys for all other outcome measures were dissimilar enough to make them incomparable.

Figure 69



Data Sources

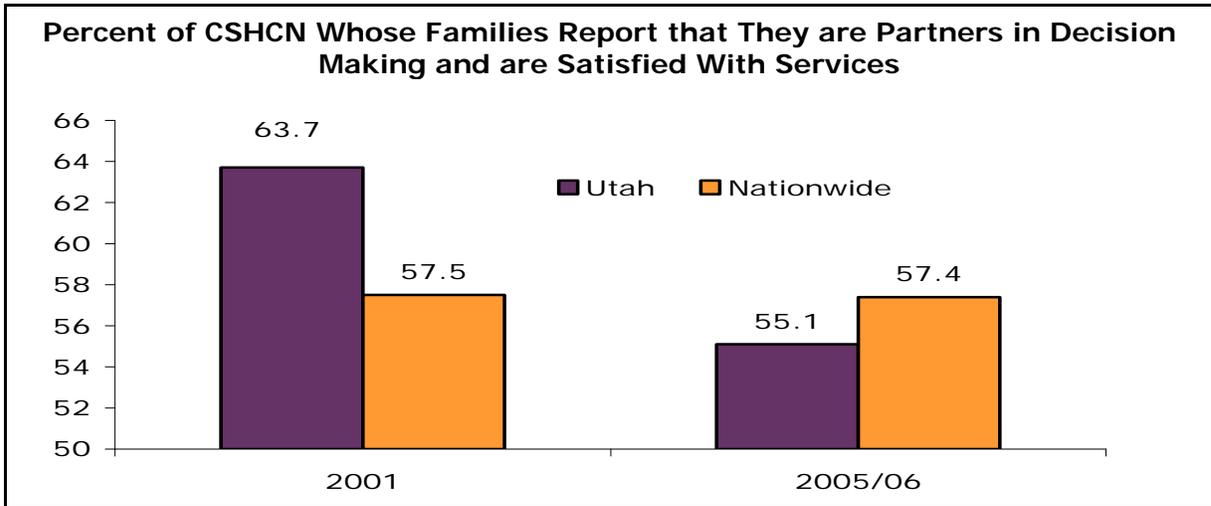
Child and Adolescent Health Measurement Initiative. *2005/06 National Survey of Children with Special Health Care Needs*, Data Resource Center for Child and Adolescent Health website.

CSHCN Core Outcome 1: Family Partnership in Decision-Making and Satisfaction

A comparison of Utah families surveyed in 2000 and families in 2005/06 surveys shows a lower percent of families report that they partner in decision making and are satisfied with the services their child receives. This outcome was evaluated using two questions from the National CSHCN Survey in 2005/06:

- Whether the doctor makes the parent feel like a partner in the child’s care
- The parent’s level of satisfaction with the child’s health services.

Figure 70



Data Sources

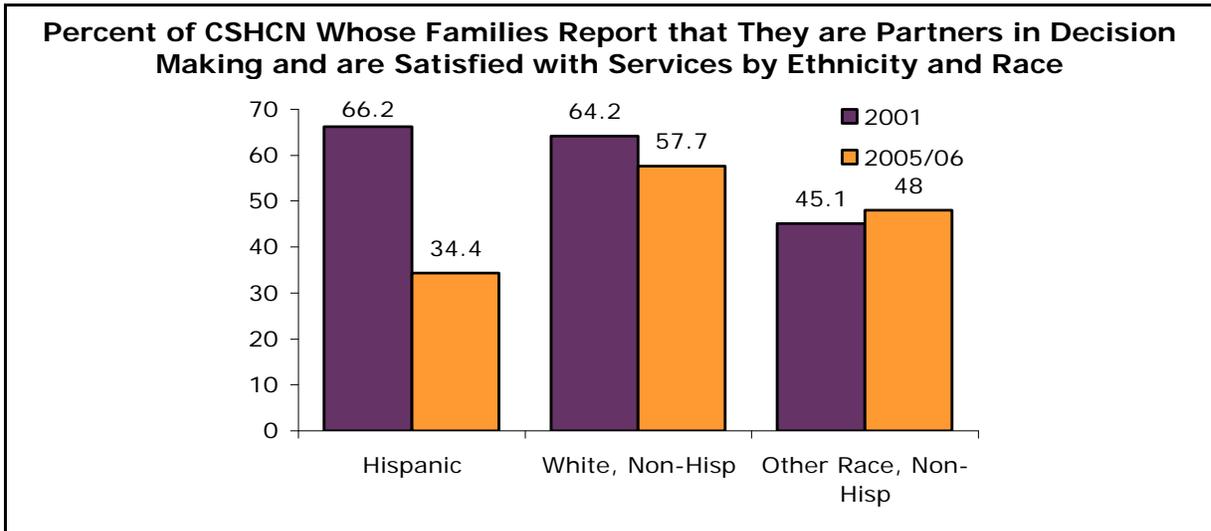
Child and Adolescent Health Measurement Initiative. *2005/06 National Survey of Children with Special Health Care Needs*, Data Resource Center for Child and Adolescent Health website.

Children whose parents reported that they usually or always feel like a partner and that they are very satisfied with care were considered to meet the overall criterion. Utah families reported achieving this outcome (55%) at a slightly lower percentage than national report of 57%.

Although the national rate of families for this indicator remained static, 2001 (57.5%) to 2005/06 (57.4%), Utah showed a decrease in satisfaction in this area for all families.

Hispanic families demonstrated a dramatic decrease in satisfaction in this area between 2001 and 2005/06. White, non-Hispanic families also were less satisfied. Other Utah non-white and non-Hispanic race responses were combined to be more reliable and demonstrated a slight increase.

Figure 71



Data Sources

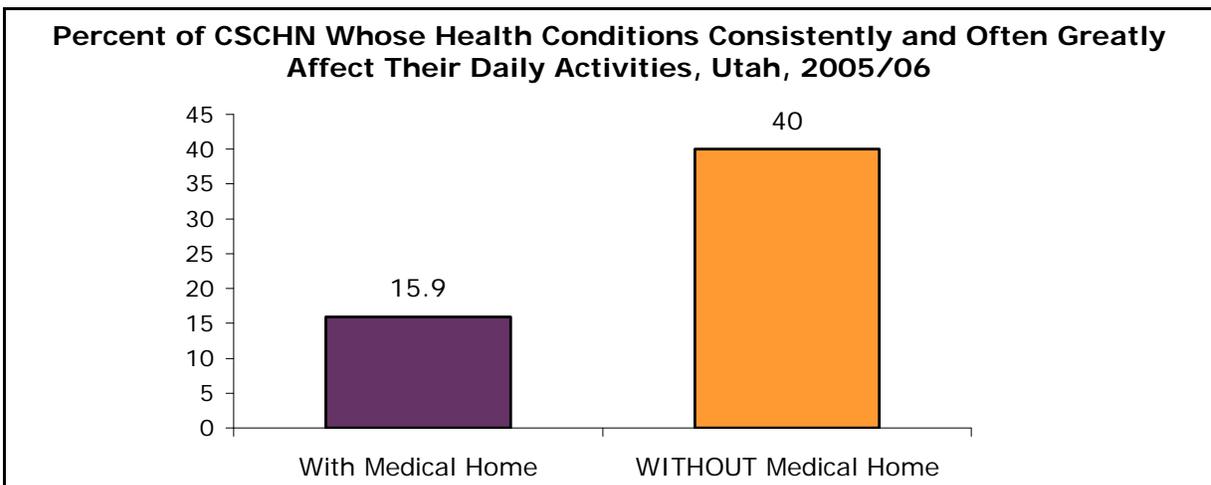
Child and Adolescent Health Measurement Initiative. *2005/06 National Survey of Children with Special Health Care Needs*, Data Resource Center for Child and Adolescent Health website.

CSHCN Core Outcome 2: Comprehensive Care through a Medical Home

Utah CSHCN Bureau continues to increase the number of trained medical home practices for CSHCN. As of 2010, there are 23 medical home practices that have received training through the Utah Medical Home Collaborative Project.

Although the affects of health conditions on children remains fairly consistent across categories, children without a medical home are affected significantly more by health conditions affecting their daily activity (see Figure 72).

Figure 72



Data Sources

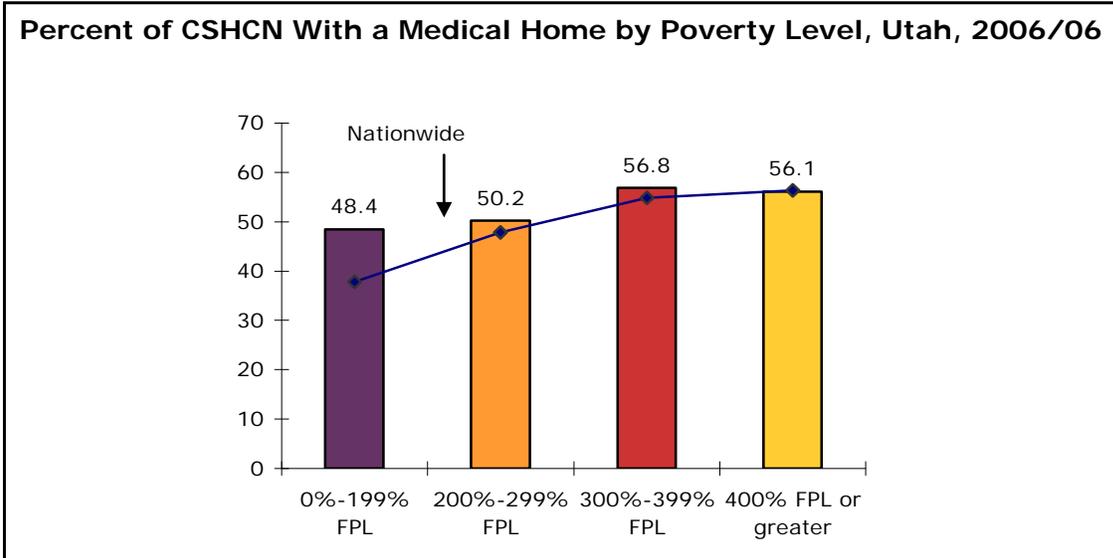
Child and Adolescent Health Measurement Initiative. *2005/06 National Survey of Children with Special Health Care Needs*, Data Resource Center for Child and Adolescent Health website.

Utah Department of Health, 2010 MCH Needs Assessment

Utah families by income level report an equal or higher rate of having a medical home than national families in all but the highest reported income brackets (see Figure 73).

Utah children with special needs with a medical home are less likely to miss seven or more days of school due to illness (see Figure 74).

Figure 73

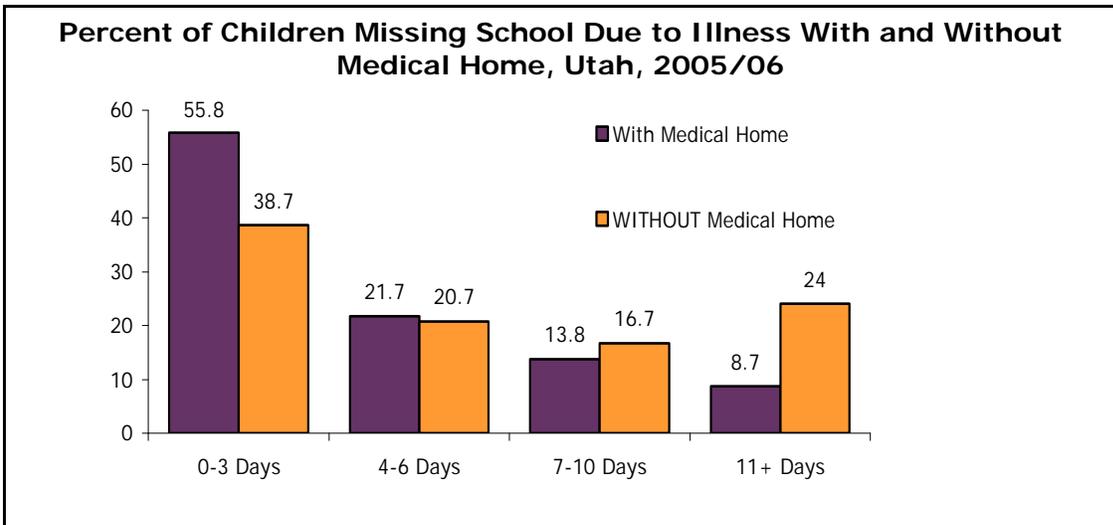


Data Sources

Child and Adolescent Health Measurement Initiative. *2005/06 National Survey of Children with Special Health Care Needs*, Data Resource Center for Child and Adolescent Health website.

Figure 74

A child’s medical home plays an important role in determining whether transition



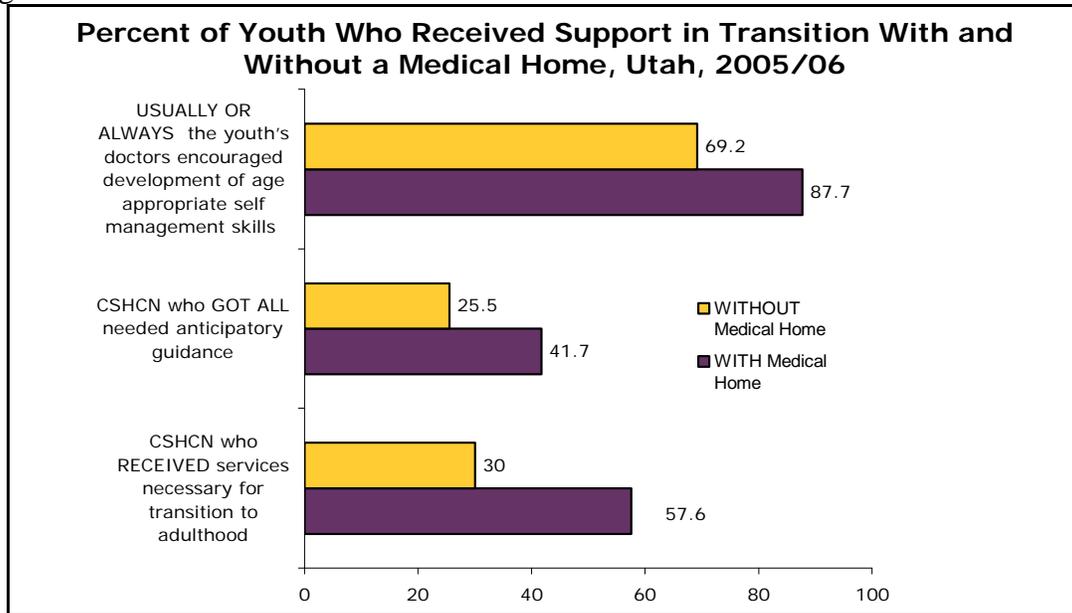
Data Sources

Child and Adolescent Health Measurement Initiative. *2005/06 National Survey of Children with Special Health Care Needs*, Data Resource Center for Child and Adolescent Health website.

outcomes were positive. Utah youth with a medical home were significantly more successful than youth without a medical home in achieving transition milestones (see Figure 75).

Families of Utah children with special needs report having a medical home in all age groups at a higher percentage than the national average in all age groups except in 15 to 17 year olds (See Figure 76).

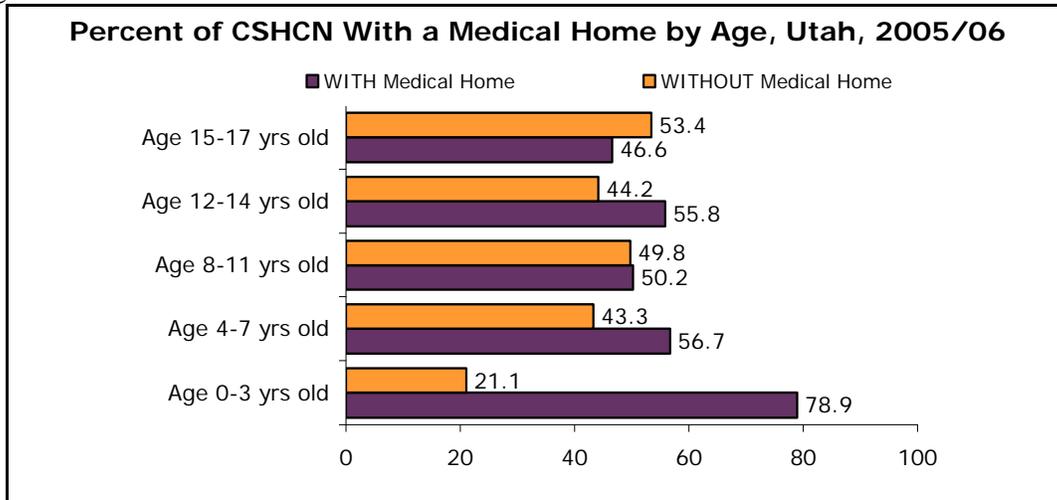
Figure 75



Data Source

Utah data from the National Survey of CSHCN 2005/06

Figure 76



Data Sources

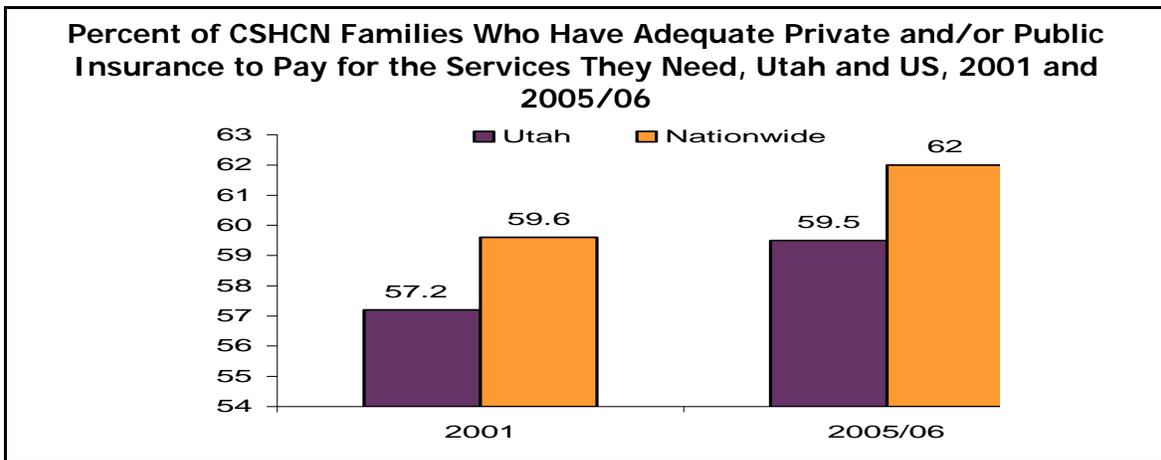
Utah data from the National Survey of CSHCN, 2005/06

CSHCN Core Outcome 3: Families have Adequate Insurance to Pay for Services

The core outcome families reporting that they have adequate public/private insurance for 2001 is comparable to the outcome in 2005/06 on the National CSHCN surveys. Utah is slightly lower than the national percentage in both years (Nation 59.6% in 2001 and 62.0% in 2005/06).

Utah families reported a modest increase in their insurance adequately covering services for their child. This could reflect the efforts that Utah has made in state health reform, expansion of the CHIP program, the relatively strong economy and high employment rate (in 2005) and the generous Medicaid coverage for children.

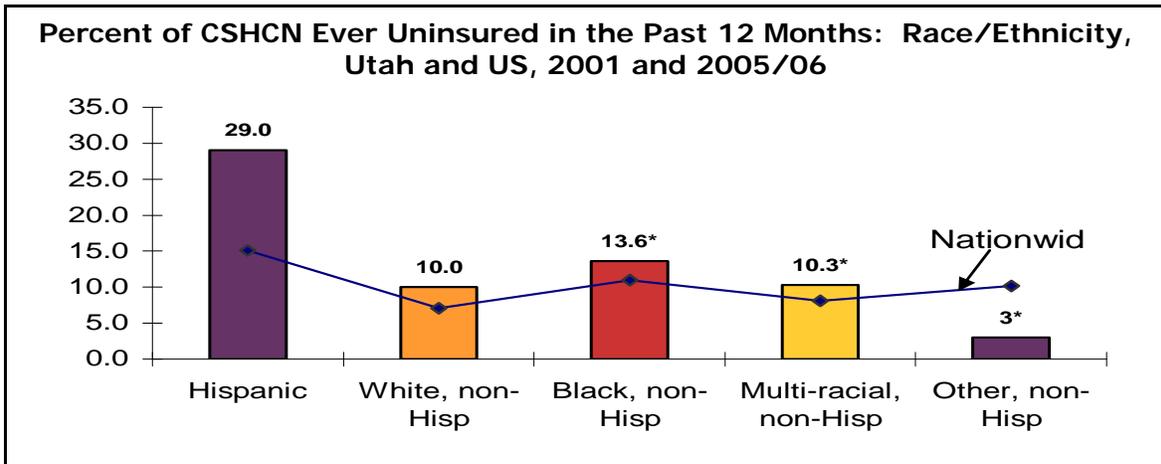
Figure 77



Data Sources

Child and Adolescent Health Measurement Initiative. *2001, 2005/06 National Survey of Children with Special Health Care Needs*, Data Resource Center for Child and Adolescent Health website.

Figure 78



Data Sources

Child and Adolescent Health Measurement Initiative. *2001, 2005/06 National Survey of Children with Special Health Care Needs*, Data Resource Center for Child and Adolescent Health website.

* Estimates cannot be determined accurately, sample sizes too small to meet standards for reliability or precision.

Although Utah families report a higher rate of adequate insurance overall, the uninsured in the past twelve months appears to be most prevalent in Hispanic families, at almost double the national rate in the 2005/06 National CSHCN survey (Figure 78).

Another public coverage to help families offset the costs of services for their child with a disability is Social Security. In Utah, if a child is eligible for SSI benefits, they usually also qualify for Medicaid coverage.

Table 26. Children/Youth 0-17 Years Receiving SSI Payments, Utah, 2008

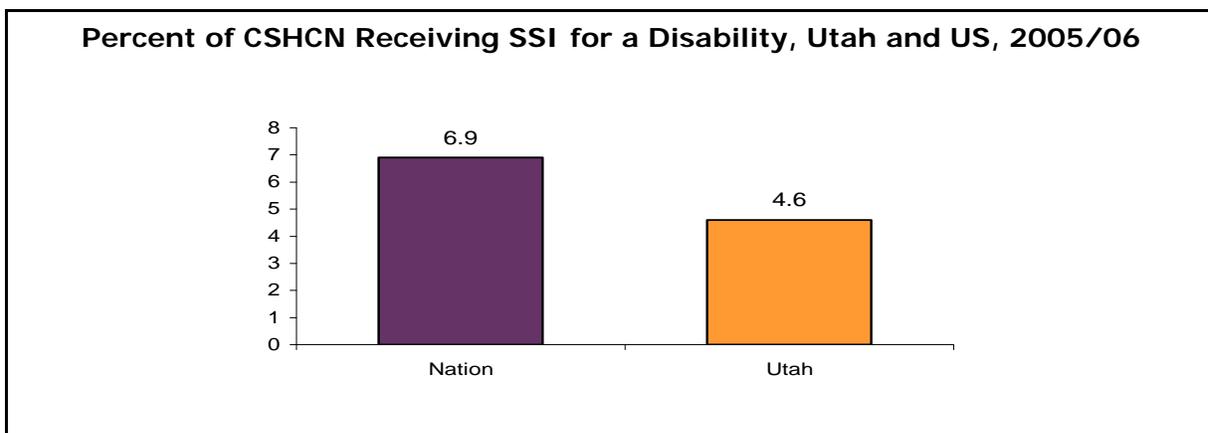
	# CSHCN	% CSHCN		# CSHCN	% CSHCN
Age (yrs)			Gender		
0-1	422	8.8	Male	3080	64.1
2-3	470	9.8	Female	1723	35.9
4-5	517	10.8	Living Arrangements		
6-7	606	12.6	Own household	708	14.7
8-9	578	12.0	Another's household	195	4.1
10-11	567	11.8	Parent's household	3703	77.1
12-13	556	11.6	Medicaid institution	197	4.1
14-15	523	10.9	Unknown	0	0
16-17	564	11.7			
Total	4803	100%			

Data Sources

Social Security Administration. Data provided to the Health and Ready to Work National Center, 2008.

The Utah National CSHCN Survey 2005/06 reports that Utah has a lower than average number of children on SSI for disability. This could be explained by the 2005/06 manpower shortage in the Utah Disability Determination Services office, which slowed processing of claims for all applicants. This problem has been addressed and hopefully Utah will see an improved rate in the 2010 CSHCN survey.

Figure 79



Data Sources

Child and Adolescent Health Measurement Initiative. 2005/06 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website.

The final impact to families of not having adequate insurance for the services their child needs is either not receiving services or paying for them out of pocket. Utah families pay more in out of pocket expenses and the cost is a greater financial burden than nationally.

Table 27. Impact on Family, Utah and US, 2001 and 2005/06

	Utah % 2005/06	US % 2005/06	Utah % 2001	US % 2001
CSHCN whose families pay \$1,000 or more out of pocket in medical expenses per year per child	26.4	20.0	15.5	11.2
CSHCN whose conditions cause financial problems for the family	22.1	18.1	22.3	20.9

Data Sources

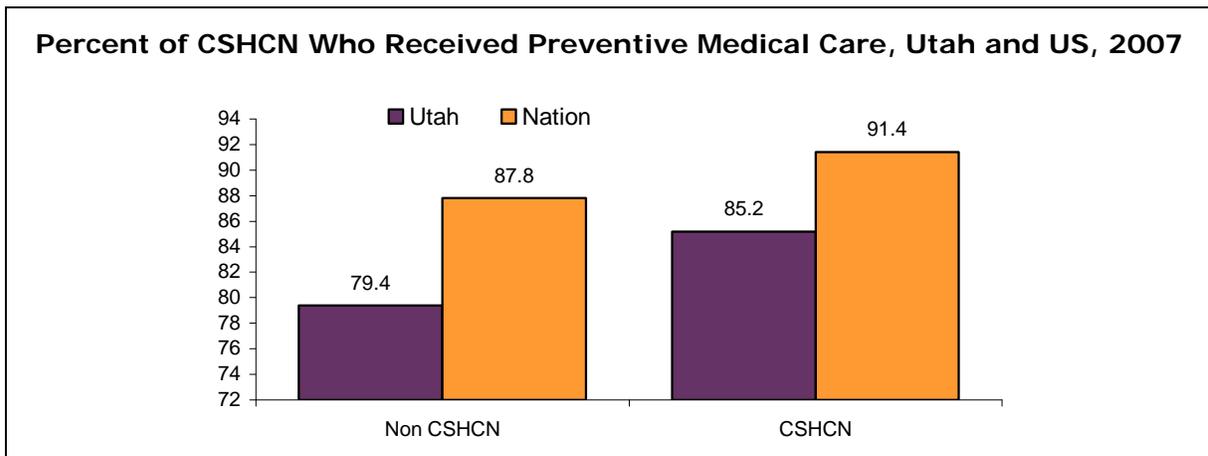
Child and Adolescent Health Measurement Initiative. *2001, 2005/06 National Survey of Children with Special Health Care Needs*, Data Resource Center for Child and Adolescent Health website.

CSHCN Core Outcome 4: Early and Continuous Screening

In the 2005/06 National CSHCN survey, Utah families report a slightly lower rate of early and continuous screening for their child than the National rate (60% vs. 63.8%). The National CSHCN survey uses two survey questions to determine this estimate: access to routine preventive medical care and access to routine preventive dental care.

In the National Children's Survey, Utah CSHCN were less likely to receive preventive medical and dental care than the National rate.

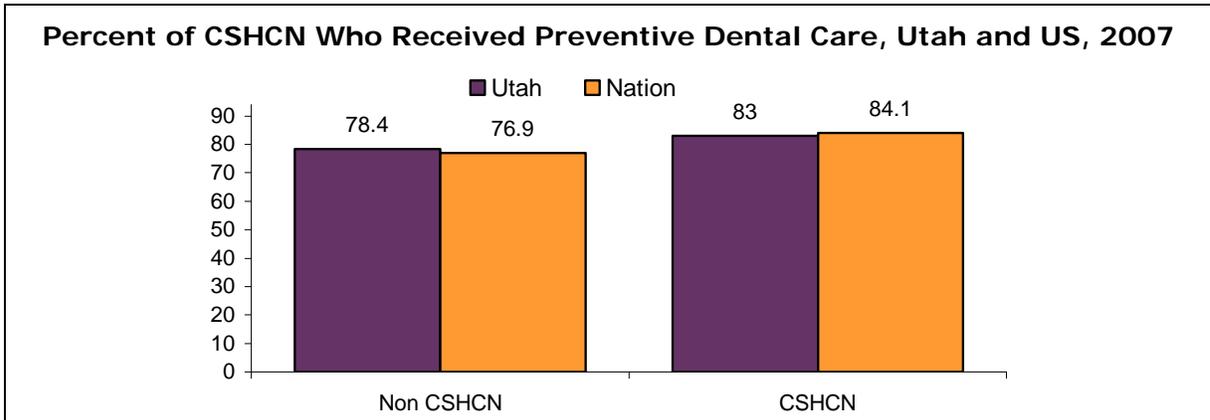
Figure 80



Data Sources

Child and Adolescent Health Measurement Initiative. *2007 National Survey of Children's Health*, Data Resource Center for Child and Adolescent Health website.

Figure 81

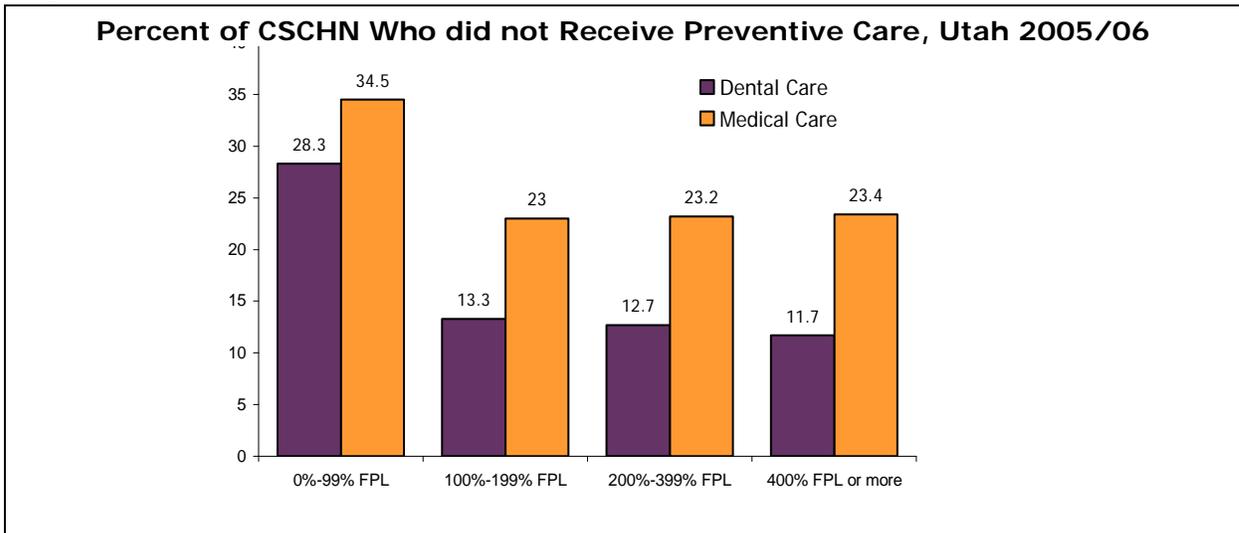


Data Sources

Child and Adolescent Health Measurement Initiative. *2007 National Survey of Children's Health*, Data Resource Center for Child and Adolescent Health website.

According to the National CSHCN Survey, family income is directly related to CSHCN receiving preventative care: Poorer families are less likely to receive preventative care, both nationally and in Utah.

Figure 82



Data Sources

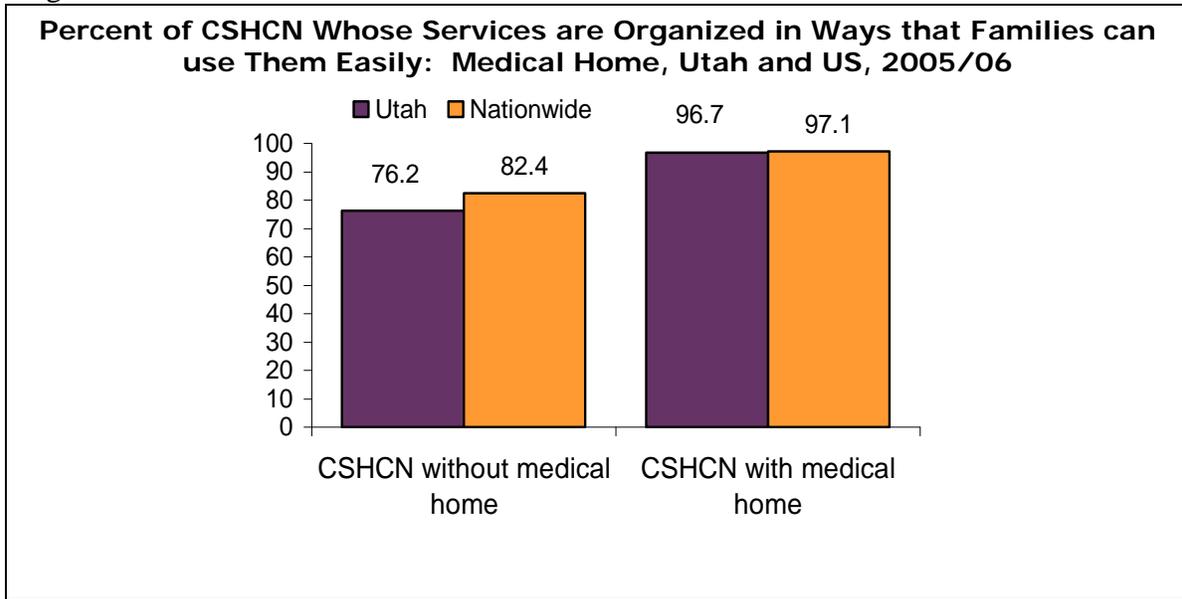
Child and Adolescent Health Measurement Initiative. *2005/06 National Survey of Children with Special Health Care Needs*, Data Resource Center for Child and Adolescent Health website.

CSHCN Core Outcome 5: Community Based Services Organized for Easy Use

A majority of Utah CSHCN families (86.2%) reported services are organized in ways that families can use them easily which was slightly lower than the national average (89.1%).

Families with a medical home are more likely to find services accessible and easy to use than families without medical homes.

Figure 83

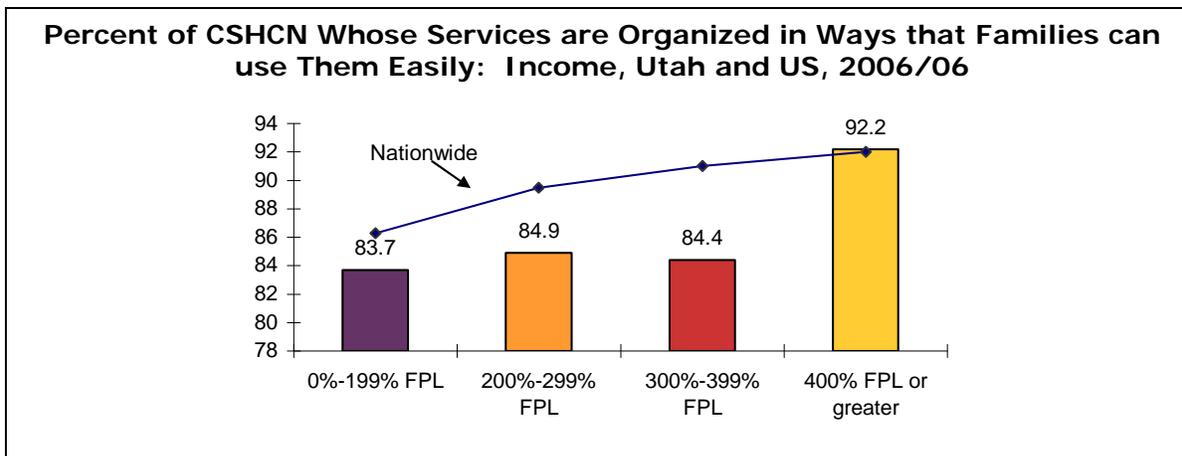


Data Sources

Child and Adolescent Health Measurement Initiative. *2005/06 National Survey of Children with Special Health Care Needs*, Data Resource Center for Child and Adolescent Health website.

Another factor which influences whether services are organized in ways that families can use them easily is income. The national average differed from 86.3% to 92.0% in the different poverty levels, increasing by 6%, whereas Utah families had a more significant difference of 8.5%. Utah families averaged the same level of satisfaction in all but the highest income level.

Figure 84



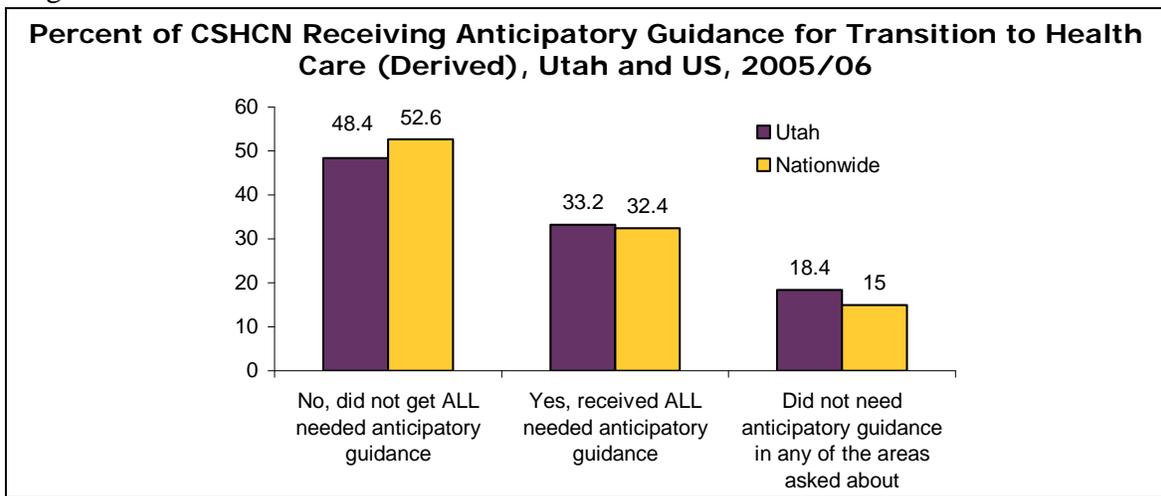
Data Sources

Child and Adolescent Health Measurement Initiative. *2005/06 National Survey of Children with Special Health Care Needs*, Data Resource Center for Child and Adolescent Health website.

CSHCN Core Outcome 6: Services for Transition to Adult Life

Over the past 20 years, health care advances have allowed CSHCN to live longer and more productive lives. The transition of these children into adult health care, work and independence has become a growing concern among providers, youth and parents alike. Over 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. Health and health care are cited as two of the major barriers to making successful transitions. Only 42.5% of Utah youth with special needs achieved successful transition to adult health care, work and independence, similar to their national peers (41.2%).

Figure 85



Data Sources

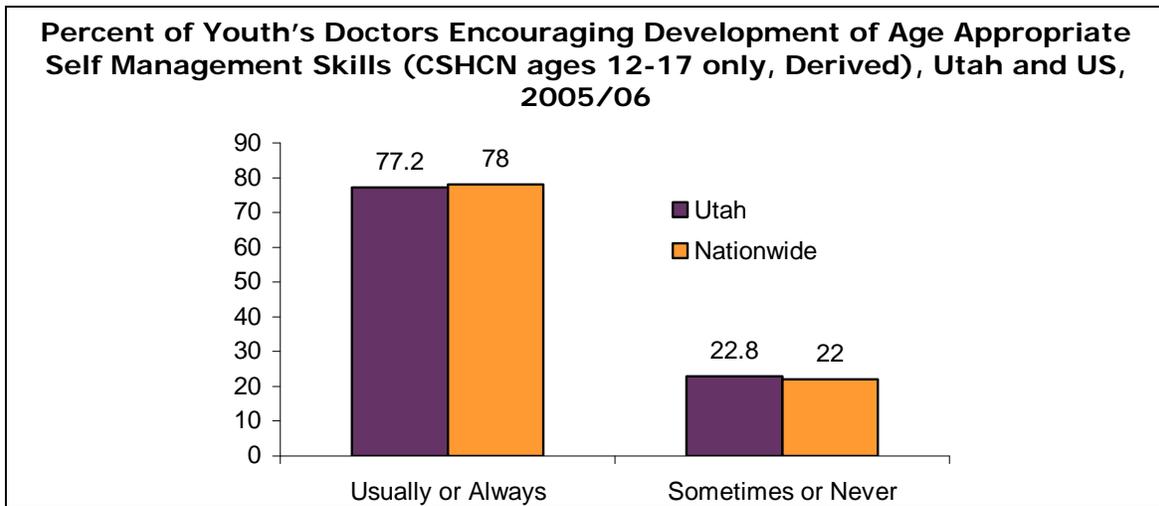
Child and Adolescent Health Measurement Initiative. *2005/06 National Survey of Children with Special Health Care Needs*, Data Resource Center for Child and Adolescent Health website.

Similar to national report, only 33.2% of Utah youth reported receiving all needed anticipatory guidance for transition to adult health care. Though they did not get support in transitioning to adult health care, youth usually or always (77%) received support in developing age appropriate self management skills.

Selected Health Conditions of Children in Foster Care

Nationally foster children have a higher incidence of chronic health conditions. On March 2, 2010 there were 2735 children in Utah's foster care system. Of these 732 children either have no conditions identified or have not been seen by a medical provider as they have been in care <30 days. Table 28 demonstrates some of the conditions found in Utah Foster Children.

Figure 86



Data Sources

Child and Adolescent Health Measurement Initiative. *2005/06 National Survey of Children with Special Health Care Needs*, Data Resource Center for Child and Adolescent Health website.

Table 28. Select Health Conditions of Children CURRENTLY in Foster Care, Utah, March 2010

Health Condition	Number of Foster Children (n=2735)	% of Foster Children
ADD/ADHD	365	13
Asperger's Syndrome	13	<1
Asthma	185	7
Autism	41	2
Blindness	7	<1
Cerebral Palsy	19	<1
Congenital Anomalies	33	1
Depression/Anxiety	378	14
Developmental Delay	151	6
Diabetes	16	1
Epilepsy	12	<1
Hyperopia/Myopia	446	16
Medication Management	278	10
Speech Delay	91	3

Data Sources

Utah data from Department of Human Services, SAFE Database, Fostering Healthy Children Program, March 2010

Gaps and Weaknesses of the System of Care for Children and Youth with Special Health Care Needs

Family Leadership, Involvement, and Support

Families of children and youth with special health care needs continue to express the need for adequate resources to meet the needs of their child and family. This includes affordable insurance that covers the services that the child needs to maintain or improve their quality of life; family support services for the family and the child to function at their maximum potential; and easily accessible resources that are current and credible. Families have unique expertise about the strengths and weaknesses of the supports that are needed. Therefore, families should partner with professionals to assist in the development of a system of care that is coordinated, cost effective and flexible (based on the individual needs of the child and not solely the diagnosis).

To address this need, the bureau of Children with Special Health Care Needs (CSHCN) is establishing the Family Leadership and Involvement Program (FLIP), designed to expand the participation of family, youth and young adult in MCH programs and other community-based and state service systems. The successful parent/professional partnerships will be implemented and modeled in various levels of the system of health care and related services. Furthermore recommendation to compensate consumer participants for their time and expertise will continually be reinforced. Information will be enhanced and expanded in the family section of the Medical Home Portal to help provide a clearinghouse of credible resources and information for families, physicians and professionals statewide. Support and technical assistance will be continued to the Utah Family Voices Family-to-Family Health Information Center (F2FHIC) and the Utah Parent Center. The partnerships and collaboration will provide support, training and information to an increased number of families of children and youth as well as young adults with special needs in accessing appropriate and affordable health care and related services across the lifespan.

Lack of Health Surveillance and Health Promotion targeted specifically to children, youth and adults with special Health Care Needs

Although the Department of Health has a strong health promotion campaign directed toward child health and prevention of chronic disease in children and adults, there is no specific program which addresses the needs of all children, youth and adults with disability. Utah Registry for Autism and Developmental Disabilities (URADD) is tasked to establish the prevalence of this population of children within Utah. It is supported with both state dollars and a CDC grant as well as in kind support from UDOH. Surveillance information from the Behavioral Risk Factor Surveillance System (BRFSS) on children, youth or adults with disabling conditions is minimal. Children with chronic conditions are living longer, so the need for promoting optimum health is increasingly important. This year the DOH and the Center for People with Disability will partner with BRFSS on a joint survey, to determine public knowledge about Autism Spectrum Disorders. Information from this survey will guide the development of a public information campaign on Autism.

The Utah Birth Defects Network (UBDN) has been awarded a three-year CDC grant which will support the development of a population-based monitoring system to provide long-term follow-up data for 19 metabolic conditions. This grant permits the UBDN to identify confirmed metabolic conditions among newborns screened in Utah during a two year period, collect demographic, phenotypic and genetic and outcome data on each infant, and identify first year of life issues that impact morbidity, mortality and quality of life.

Developmental Evaluation Resources for Children

There continue to be national and statewide shortages in developmental pediatricians. There are also shortages in related pediatric subspecialties such as neurology, genetics and orthopedics. Shortages also include ancillary pediatric service providers, such as occupational and physical therapists, audiologists, speech and language therapists and child psychologists with specialty training in areas such as behavioral intervention, neurodevelopment and autism spectrum disorder.

CSHCN has undergone strategic planning, looking specifically at the communities which surround the rural CSHCN itinerant diagnostic clinics. Surveys have been developed and distributed to both the providers and the families with children with special health care needs who reside in these communities. It is clear that these communities do not have the local expertise to provide pediatric developmental diagnostic services.

Recent dramatic cuts in state funding has put a increase strain on UDOH's ability to offer diagnostic evaluations to children in Utah with developmental disabilities in an effort to identify early and refer for appropriate intervention. Although CSHCN clinics cannot cover all children who need these services, the bureau will continue to support, collaborate and support educational efforts for Medical Homes. This will be done through joint projects with UPIQ, collaboration with the University of Utah, the Utah Medical Home Portal, training of leaders in neurodevelopment through the URLEND projects and future efforts. Additionally, the bureau will continue to support families as partners' at all health care system levels.

Clinical Follow-up for Preterm and Low Birth weight Infants

Preterm/very low birth weight children have a disadvantage in multiple domains: academic achievement (mathematics, reading, and spelling), executive function (verbal fluency, working memory), neurosensory outcome (cerebral palsy, mental retardation, blindness, hearing loss), general health area (chronic lung disease, failure to thrive) and behavioral problems (attention deficit). Adverse outcome are inversely related to birth weight and gestational age. In spite of emphasis on prenatal care, we have not been able to interrupt spontaneous preterm labor or prevent preterm rupture of membranes.

With the introduction of antenatal steroids and surfactant, survival of the extremely premature babies and those most at risk for long term neurodevelopmental disability has improved significantly (85% of infants with birth weight between 501-1500 survive). Availability of assisted reproductive technology has contributed to an increase of preterm birth as well (frequency of twins increased by 75% and higher order multiples by 220%).

Since 1990 in the United States there has been a 21% rise in preterm births, yet there is disparity between increased need and lack of finances required to provide staff and services. To improve the care of this population, the UDOH Neonatal Follow-Up Program (NFP) provides multidisciplinary clinics for newborns whose birth weight was less than 1500 grams.

Recent cuts in state funding have impacted the ability for NFP to provide multidisciplinary clinics to all premature infants in Utah. In 2009, in a response to budget cuts, NFP narrowed its eligibility for clinics from 2000 grams to 1500 grams birth weight. To offset the reduction in clinic services, the program will step up efforts in communication with Medical Homes and provide more long term follow up to state Neonatal Intensive Care Units (NICU's) to help improve outcomes of these infants. NFP has developed an electronic medical record/comprehensive database, DRAMA, which allows which supports the collection of outcome data. This data will be shared both with Medical Homes, early intervention services and referring NICU's via consultation reports. NFP has recently completed a 20 year outcome report, which will also be made available to NICU's. Finally, as an outcome improvement demonstration, NFP has partnered with the University of Utah, Department of Obstetrics and Gynecology, to pilot having obstetrical staff available to parents during the NFP clinics to offer parents anticipatory obstetrical guidance.

Children and youth in foster care and out of home care

Nationally and in Utah, children who are removed from their homes and placed in foster care are an at-risk population for many reasons. Among the concerns for these children is often dental, medical and developmental neglect, as well as mental health impacts that accompany the children's removal from the family. Unfortunately, due to the complicated, uncoordinated and often underfunded systems of human services, foster care, health care, Medicaid and mental health, children in foster care may continue to miss their routine or rehabilitative health care. This situation has prompted many lawsuits throughout the nation by the National Center for Youth Law against the state agencies who oversee these children. During fiscal year 2009 in Utah there were 20,649 investigations related to child protection issues, of these, 46% were supported for child abuse or neglect. Domestic violence accounted for 31% of the supported cases and in 29% of the supported cases, alcohol or drugs were a contributing factor. The number of children in Utah foster care, including kinship placement, has risen from 3974 in 2007 to 4599 in 2009, despite the fact that the child population (birth to 18 years) for those years has remained stable (see Table X). The rising numbers are attributable to an increase of families with children living in poverty (Table X), an overall declining economy, and improvement in drug screening of children as they are removed from homes.

The Department of Human Services (DHS) has contracted with the Department of Health to oversee the health (dental, medical, mental health) of children in foster care. The Fostering Healthy Children Program (FHCP) public health nurses are co-located with DHS caseworkers, and have the responsibility to help coordinate the required follow-up medical needs within the Medicaid system. The nurses help with access to care, medical training and education of foster parents, biological parents, and caseworkers on the

special health needs of the child. They are part of the Child and Family Team. This program has achieved national recognition by the Annie E. Casey foundation and the federal GAO as a model program in insuring optimum health care for this population.

Part of the success of the FHCP is attributed to the development the SAFE database system, which provides a means to track improvement in key health indicators. An example of the SAFE system's benefit can be seen in the recent study of psychotropic medication prescribed for children in foster care. With a national focus on psychotropic medication use in foster children, Utah DOH, DHS and Medicaid used the SAFE database to compare data on the use of psychotropic drugs for children in foster care compared to the general Medicaid population. Data showed that only 31% of children in foster care are prescribed psychotropic medications. National studies showed that psychiatric medication usage had increased from 3% in 1987 to 23% in 1996 and prescribing one medication to two increased 25 times in the 10 year period. Review of Utah data indicated that the number of children on multiple psychiatric medications has remained constant for the past two years.

This year, the Utah Department of Human Services was removed from federal court oversight. Although health care was one of the improvements which led to this success, a number of barriers and service gaps continue to face these children. Access to dental, mental health and medical specialty care for these children is still difficult. There are not enough dentists who will accept Medicaid, which was made worse by a recent decrease in Medicaid rates for dental providers. In addition, although the Child Abuse Prevention and Treatment Act (CAPTA) require that the referral of children in Foster Care to Early Intervention, Utah's program eligibility requires that a child must have a moderate to severe developmental delay. The reason for this policy is mainly funding constraints. However, many abused or neglected children enter care with mild delay so they are not eligible for Early Intervention services. This continues to be a shortfall of the support system for these children. Providing early developmental services is needed for these children to increase successful outcomes.

Traumatic Brain Injury-Early and Accurate Identification and Adequate Treatment Access

Utah children who sustain traumatic brain injuries often go undetected and untreated. The National Brain Injury Association calls TBI "the silent epidemic," because many children have no visible impairments after a head injury, although they often experience a complex array of problems including cognitive and physical impairments, communication delays, and/or psychosocial/behavioral problems, which can be either temporary or permanent. This may cause partial or total functional disability as well as psychosocial maladjustment (CDC, July 2006). Although it is described as one of the leading cause of disability in children, supportive data are lacking due to frequently unrecognized and unreported incidences. In 2010, UDOH Violence and Injury Prevention Program received a four year HRSA TBI Demonstration grant. The goals of this grant are to 1) Advocate for the improvement of improving the TBI service public and private delivery system in Utah; 2) Advocate for access by children and adults to a full array of coordinated and comprehensive community services; and 3) Continue to

refine, expand, and deliver TBI awareness, education, and training to children and adults with TBI and their families, providers, health care professionals, educators, and the public.

Transition to Adulthood

As documented in the Health Status section, there continue to be service gaps for children and youth with special health care needs as they transition to adult health life. The 2008 Medical Home Provider Transition Survey indicated that trained medical homes, even after learning about suggested strategies to improve transition services, generally did not develop written policies (0%) or standardized approaches (13%) to support youth as they transitioned to adulthood. The surveyed medical homes generally (62%) discussed approaches to improve transition services but did not implement them in a standardized fashion. The National Survey of Children with Special Health Care Needs revealed that many (48.4%) Utah youth did not get all the anticipatory guidance that they needed from their medical providers.

CSHCN Bureau surveys from 2009 and 2010 revealed that medical providers are interested in a wide range of transition topics including, but not limited to, employment, education, adult health care, insurance, independent living, and transportation. Providers indicated they would like information in a variety of formats including face-to-face consultations with patients at itinerant clinics. CSHCN Bureau collaborates with other agencies and organizations, including the Becoming Leaders for Tomorrow (BLT) Project from Utah State University, to provide training to medical providers in urban and rural areas of Utah. Training includes familiarization with websites containing transition information, such as the Medical Home Portal; distribution of traditional print brochures with lists of statewide resources; and distribution of multimedia resources including the Youth Leadership Toolkit with a guidebook and DVD. Additionally, monthly training events, agency conferences, and school-district fairs provide information for youth and young adults to help them find resources and improve their self-advocacy skills.

Reports from the Utah State Office of Rehabilitation also indicated that many youth face challenges in receiving Vocational Rehabilitation (VR) services due to the common practice of youth serving religious and humanitarian missions immediately after high school, thereby forcing them to reapply for VR upon return and entry into postsecondary educational settings. In an effort to provide better service beginning in 2010, high school students may apply for VR and be placed in an “interrupted” status allowing them to resume services without reapplication upon entry into postsecondary education settings.

Loss of State funding for the bureau of CSHCN

In FY 2009 and 2010, CSHCN Bureau sustained a loss of approximately \$1.5 million, due to state and national tax revenue shortfalls. In order to absorb these losses, the bureau has cut back on rural clinics in Cedar City and Provo and has lost over 15 professional and support staff (approximately 10%) in the central CSHCN office. This has forced CSHCN administration to revamp longstanding service delivery systems, to improve efficiency and cut costs. Although some of the rural services, audiology and locally based nurse care coordination in particular, have been decreased, the bureau has

been able to maintain most of the specialty and sub-specialty multidisciplinary clinic services in rural and underserved areas. Because the majority of pediatric specialty services and sub specialty services continue to be located along the Wasatch Front, delivery of rural multidisciplinary clinics continues to be a priority. The bureau is looking into new ways of delivering these services, including and web based electronic health records and care coordination modules.

Complex Medicaid System for families of CSHCN

Utah continues to have very generous and broad Medicaid coverage for children. Children enrolled in Medicaid generally receive a more comprehensive service package through their Medicaid benefits than children covered by private insurance or CHIP. Although CHIP benefits are not as generous as Medicaid, it is beneficial for the many children with mild chronic health conditions.

Although Utah Medicaid is fairly robust for children, the managed medical care and a separate pre-paid mental health plan make coordination of coverage difficult for children on Medicaid who need both mental health and medical care for their conditions, such as Autism Spectrum Disorders. Coordination of Medicaid payment for these services is complicated and difficult for even the most experienced case manager or parent navigator. Adding to this burden for families has been the centralization of application for Medicaid to the office of Workforce Services in the Utah Department of Human Services. This change has created efficiencies and allows a low income family to apply more easily for many types of online services at one website. However, the DOH has lost the ability to provide training and support to intake workers on how to support families of CSHCN as they apply for disability Medicaid.

Lack of state support for adequately funding a Utah birth defects surveillance and prevention

The Utah Birth Defect Network (UBDN) is a statewide public health program that monitors and assesses all major structural birth defects in Utah. In FY 2009 and FY 2010, due to the national economic downturn, state general funds for all CSHCN programs have been decreased by \$1 million. The UBDN's federally funded research grants (e.g., National Birth Defects Prevention Study) are based on an active population-based and statewide surveillance system supported by the state. UBDN and senior UDOH staff are collaborating with the Utah Chapter of the March of Dimes to work with key state legislators to inform them of the importance of continuing and increasing state funds for optimum birth defect surveillance of newborns. Though the cause of the majority of birth defects is unknown, preventing some birth defects is now possible.

In Utah, birth defects are common (1 in 33 babies), the leading cause of infant deaths and a major cause of pediatric hospitalizations. Of concern, is the increasing prevalence in Utah for several birth defects: gastroschisis, neural tube defects and hypospadias. The reasons for the increase in these birth defects are not understood.

Children's Mental Health Services

Public mental health services are located throughout Utah and are covered by Utah Medicaid Prepaid Mental Health Waiver. These mental health services however are largely only available to clients who receive Medicaid coverage. Public and private mental health services for children in rural Utah vary widely in quality and availability, due to sparse availability of trained child mental health professionals in some areas. Infant mental health services are generally only available through the statewide Baby Watch Early Intervention (BWEI) centers, to children who qualify for the BWEI birth to three developmental programs. Due to funding constraints, the BWEI program only serves children with moderate to severe developmental delays, therefore, infants and toddlers with mild delays may not qualify for BWEI. The Baby Watch program has launched BWEI provider training for earlier and more systematic identification of toddlers with Autism Spectrum Disorder, and is also providing training on evidence based autism intervention. CSHCN psychologists provide evaluations through our CSHCN diagnostic clinics. These children are referred to other mental health providers, as needed. Such providers are a limited resource in Utah.

Health and mental health insurance parity legislation for children and their families has been introduced in Utah for the past several years, but has not yet passed. This means that many middle income families with traditional insurance are still unable to access appropriate mental health or family support services.

Rural Healthcare Access

Access to early diagnosis, treatment and support is still problematic for most children living in rural Utah, although resources for children have expanded in the St. George area largely due to the efforts of Intermountain Healthcare. In 2009, the Southwest Utah Local Health department discontinued the CSHCN satellite clinic contract, due to funding constraints, citing that CSHCN clinic were no longer consistent with their mission and goals. The CSHCN Bureau will continue to address access to care in rural areas through ongoing itinerant clinics and satellite case management through local health department. Through collaboration with local providers, CSHCN staff will address the difficulties that rural families face in accessing subspecialty services, due to geographic location, socio-economic and cultural factors. This effort is supported by a recently implemented referral form system, set up statewide between CSHCN clinicians and Medical Homes to improve communication. CSHCN will continue to support and develop the capacity for local providers to care for children and youth with special health care needs through the Medical Home training, website and newsletter.

Another effort which helps to address health care access in both rural and urban Utah, are web based application to services offered through state programs. In 2009, the State of Utah has successfully implemented the electronic Resource & Eligibility Product (eREP). This multi-agency initiative empowers Utah to increase human services programs efficiency, improving the quality of service delivery to citizens and reducing operational costs. Electronic application to Medicaid was moved from Utah Clicks, to eRep and consolidated with other Division of Workforce Service services applications, including food stamps, low income housing and employment support. Although Medicaid funding

support for Utah Clicks was lost in this move, Utah Clicks will continue to provide web-based application access for families to UDOH resources such as CSHCN clinics and Early Intervention.

Over the next five years, CSHCN hopes to revisit options for delivering subspecialty health services and information to rural families, children and health care providers. The Salt Lake City CSHCN center and the Utah Network continue to work together to provide different types of services. However, due to funding, the CSHCN system purchased over 8 years ago has become outdated. The system is limited and is currently used mostly for training, but has never been a successful tool to provide multi-specialty care for children. Over the next five years, CSHN plans to seek funding and consultation on how to improve healthcare delivery, in order to continue to provide high quality subspecialty services in collaboration with Medical Homes in a time of dwindling resources.

Needs of Minority Racial and Ethnic Groups

Information for Utah from the National Survey on Children with Special Health Care Needs (2001 & 2005) was limited in significance because of the small number of Hispanic or non-white families. The Utah Children with Special Health Care Needs Parent Survey (2010) however did show a higher representation of families from ethnic and racial minorities than the National Utah information.

Table 29. CSHCN Demographics, Race and Ethnicity, Utah, 2010

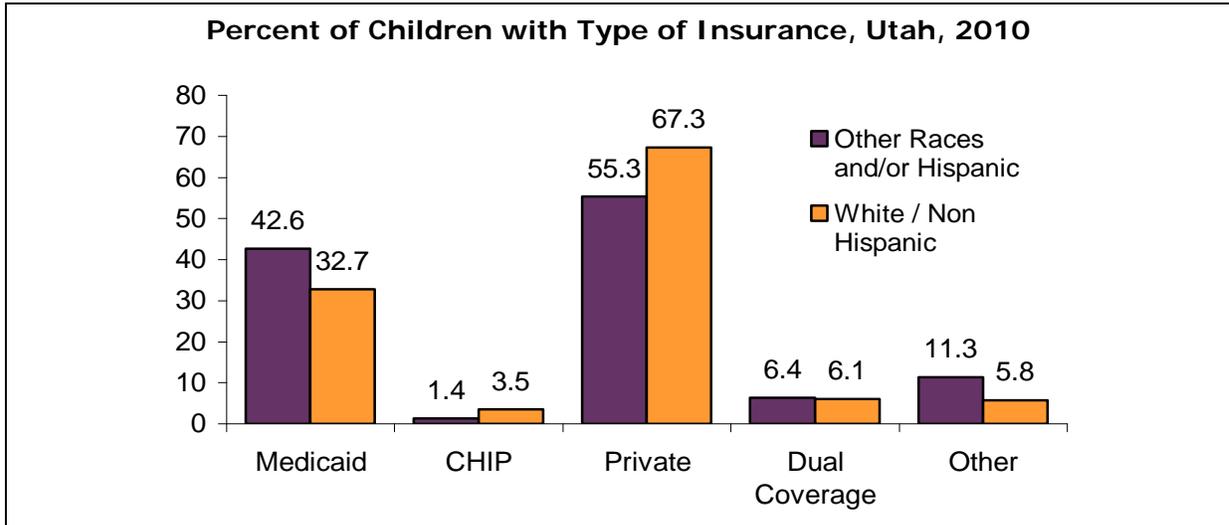
Race	Percent
White	84.3
Black/African American	2.1
Asian	1.2
American Indian/Alaskan Native	1.7
Hawaiian/Pacific Islander	0.5
Other/Multiple Race	5.5
Ethnicity	Percent
Hispanic or Latino Origin	8.9
Non-Hispanic	90.2
Unknown	0.9

Data Sources

Utah CSHCN Parent Survey

The White Non-Hispanic compared to the Hispanic and respondents of other racial backgrounds showed no significant differences in age of children, severity of the children's conditions, and surprisingly, having health insurance (yes/no). However, when type of insurance was compared between White Non-Hispanic and the Hispanic or other racial background families (Figure 87), the White Non-Hispanic showed a higher rate of private insurance, a lower rate of Medicaid and CHIP.

Figure 87



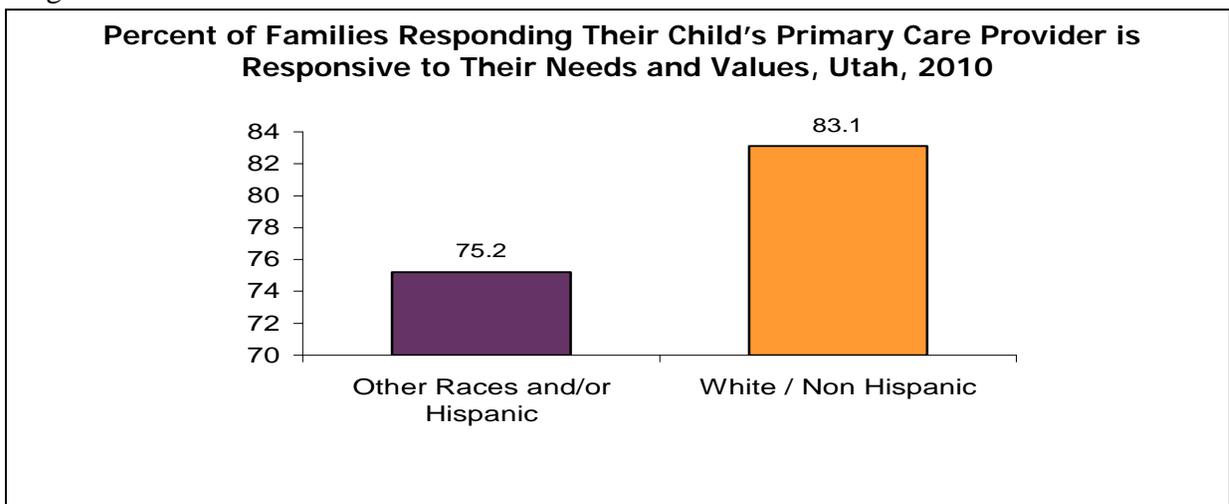
Data Sources

Utah CSHCN Parent Survey

The White Non-Hispanic had a lower rate of “other.” When the “other” category was examined more closely, however, it was apparent that the Hispanic families and families from other racial background did not understand the question. Many reported private insurance under “other.”

When responding to the question, “Is your primary care provider responsive to your family needs and values,” there was a significant difference between White Non-Hispanic families and other Races and/or Hispanic families, which coincides with data from the National Survey of CSHCN.

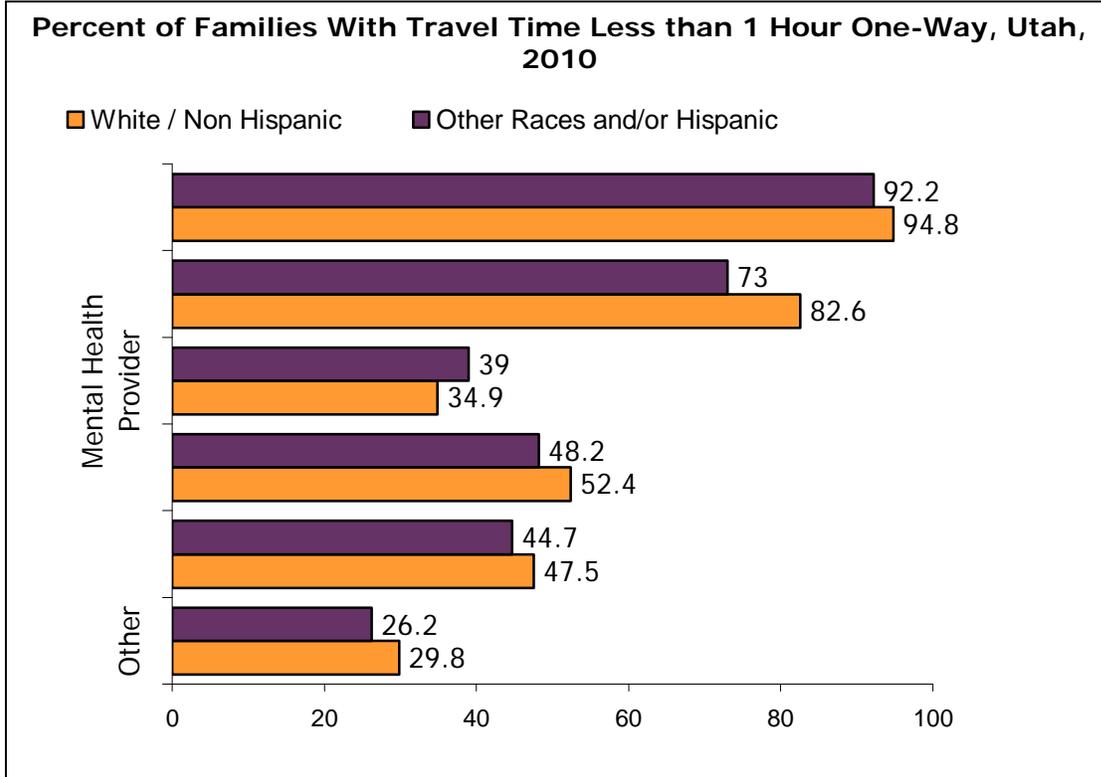
Figure 88



Data Sources

Utah CSHCN Parent Survey

Figure 89



Data Sources

Utah CSHCN Parent Survey

The 2010 CSHCN survey shows that travel time for culturally diverse families to get to primary and specialty care appointments is generally greater, with travel time 1-2 hours one-way for Other Race and/or Hispanic families higher than White Non-Hispanic families.

The bureau of CSHCN traveling clinic staff report that Native American issues pose unique cultural challenges. The CSHCN multidisciplinary clinics and local rural clinic staff are making outreach via Indian Health Services and other agencies directly involved with the populations served by our clinics. Collaboration is focused on improved contact with the families in need, and advocacy and support in making sure these populations have the information, resources and ability to access the needed CSHCN services.

Strengths of the System of Care for Children and Youth with Special Health Care Needs

Child Health Advanced Records Management (CHARM), Clinical Health Information Exchange (cHIE)

Data exists in an array of public and private health sectors and each database serves its own users and is not always shared across organizations or health programs. Services are often not coordinated and typically do not provide a network of care for families. As a result, many children do not receive critical follow-up. The Utah Child Health Advanced Records Management (CHARM) Project is a coordinated, DOH-wide effort that creates an electronic virtual health profile for children in Utah, and allows electronic access and data sharing among appropriate health care programs and partners. The CHARM vision is to become a shareable repository of child-specific public health information with secure role-based confidential access to a comprehensive set of integrated public health data accessible by people with a “need to know,” that promotes timely and efficient access to needed services, and supports program planning and evaluation. Integrating the State's health care databases provides for immediate access to information that is stored in specific databases to track and monitor health status for children and their families.

CHARM has linked the databases from the following participating programs: 1) Vital Records, (Birth and Death Certificates), 2) Utah Statewide Immunization Information System (USIIS), 3) Early Hearing Detection and Intervention (EHDI), 4) the Baby Watch Early Intervention Program, and 5) the Office of Recovery Services. The Newborn Screening (heelstick) Program is currently being integrated. Following the integration of that program, plans are to evaluate the feasibility of linking the Fostering Healthy Children and Neonatal Follow-up Programs to CHARM. Through data-sharing and tracking between integrated programs, CHARM's goal is to reduce the number of children lost to follow-up statewide by 50% and ultimately to provide more accurate and timely information to the child's medical home through web access.

CHARM is also working with the UDOH clinical Health Information Exchange (cHIE) was recently been chosen along with five other states to receive supporting HRSA grant funding to create the infrastructure for this clinical health exchange. One goal of the cHIE/CHARM effort is a pilot project to make hearing screening results and immunization information more available to community physicians through the Utah Health Information Network (UHIN). UHIN is a coalition of health care providers, insurers, and other interested parties, including state government, to integrate public health data that can be shared with physicians.

In addition, the cHIE is working on a Universal Newborn Screening/Clinical Health Exchange (UNSchIE) grant project. The Bureau of Special Health Care Needs' CHARM, EHDI, and Newborn Blood Spot Programs are major participants in this grant effort. The project is designed to enhance the effectiveness of short and long-term follow-up of infants identified through newborn hearing screening, and to make hearing and newborn blood spot results available to the medical community's Electronic Health Records through the cHIE. The lost to follow-up rate for the EHDI program (those who

had an abnormal first screen but did not have a second screen or did not follow-up with an appropriate evaluation) for 2008 was .8%. Through this project, this lost to follow-up rate, or inversely, the percent of those who had an initial abnormal screen who complete the hearing screening and evaluation process will likely improve as a result of: 1) electronic access to EHDI results, 2) the ability for physicians to access screening results readily, and 3) the ability of audiologists to notify EHDI electronically. Also, because physicians and audiologists will be able to electronically access screening results, the delay in completion of diagnosis (overall average of completed diagnosis of hearing loss is just over 4.5 months) should improve.

The UNScHIE project has a four pronged approach which includes developing, 1) technical support capacity for secured electronic exchange of the data, 2) confidentiality, privacy and security policies/procedures for sharing newborn screening information through the cHIE, 3) processes for Medical Homes to improve short and long-term follow-up through the Utah Pediatric Partnership to Improve Healthcare Quality (UPIQ), as well as a curriculum that supports decision support at the point of care for physicians, and 4) formative evaluation.

Extended Family and Community Support

Utah families often live near and depend on extended family support. The open ended question from the 2010 CSHCN survey “What is working well for your child and family in your community?” revealed that schools and education rank highest as working well for their child. Families then reported that community, family, church and other neighborhood resources are helpful. Parents stated the following:

- Extended family and neighbors were “sympathetic to their child’s needs”
- “we have incredible support through extended family and neighbors”
- “our community is very tolerant of children with special health care needs, we have people who allow our child [with autism] to go on truck rides and fire engine rides”
- “people in general are caring and understanding”
- “We have great neighbors and friends who try to watch out for our child [with FAS, ADHD] and help meet her needs.”

CSHCN will continue to promote the positive support systems offered in communities by working local resources and providers to strengthen community service systems. The bureau will also work to strengthen the role of parents as strong partners in their child’s care with their community based Medical Home provider.

Collaboration with University of Utah

CSHCN is fortunate to work closely with the U of U Divisions of Pediatric Neurology, Genetics and Developmental physicians. Through a number of different funding mechanisms, physicians from the U of U provide services through our CSHCN services. There is a long and positive relationship with these divisions of the U of U and efforts to think outside the box to improve access to services for children with special health care needs are fully supported.

Medical Home

In collaboration with the University of Utah (U of U), the Centers for Persons with Disabilities (CPD) at Utah State University (USU), Utah Family Voices (UFV) and Medicaid, the Bureau of Children with Special Health Care Needs (CSHCN) implemented a program in 1999 to train and support Pediatric and Family Practice groups in the Medical Home (MH) model of care for CSHCN. Through several MCH grants the program has trained and continues to support 23 pediatric groups, 6 dental groups, employs a part time MH coordinator and Parent Partner, and developed a medical home website providing resources and support to practices. The website also provides information and support for families, other health care professionals and educators. Several of the Medical Home practices focus on providing care to a diverse ethnic population including the University of Utah Redwood and Greenwood campuses, (variety of ethnic groups) South Main U of U (Hispanic) and Montezuma Creek Community Health Center (Native American).

Most of the trained Medical homes are located along the Wasatch Front where most of the population resides with only a few rural areas represented. There are 8 Counties with active Medical Homes leaving 21 counties devoid of a trained medical home. Family practitioners are under-represented despite an active recruitment process to that group. Currently 6-8 new practices are being recruited to participate in a peer-mentored MH training. The program is also developing a distance-learning module to train more rural practices in the model of care.

Utah Regional Leadership Education in Neurodevelopmental Disabilities (URLEND)

Over the past 5 years, numerous successful public and private projects have expanded and improved the service system for Utah children and youth with special health care needs and families at both the state and community level, including the Utah Leadership Education in Neurodevelopmental Disabilities grant, the Utah Registry for Autism and Developmental Delay grant, the Newborn Hearing Screening grants and Birth Defect Surveillance grants. Through these grants and many other collaborative efforts, the Bureau enjoys a strong working relationship with the majority of key players in service provision and advocacy for children and youth with special health care needs in our community.

Specialty and Tertiary Pediatric Health Care

Utah is also fortunate to have excellent health care resources for children, including University of Utah Health Sciences Center, Primary Children's Medical Center and Shriners' Hospital for Children. The CSHCN Bureau enjoys an excellent working relationship with Utah State University's Center for People with Disabilities, the Utah Center of Excellence for People with Developmental Disabilities. The Bureau is working toward collaborative multidisciplinary developmental clinics with the University of Utah, Department of Pediatrics. This year the bureau and the Department of Pediatrics established their first joint clinics at the Salt Lake CSHCN center. The Department of Pediatrics provides pediatricians for the clinics and bills families directly for evaluations. CSHCN Bureau provides clinic space, clerical and nurse or social work support, and makes other therapy evaluations available as needed to children up to 8 years of age.

CSHCN clinic services are billed to the family's insurance, Medicaid or CHIP on a sliding scale. MCH funds are used to support these clinics. The clinics will be evaluated to determine if this model is cost neutral for the Department of Pediatrics. If successful, the model will be expanded to rural traveling clinics. Similar efforts will be undertaken with the CSHCN orthopedic clinics in SLC in Fiscal year 2011 and if successful, will be expanded to the other CSHCN Orthopedics clinic sites.

Emergency Medical Services

Through the Division of Emergency Preparedness, the Emergency Medical Services for Children (EMSC) has established a program, specifically tailored to children with special health care needs and their families (CSHCN Program). Since children with special health care needs are more likely to need EMS, the CSHCN program has developed the program, including the web site at <https://health.utah.gov/ems/emsc/cshcn/> to aid families in gathering pertinent information in an area that EMS providers will look for it. The service will enable parents or guardians of children with special health care needs to fill out information sheets about their children, in an effort to facilitate better emergency care by EMS responders and hospitals. Currently there are 45 registered special needs participants in the program. The CSCHN program of EMSC has been working to make the web site more user-friendly and accessible to families. They have also been attending community sponsored events, i.e. Hill Air Force Base health fairs to raise family awareness of the service.

CSHCN Executive Group (CEG) and other collaboration

Over the past 10 years, through numerous grants and projects, CSHCN has established strong collaborative relationships with many of the key state agencies and advocacy groups supporting children and youth with special needs. Partners include the University of Utah Department of Pediatrics, Utah State University-Center for Persons with Disabilities, Utah Family Voices, and Legislative Coalition for People with Disabilities, Utah Family Voices, the Disability Law Center, Utah Developmental Disability Council, and the Utah State Office of Education/State Rehabilitation Council.

In 2008, at the close of the MCH Utah Integrated Services Grant, the CSHCN Executive Group (CEG) was established, to provide monthly consultation and advice to the Bureau. A relatively small group, the CEG is comprised of CSHCN senior staff, University of Utah Department of Pediatrics, Utah Family Voices/Utah Parent Center, Utah State University-Early Intervention Research Institute and Center for People with Disabilities. CEG has been invaluable in guiding CSHCN in new projects and grant applications.

The Bureau is also closely involved with the new Family-to-Family Health Information Center. Not only does the Bureau support the Center financially, but the Bureau has hired this person as the Family Involvement and Leadership Program manager. CSHCN Bureau staff is also on the Advisory Board for the Family to Family Center. In addition, the Bureau is working with the Utah Family Voices Director as they complete their technical assistance focus groups on health insurance information needed by Utah families. Ultimately this information will be used to develop insurance information modules on the Utah Medical Home Portal website.

The CSHCN ASD project staff and contractors have been a model of collaboration and coordination between federal, state, community and family partners. Partnerships include the Autism Council of Utah, the Utah Autism Initiative, Utah Parent Center, Utah Family Voices, Parent to Parent Health Information Center, the University of Utah Department of Pediatrics, Utah State University Center for Persons with Disabilities, families trained to assist other families, Medicaid, Early Intervention, Medical Home, private providers, among many others.

Another successful collaboration with Utah's Medicaid Infrastructure Grant (MIG) and Work Ability Utah was initiated to support outreach and training to medical practices specifically in the area of employment as a viable option in futures planning for youth with medical disabilities. Adult health care, health care financing and work incentives and supports are all key pieces to bringing young adults successfully to employment.

Section 4: MCH Program Capacity by Pyramid Levels

A major component of the 2011 Needs Assessment was the statewide Stakeholder Survey, which surveyed individuals representing Department programs, other state agencies with whom the Department partners, community-based agencies, advocacy organizations and parents regarding their perceptions of needs for mothers, children, and children and youth with special health care needs and their families in the state. The results of the Stakeholder Survey and the CSHCN Parent Survey, along with key data, such as Performance Measures, Outcome Measures, Key Informant Interviews, were reviewed to determine the state's priorities for FY2011 - 2016.

Priority concerns for women of reproductive age include:

- Increasing rate of primary cesarean section deliveries among low risk women
- Increasing rate of late preterm births
- Decreasing rate of folic acid consumption
- Increasing rate of maternal mortality
- Increasing rate of elective inductions of labor
- Increasing rate of pre-pregnancy obesity
- High proportion of women who gain above the recommended weight during pregnancy
- High rate of very short interpregnancy intervals
- Stagnant trend of fetal mortality
- Increasing treatment for postpartum depression

Priority concerns for children include:

- Abuse and neglect
- Mental health (suicide)
- Obesity and physical activity
- Oral health
- Sex education/teen pregnancy and STD prevention
- Drug, alcohol and tobacco use
- Child development screening

Priority concerns for children and youth with special health care needs include:

- Improve awareness, access and knowledge of mental health services
- Provide and promote early screening and identification/diagnosis of developmental delay, ASD/DD and other chronic and disabling conditions
- Promote the development of infrastructure to promote statewide electronic health record
- Adequate and affordable insurance coverage
- Promote coordinated system of community and state support and service systems
- Promote family involvement and leadership

- Promote the development and improvement of transition to adulthood
- Improved oral health/dental home and family awareness and education about children and youth with special needs
- Continue to promote and provide increased rural access

Needs assessment for the two levels of the pyramid of services (Direct Services and Enabling Services) were combined into one section as they are so interrelated.

Direct Health Care Services and Enabling Services

Availability of Care

Direct and enabling health care services in Utah are available through both public and private providers. Local health departments and community health centers are critical resources for services for the maternal and child health populations. In Utah, local health departments and 12 community health centers, as well as the migrant centers provide public care. Recently two new free health centers were opened in Salt Lake County to attempt to address the demand for health care services for low-income uninsured individuals. Local health departments provide direct and enabling services, but no primary care. Services for children with special health care needs are provided by the State CSHCN programs, rural clinic sites in collaboration with local health departments, and through private providers. Division staff provides technical assistance, consultation (administrative and clinical), training and/or mentoring as needed to local health departments and community health centers providing services to women and children, such as prenatal, family planning, immunizations, nurse home visiting and school health/nursing. Program monitoring and data collection are conducted at the state level to assist in program planning and evaluation.

Each local health department determines which MCH services it will provide based on available resources, community priorities and need. The Division provides each district with MCH block grant funds for provision of services for the MCH population, although each varies in offered services. Clearly, demand and need for services exceed the system's capacity to provide them. The requirements of the MCH Block Grant contracts focus on core public health functions. The contracts require reporting of numbers served, financial reporting and report on activities that LHDs provide for mothers, children and children with special health care needs. The local health departments have shifted from direct services. An example of this "shift" is the Southwest Utah Health Department discontinuing their contract with the Bureau of CSHCN, stating that direct care for this population of children was not in their mission. CSHCN was able to negotiate with the St. George based Intermountain Women's and Children's Center to donate office space and computer support for the locally based CSHCN care coordinator clinics, which now serve the five county region, without support from the local health department.

Reproductive health services, of varying degrees, are available in all twelve local health departments. Direct prenatal services are available in two Wasatch Front local health departments, Salt Lake Valley Health Department, through a contract with the University

of Utah Health Sciences Center, to utilize these agencies' facilities and support staff in providing low cost prenatal care. The second site, Weber-Morgan Health Department provides support to the CHC to provide prenatal care in a cost effective way, Presumptive eligibility screening and various enhanced prenatal services are available at both sites. Both programs serve numerous Hispanic women, many of who are of undocumented status. Although both clinics employ bilingual personnel, many providers utilize interpreters to communicate with women served in these clinics.

Ten local health departments provide some type of pregnancy related care including perinatal care coordination (PCC). PCC assesses prenatal clients for risk factors that might negatively affect their pregnancies, develops action plans based on these risk factors, and assist clients in obtaining needed services throughout their pregnancy and postpartum periods. The actual number of perinatal care coordination visits varies across local health districts and even between the various satellite sites within a health district. Most of the local health departments that do PCC also provide pre- and postnatal home visiting for Medicaid women. Again, the extent of home visiting varies across local health districts and between a health district's offices. Some health districts visit many of their prenatal mothers; others visit only those at extremely high risk and some lack staff to provide prenatal home visiting services at all. One local health department provides presumptive eligibility only.

Among the 3,621 women served for family planning services in 2008, 42.1% were of Hispanic origin and 2.8% were of other than white race. Almost 90% (89.1%) of women served had no health coverage and 5.9% had Medicaid. Among infants served, 57.8% were Hispanic, and 8.2% were of other than white race. Health Coverage distribution was the 4.7% had no insurance, 85.9% were on Medicaid and 0.9% were covered by CHIP. Of Children 1 – 22, 62.9% were Hispanic, and 22.9% were of other than white race. The breakdown by health coverage revealed that 81.2% had no health insurance and only 11.6% were covered by Medicaid, and 1% by CHIP. Individuals of Hispanic ethnicity are overrepresented in the population served by local public health entities.

Individual nutritional counseling for women at high nutritional risk is available through WIC or private registered dietitians. Psychosocial counseling is also available, usually by county mental health programs to the same group of women. Medicaid reimbursable group childbirth education is offered through most hospitals.

The Utah WIC Program has 49 clinic sites throughout the state serving approximately 76,260 women, infants and children. Clinics are located in urban and rural areas, including a clinic in Roosevelt Utah that serves the majority of Ute Indians from Fort Duchesne. Rural areas often staff several satellite clinics offered at different times during the month. Because multiple counties are incorporated into rural health departments, clinic hours are more limited than those in urban sites, which are generally open more days and offer a larger range of clinic hours to meet participant needs. Rural clinics tend to have more personalized and efficient services, while urban clinics are staffed with a greater number of Registered Dietitians and bilingual staff.

At present, the WIC Program has sufficient funds to serve the existing level of participation. However, with the new food packages that include fresh fruits and vegetables, whole grains that include whole wheat tortillas, whole wheat bread or brown rice, we have found that our food costs have increased since the new food rule was implemented on October 1, 2009. We make it a priority to continue to monitor both our administrative and food dollars so we can serve as many individuals as possible. Utah WIC continues to be able to serve all individuals that need services this year. Though WIC enrollment numbers have increased over the past year with the decline in the economy, we have monies remaining to add eligible women, infants and children who are in need of our services.

Local WIC staff analyze the CDC Pediatric (PedNSS) and Pregnancy (PNSS) Surveillance data annually to identify specific areas of declining nutrition and health-related indicators, such as increasing rates of anemia, obesity and / or malnutrition as reflected in inadequate weight gain or growth patterns. Following the analysis, local WIC staff develops goals and action plans to reduce the prevalence of any increasing rates of adverse health indicators. In the Utah WIC Program, two new effective nutrition intervention strategies, Family Centered Education and Facilitated Group Discussion, have been implemented to increase family involvement and interaction. Many WIC mothers lead very busy lives and find that our new offering of online nutrition education classes that can be taken on computers in the clinics or libraries or in participants' homes to be very convenient. These strategies have resulted in positive behavior changes related to improved nutritional consumption and greater physical activity among WIC participants.

In 2004, the Utah WIC Program received funding from the USDA to implement the *Best Start Loving Support* Breastfeeding Peer Counselor Program. The funding will enhance the local infrastructure of the Peer Counselor Program by increasing the work hours of existing peer counselors, hiring new peer counselors, raising the hourly salary rate, and providing training for all peer counselors to maintain a current knowledge base. These enhancements will provide better support for breast-feeding mothers. It is known that utilizing Peer Counselors within the scope of the overall services provided to WIC participants will result in an increase in breastfeeding initiation and duration rates. A major benefit that Peer Counselors provide to breastfeeding mothers is the peer mom-to-mom support with anticipatory guidance for the prevention of problems, such as sore nipples, improper positioning, and engorgement, as well as early appropriate referrals for medically related problems, such as thrush, mastitis, etc.

WIC serves as a referral source to many preventive and primary care programs. Since local WIC staff see participants at regular intervals over an extended period, they are a vital link in providing access to other services. Women who have not received prenatal care at the time of enrollment into WIC are assigned the risk factor "Inadequate Prenatal Care", referred to prenatal care, and tracked until care has been established. WIC staff also refers participants to Medicaid and CHIP if not already enrolled. Some WIC clinics coordinate with other services such as well child exams, immunizations, Baby Your Baby appointments, and family planning.

The Division of Family Health and Preparedness and the State WIC Program work with the WIC Advisory Council, which includes representation of local WIC administration, local vendors, advocacy groups as well as WIC participants. The focus of the Council's input has been broadened from budget issues to include program issues, such as access to services, certified versus vouchered participants, and policy changes, e.g., three-month vouchering. The Council has provided important input into program issues.

A growing segment of the population unable to obtain prenatal services is undocumented women. These women do not qualify for presumptive eligibility and Medicaid is available to them only under the Emergency Medicaid Program for labor and delivery services. One Wasatch Front local health department provides on-site prenatal care through the University of Utah OB Department and enrolls increasing numbers of undocumented, often non-English speaking, women in their prenatal clinics. For these women, paying for needed outpatient and laboratory services is difficult. Another local health department provides similar support for prenatal care through the family physician residency program. Community health centers along the Wasatch Front have been faced with the same growing numbers of undocumented women and have had to cap the number of prenatal women they are able to see.

In rural areas of the state, access to prenatal care is difficult for women without a payer as there may be no community health center or providers may not be willing to see them. As a result, some undocumented women are unable to obtain prenatal care and seek medical care only at the time of labor via hospital emergency rooms.

Easily accessible, affordable family planning services remain problematic for many Utah women. Women on Prenatal Medicaid are only eligible for health care coverage, including family planning, for approximately 2 months following delivery. Following termination of their Medicaid eligibility, many women are unable to afford family planning services. The Primary Care Network, a Utah 1115 Demonstration Waiver project, will enable some women in this category to have coverage for primary care services, including family planning. However, a fifty-dollar enrollment fee, citizenship requirements and limited periods of enrollment are barriers. The Utah Health Policy Project, a non-profit organization that is very active in Utah in the area of healthcare reform published a fact sheet to promote Utah adopting family planning coverage for all women of reproductive age who are at or below 133% of the federal poverty level. The MCH Bureau is hopeful that this will help to move political will toward the implementation of this much needed resource in Utah.

Due to funding limitations, local health departments, community health centers and Title X clinics have not been able to meet the demands for women needing family planning services. Most rural local health districts, unable to fund midlevel practitioners to provide family planning services, provide family planning education and subsidize visits to private health care providers for family planning examinations and contraceptive prescriptions.

The local health departments may also subsidize purchase of oral contraceptives; however, this service has been significantly reduced due to loss of public health discounted funding by pharmaceutical companies. Many rural areas have no community health center or Title X funded clinics leaving women to navigate private sector providers who are often unwilling / unable to see those who are non-paying. Local boards of health may limit the provision or promotion of emergency contraception. Family planning services are not available at all in one rural local health district, which does not have a community health center or Title X clinic.

One of the community health centers in the Salt Lake City area has limited family planning services for established patients only. Many teens, at increased risk for unintended pregnancies, are not able to access a Title X clinic (offered through Planned Parenthood Association of Utah, the state's Title X grantee - that does not require parental consent), especially in rural areas. The state law requiring government agencies to obtain parental consent prior to discussing or providing family planning information or services to minors continues to present a barrier to teens needing these services.

Barriers that Impact Accessibility of Care

According to the 2008 Utah Healthcare Access Survey (UHAS), the percentage of Utahns with no health insurance increased from 2001 through 2006 and then began to slowly decline. Those aged 18 to 34 years were most likely to report no health insurance, with males more likely than females to lack health insurance. In 2008, 15.4% of Utah women 18-34 years of age had no insurance, showing no change since 2004. The 2008 UHAS indicates that 8.4% of children birth to 17 years of age representing more than 71,000 children was without any type of health care coverage. CSHCN were more likely to be insured than other children with 4.2% of CSHCN not having insurance (according to National CSHCN Survey, 2005/06).

Being uninsured, underinsured or uninsurable are three critical barriers to accessing health care for women of childbearing ages and children, but especially for children and youth with special health care needs. Issues, such as living in rural areas, low socio-economic status, personal beliefs about health care, primary language, or ethnicity affect access to health care. The low or non-existent providers in Utah especially in rural areas compounds access to care and the paucity of available mental health and dental services are seen as an issue for women of childbearing ages, children and youth, especially for those with special health care needs. Direct and enabling services for children and youth with special health care needs are available through many private providers and Utah's tertiary care centers along the Wasatch Front, but the same is not true for the less populated areas. Certain types of specialists or services continue to be difficult for families living in these areas to access, including high-risk obstetrical care, home health nursing, dental, genetics, orthopedics, neurology, multi-disciplinary evaluation services for developmental delay and pediatric mental health. Certain preventive and support services are especially difficult for families of children and youth with special needs to access, such as dental services, physical, occupational, speech or language therapies,

respite care, vocational rehabilitation and transition to adult health care. Problems with access to care are compounded by the increasing complexity of insurance coverage.

The uninsured in the state have a significant impact on private providers, local health departments, community health centers, hospitals and safety net providers. Some private providers offer reduced or no cost health services, but that is an individual provider decision. Local health departments (LHD) often report that they provide immunizations and other services to uninsured families. They believe that private providers send uninsured families to the LHDs because they are not able to pay the administration costs for immunizations. VFC requires VFC providers to waive administration fees for those unable to pay. If true, this places an undue burden on the LHDs. Community health centers are maxed out with uninsured individuals who seek their services. They have placed limits on new patients in a number of their centers as the demands increase beyond their capacity to serve. Safety net clinics have opened to serve the uninsured, but to what extent they are able to maintain services we do not know.

Intermountain (formerly IHC) is a not for profit health care system and as such is required to provide a certain level of charity care. Intermountain does provide charity care as part of their commitment to the community. In addition, the University of Utah Hospital provides services to a large percent of the uninsured population, taxing their limited resources.

Eligibility for Utah's Prenatal Medicaid program has not been increased from the 133% of the federal poverty level (FPL) since its inception in 1990 and continues to require an asset test for enrollment. During the 2010 state legislative session, the asset limit was decreased from no more than \$5,000 in assets to no more than \$3,000 in assets to qualify for prenatal Medicaid. It is estimated that this will impact about 2,500 women who would have previously qualified, but will not with the decreased limit. Many women and their families, best categorized as working poor, are ineligible for health care coverage, making it difficult for them to access health care, especially prenatal and family planning services. In April of 2004, the Presumptive Eligibility application was revised to more closely reflect Medicaid guidelines. These revisions resulted in a more stringent citizenship question requiring applicants to have permanent residency status. The changes also more closely defined household membership.

Utah's Primary Care Network (PCN) Waiver was approved by DHHS to enable the state to provide coverage for an additional 25,000 individuals for a reduced package of primary care services. However, PCN has reached enrollment capacity and applications are currently only accepted during designated enrollment periods. Additionally, no prenatal coverage is available through the program, undocumented women are not eligible for coverage under PCN and anecdotal information indicates that the fifty-dollar enrollment fee may pose a barrier for some women. Medicaid's current eligibility level for children birth -5 years of age is 133% FPL and 100% FPL for children 6-18 years of age. The Utah CHIP eligibility level is 200% FPL for children from birth to age 18 years. The Department of Health has created the UPP program (Utah's Premium Partnership for Health Insurance), which helps make health insurance more affordable for

working individuals and families. UPP helps eligible adults and children pay monthly insurance premiums when they enroll in their employer's health insurance plan. UPP eligibility is based on family size, income and if the applicant's employer's health insurance plan meets basic guidelines. UPP reimburses eligible individuals/families up to \$150 per adult and \$120 per child in the family each month for their monthly health plan premiums.

Financial barriers to family planning services are significant. The state does not allocate any state dollars to family planning services with exception of the state match for Medicaid family planning services. State law mandates that state agencies and political subdivisions of the state obtain parental consent prior to provision of family planning information or services to unmarried minors, such as educational curricula in the schools on reproductive health. As a result, many adolescents desiring family planning services through the low cost clinics available in local health departments are unable to access them.

Over the past few years, local health districts have not been able to purchase discounted oral contraceptives from the pharmaceutical companies on the grounds that they do not meet the qualifications for eligible entities described in Section 340B(a) of the Public Health Service Act. Local health departments in Utah do not receive Title X funding, 330 funding or any other funding source listed in the act as eligible for this vital coverage. Title V Maternal and Child Health Block Grant funded agencies are not among those qualifying for 340B Program participation. Without 340B discounts, women in the local health districts have to pay retail for their oral contraceptives making purchase of them impossible for many. As a result, some local health departments have formed purchasing alliances that enable them to purchase contraceptives at discounted rates. Others have applied for and received Primary Care Grants that are utilized for purchase of contraceptives. However, if more of the health districts lose the 340B discount or Primary Care Grant, provision of oral contraceptives will become more limited. Additionally, several local health departments have removed Depo Provera from their formularies due to prohibitive retail costs due to loss of the discount purchasing

Medicaid enrollment of children has also increased to more than 188,000 children, an increase of 15% from the previous year. Utah children with Medicaid enjoy a relatively generous Medicaid package. Medicaid benefits do not extend to those children with special health care needs or their families who are of undocumented citizenship status unless they have a life-threatening condition. Children who are eligible for SSI disability benefits are also eligible to apply for Medicaid coverage, although they must complete a separate application. Although more children are able to access care through Medicaid outreach and the availability of CHIP, some children still remain uninsured either due to financial factors or inability of the parents to follow through with the application process.

To improve access to services for young children, Medicaid developed the Early Childhood Targeted Case Management Service for Medicaid-eligible infants and young children provided by public health nurses to assess the young child's health needs and referral to a medical home and other needed health care and social services. Public health

nurse staffing shortages and challenges in providing matching funds have prevented Medicaid's Early Childhood Targeted Case Management Service from reaching its full potential.

Utah Medicaid offers a number of different options, which are designed to maximize financing of care through Medicaid. The CSHCN Bureau has negotiated several different types of reimbursement options with Medicaid, such as reimbursement for specific clinical and case management services provided through a Medicaid Administrative Case Management contract.

Out-stationed Medicaid eligibility workers, a shortened enrollment form, an electronic application system, and other efforts have helped increase accessibility to enrollment and coverage for families has been promoted.

The Utah Children's Health Insurance Program (CHIP), implemented in August 1998, is a state-developed health coverage assistance program for children who do not have other health insurance and who meet the program's eligibility criteria. To be eligible for Utah's CHIP Program, a child must be age 18 or younger, not covered by an insurance plan and not eligible for Medicaid. The family's income must be below 200% of the federal poverty level (FPL) and above the Medicaid's income standard of 133% of the FPL for children birth through 5 and 100% of the FPL for children ages six through 18. The program initially suffered from inadequate funding to maintain open enrollment, but the State Legislature has over the past several years allocated enough funding to maintain open enrollment. This financial support has helped so many families who were confused about when CHIP was "open" or not. Now the program has more than 41,000 children enrolled, a 10.4% increase since 12 months ago.

Though Utah's CHIP Program provides access to routine health care, it was not designed to provide adequate coverage for the special needs populations, putting them at risk of being underinsured. Low-income children and youth in Utah with special health care needs are often eligible for Medicaid through the "disability" category that gives the child access to relatively more extensive health coverage than CHIP.

Due to budgetary concerns, CHIP imposed co-payments for health services as well as premiums in January 2002. Although these requirements are compliant with federal regulations, they may have resulted in a higher number of disenrolled children than previously seen.

Enrolled families tend to drift in and out of the programs often depending on changes in income levels or in health status. Enrollment may lapse during periods of health with reapplication in time of medical need. In an effort to address enrollment challenges, CHIP made rule changes in 2004 that allowed children being disenrolled from Medicaid due to income and age limitations to be enrolled in CHIP, and that allowed newborn or adopted children (if they met the eligibility requirements) of families enrolled in CHIP to be enrolled without having to wait for the next open enrollment period. In 2004, rule

changes allowed families that were delinquent in premium payments to make back payments and re-enroll within a one-year time period.

Some Hispanic parents who are legal residents or of undocumented citizenship status may not enroll their children in Medicaid or CHIP for fear of negatively impacting their citizenship application, being reported to the U.S. Citizenship and Immigration Services, or possible deportation. Outreach to this community has been done through Spanish-language print materials, radio and television ads, and newspaper articles.

It is anticipated that more families, once enrolled in CHIP or Medicaid, will utilize the system in a way that emphasizes preventive health care and decreases the use of emergency rooms and insta-care facilities as “primary care”. However, for families with children with special needs, many needed services are not covered by private insurance or CHIP. Financial barriers continue to exist for families and children whose condition and/or services are not covered by third party payers or managed care organizations (e.g., pre-existing conditions, therapy, orthodontia, dental and surgical exclusions). These families experience high out-of-pocket costs to obtain needed health care.

Limited provider panels offered through managed health care plans reduce the accessibility to qualified specialty care available for children. Utah CHIP has improved basic medical coverage for uninsured children but specialty services are not covered. Though Utah’s CHIP provides access to routine health care, it was not designed to provide adequate coverage for the special needs populations, putting them at risk of being underinsured.

Access to immunizations may be difficult for children who are underinsured, for example, children whose family income is between 100 - 200% of the federal poverty level who would qualify for CHIP except for the fact that they have some medical insurance. The State Immunization Program’s Vaccine for Children (VFC) Program is available for children who are on Medicaid, uninsured, underinsured, or of American Indian/Alaska Native heritage. VFC provides free publicly funded vaccine to enrolled providers, which has greatly increased over the past five years to include many more private providers enrolled in the program. Local health departments charge an administration fee for immunizations between \$5.00 - \$15.00, which can be waived for families unable to pay.

Access to dental services is problematic for many children. Children who would otherwise be eligible for CHIP have no dental coverage because they have health insurance without dental coverage. As a result, they are not able to easily access dental health services unless their parents are able to pay out of pocket for the services. Provider reimbursement rates have made it difficult for families on Medicaid to find a provider willing to provide care for such low rates.

Many low-income families are not able to afford medical nutrition therapy due to lack of insurance coverage or funds to pay for these services out of pocket. The Utah WIC Program provides comprehensive nutritional services, along with needed food

supplements to eligible women, infants and children. Despite fairly significant participation increases through FFY 2009, the WIC Program has been able to serve all individuals seeking services. During FFY2009, the Utah WIC Program increased enrollment from approximately 66,000 to 76,500 participants. As of April 2010, program enrollment has dropped slightly to 76,260. Utah WIC appreciates the current administrations' determination in fully-funding the WIC Program with the amount of money required to serve all those who are need of services at this time. Even with Utah's high birth rate, the Utah WIC Program is optimistic that we will be able to serve all individuals who seek services until the current economic situation rebounds.

According to the National Children's Survey (2007), Utah children with special health care needs are not as likely as other children to have adequate health insurance, with 79.3% of children without special needs reported that their current insurance coverage is adequate to meet their child's needs. This compares to only 74.6% of children with special health care needs reported having adequate insurance. The CSHCN Survey (2005/06) shows that the birth to 5 year old population was insured in the previous 12 months at 85%, followed by the 6-11 year old population at 88.9% and older CSHCN (12- 17 years) at 90%. Another interesting finding in the 2005/06 CSHCN Survey is that families who lived at less than 200% FPL were more likely to experience gaps in insurance coverage than those living above 200% FPL. Utah families that are at or below 200% of FPL in Utah are usually eligible for CHIP or Medicaid, but are more likely to experience loss of insurance coverage. It may be that, outreach efforts to this population need to be increased.

Families with older children (12-17 years) are more likely to report spending \$1000 or more on out of pocket medical expenses (30.1%) than families with younger children (birth to 5 years old) (22.2%). Parents of older children and those with lower incomes were more likely to have lower out of pocket expenses than those who are at 400% FPL or higher. (CSHCN Survey 2005/06) The Utah Needs Assessment Stakeholder Survey 2010 validated these data, with parents reporting that the primary challenge in caring for their child with special needs was the financial impact on the family.

Utah children with Medicaid enjoy a relatively generous Medicaid package, and children with moderate to severe health conditions are often eligible for this comprehensive coverage. Children with mild conditions, however, may not qualify for Medicaid. Additionally, children with special health care needs who are of undocumented citizenship status are not eligible for Medicaid unless they have a life-threatening condition. Children who are eligible for SSI disability benefits are also eligible to apply for Medicaid coverage, although they must complete a separate application. Although more children are able to access care through Medicaid outreach and the availability of CHIP, some children still remain uninsured either due to financial factors or inability of the parents to follow through with the application process.

Health Care Reform changes, beginning in 2014, will greatly increase the number of families who can access health insurance, Medicaid or CHIP for their children. It is anticipated that all states will be required to extend Medicaid coverage for all people to

133% of Federal Poverty Level. Many of the families currently covered by Utah CHIP, the Primary Care Network (PCN), or the Utah Premium Partnership for Health Insurance (UPPS) will be shifted to Medicaid coverage, which has a more comprehensive benefit package. This will be especially beneficial to families whose children have complex medical or developmental conditions. Additionally, Utah has already begun to develop “insurance pool” options for families, and many Utah insurances already cover unmarried dependent children up to age 26 years.

Only 48.9% of parents rated their health insurance plan as “adequate” in covering all the health care costs associated with their child with special health care needs. Insurances and CHIP offer some rehabilitative services for a child, such as physical, occupational or speech/language therapies, but the number of visits is so limited that the needs of children with very critical needs may not be covered. Special education can augment these services, but therapies at school are still often inadequate.

While most families (58.6%) indicated that their annual out-of-pocket costs were less than \$500, 2.2% reported annual expenses of \$5,000 or more. The most common reason that parents reported for having a problem with access to medical, dental or other types of care was “could not afford services” cited by 20.9% of parents. Parents of older children and those with lower incomes were more likely to report that cost had prevented or delayed getting services for their child.

Utah Medicaid offers a number of different options, which are designed to maximize financing of care through Medicaid. The Bureau of CSHCN has negotiated several different types of reimbursement options with Medicaid, such as reimbursement for specific clinical and case management services provided through a Medicaid Management contract. Funding collected for these Medicaid administrative activities is returned to the programs that generate the matching funds, CSHCN clinic and care coordination services and the Fostering Healthy Children Programs.

The Baby Watch/Early Intervention Program (BWEIP) has negotiated Medicaid reimbursement for services for children between the ages of birth to three years. Approximately 30% of children in BWEIP are Medicaid eligible. Covered services include: case management, individual physical, occupational and speech therapy, nursing and referral to other resources in the community. Medicaid also reimburses for “child find” activities and general administration of the program for Medicaid eligible children.

Additionally, through an intra-agency Memorandum of Agreement with Medicaid, CSHCN Bureau receives funding to provide the day-to-day administration and case management for the Technology Dependent Waiver Program. This waiver program offers the choice of home and community-based alternatives for technology dependent, medically fragile individuals with complex medical conditions, who would otherwise require placement in a Medicaid, enrolled Nursing Facility to obtain needed services. The waiver operates statewide, and serves a maximum of 120 recipients at any point in time.

Under "waivers" of specific (statutory) comparability and eligibility requirements, this waiver program provides Medicaid eligibility for children by waiving certain financial eligibility requirements. Recipients receive the traditional Medicaid scope of services and in addition "extra" waiver services. Services beyond the regular Medicaid program available for children on this waiver program include: Skilled Nursing Respite Care, Family Support Services, Home Health Certified Nursing Assistant, Extended Private Duty Nursing, In-Home Feeding Therapy, Financial Management Services and Family Directed Support.

The following Home and Community Based waivers are currently in effect for the State of Utah: (1) Community Supports Waiver for Individuals with Intellectual Disabilities and Other Related Conditions (CSW); (2) Individuals 65 and Over; (3) Technology Dependent/Medically Fragile Recipients (TD/MF); (4) Acquired Brain Injury for Persons 18 and Over (ABI); (5) Physically Disabled Adults 18 and over (PDW); and (6) New Choices Waiver for Person 21 and Over (NCW).

The CSHCN transition specialist provides training, consultation, and support to CSHCN Bureau staff and community partners in the area of adolescent and young adult transition services. These services include planning for financing ongoing health care and transitioning to adult health services. CSHCN Bureau staff in clinical and community-based, rural programs receive assistance and education in the process of supporting families throughout the SSI application. Training is provided in identifying potential candidates for SSI participation and increasing successful referrals of children. The Specialty Services SSI specialist maintains a statewide database of potential SSI eligible children age 16 and under.

Shortages of Specific Types of Health Care Providers

Availability of services is obviously a function of the health care workforce, hospitals, and public health workforce. Seventy-five percent of the state is classified as rural and frontier, leaving huge gaps in availability of providers. The state Health Professional Shortage Areas indicate a shortage of family medicine, obstetric/gynecologic, and pediatric physicians, as well as dentists in the state. The maps in Appendix D detail areas of the state with provider shortages for medical and dental providers. It is very clear that Utahns, especially residents of the huge rural and frontier areas of the state have little to no access to provider, especially to specialty providers. These gaps require rural residents to travel great distances to access the care they need, especially for pediatrics, obstetricians and pediatric dentists. For example, for Family Medicine Physicians (FMP), one county has no family medicine physician, five with ratios ranging from 5541-9330:1 and 9931-22864:1; thirteen with a 2965-5540:1 ratio with ten having a 1-2964:1 ratio of population to FMP.

A priority concern for women of reproductive age is geographic availability of prenatal and family planning services for rural and frontier residents. According to Health Professional Shortage Area surveys, there are areas in Utah with very high ratios of women of childbearing age to providers, resulting in very limited access to a prenatal

provider in their area. Women in rural communities may have to travel many miles to a provider and/or hospital. More than half of the counties (15 out of 29) are without any obstetrician; two range between 2935-4807:1 to 4808-9438:1 obstetrician and twelve counties range from 1-2225:1 to 2252-2934:1 population to obstetrician. Five counties have population to family medicine physician ratio ranging between 5541-22864:1. One rural county has no prenatal care or family planning provider of any kind and one county reported as few as 1 provider to 10,000 women of childbearing age.

According to the 2008 Utah Healthcare Access Survey, more than 6% (6.4%) of children had problems accessing health care. Of parents surveyed about their child's health status for the 2008 Utah Health Care Access Survey, almost 60% (58.8%) were excellent; 24.4% were very good; 13% were in good health; and, 3.8% reported their child's health as being poor. Results from the 2008 UHAS indicate that 20.9% of children did not receive a routine medical check-up in the previous twelve months, a 7% decline from 2003. Lack of access to needed medical, dental, or mental health care was reported for 6.4% of children

Access to dental care is a priority concern, especially for Utah children, including those with special needs. Dentists willing to take Medicaid-enrolled children are becoming more of a problem than ever due to low dental reimbursement rates. In addition, the misperception that oral health is not related to overall general health remains a challenge to overcome. The 2007 National Survey of Children's Health found that only 79.1% of Utah respondents had a preventive dental visit within the previous year. The NSCH also found that 7.6% of parents said the condition of their child's teeth was fair or poor. Access to a dentist is problematic for large portions of the state (refer to Appendix D for HPSA maps). Two counties have no general dentist; five counties have a population to dentist ratio of between 2727 - 6943:1.

Local agency capacity to assist with presumptive eligibility determinations for prenatal Medicaid has been problematic in some areas of the state, especially in the urban areas with limited Presumptive Eligibility (PE) sites, mainly due to lack of reimbursement for the service. The Division instituted the "Baby-Your-Baby by Phone" to provide PE screening over the telephone for Salt Lake County women and screened close to 2000 women for PE in 2009. For sites with long wait times for appointments women are referred directly to the Department of Workforce Services' workers to make a Medicaid application.

Fourteen counties in Utah lack pediatricians; five have population to pediatrician ratios that range from 5541-9330:1 to 9931-22864:1 pediatrician; and seven have a 1-2324:1 ratio of population to pediatrician. One county has no family physician. Access to pediatric subspecialty care is often very limited by geography and by the number of subspecialists available. About 220,000 children live in the rural/frontier areas of the state.

Access to low cost prenatal care and family planning through community health centers, local health departments and clinics operated by Planned Parenthood Association of

Utah, the state's Title X grantee has been difficult in many areas of the state, especially in the rural areas without community health centers or other clinics. Although sliding fee schedules are available, the demand for low cost health care often exceeds capacity, especially for women without documentation.

Access to dentists in Utah is also a major issue for Medicaid participants and for individuals living in rural or frontier areas of the state because there are few dentists in the rural areas. The Oral Health Program initiated an Oral Health Summit designed to look at issues related to oral health in the state with the plan to develop workgroups to identify priorities and strategies to address these issues. The difficulty of finding a dentist, especially in the rural communities, was identified as a major barrier to oral health care access. One solution suggested was the inclusion of dentists and possibly dental hygienists in the state primary care grants and in the loan repayment program for working in health professional shortage areas. The legislature has created the Utah Health Care Work Force Financial Assistance Program and now dentists are eligible for loan repayment opportunities for working in rural dental health professional shortage areas. This program was discontinued in the 2010 legislative session because of budgetary reasons, but the professionals currently in the program will remain until their contract has ended. Two counties have no general dentist; one county has a population to dentist ratio of 4235-6943:1; four counties have a population to dentist ratio of 2727-4234:1; thirteen counties have a ratio of 1872-2726:1, with the remaining 9 counties with a ratio of 1 – 1871:1. Nineteen counties have no pediatric dentists available in their communities; one county has a ratio of 11634-14583:1 pediatric dentist; three counties have a ratio of 8701-11633:1; three counties have a ratio of 5685-8700:1; and three have a ratio of 1-5684:1.

Remote or rural areas of the state continue to suffer from a shortage of pediatricians, family practice and especially pediatric sub-specialists, such as pediatric ophthalmologist, neurologists, orthopedists, geneticists, and neonatologists. In Southwest Utah, St. George, Intermountain Healthcare has established a "Women's and Children's Health Center." This has been one of the most promising rural efforts to establish subspecialty services for children who have chronic health conditions. In order to maximize scant resources and to improve the community based options for children, Intermountain Healthcare donated clinic and office space, as well as phones and internet to the CSHCN clinics in St. George. The CSHCN care coordination team is now housed in the Intermountain Facility in St. George and oversees the traveling CSHCN clinics. This year, Intermountain, CSHCN and the University of Utah Genetics department are jointly funding a part time geneticist in the St. George clinic.

There is also a notable shortage in physical, occupational and speech therapists as well as pediatric audiologists. The Baby Watch/Early Intervention Program (BWEIP) oversees a statewide credentialing program for professionals in the early intervention field working with children birth to 3 years. BWEIP has agreements with the University of Utah and Utah State University for pre-approved programs of study that will allow graduates in early childhood education to receive the state early intervention credentials. The CSHCN Bureau has received a three year HRSA grant to provide targeted infant and pediatric

audiology training to current and newly trained audiologists to help improve state shortages. Most audiologists trained prior to the last half decade did not receive specific training to provide services to pediatric patients.

Another example of the shortages of therapists is illustrated by the need for Speech and Language Pathologists (SLP), who continue to be in high demand locally and nationally. A recent Utah State University study reported critical shortages statewide in all related service specialists, such as speech language pathologists, psychologists, physical therapists and occupational therapists. The study indicated that aside from stiff competition in hiring, Utah colleges and universities aren't graduating enough students to meet the demand. Anecdotal information suggests that shortages likely exist in urban and rural areas, school settings, and for the provision of services to culturally and linguistically diverse populations.

CSHCN staff members are also working with Utah Leadership Education in Neurodevelopmental Disabilities (ULEND) trainees to provide direct services for children and consultation to local BWEIP home visiting staff in rural Utah for children under three. Additionally, the BWEIP and the State Office of Education collaborate on the Signal Project, which is a state improvement grant through the Federal Office of Special Education Programs that addresses the recruitment and retention of specialized personnel in early intervention and special education. The grant develops and targets strategies at the pre-service and in-service levels for personnel working in the special education field.

Shortages of public health nurses is becoming more apparent as the workforce ages and new nurses coming into public health often have little if any formal public health training or experience. Local health nurses in most health districts do not have a bachelor's degree which is a reflection of the nursing environment in Utah in terms of capacity, education and numbers. Limited resources preclude hiring additional public health nurses to provide more in-depth services to the maternal and child populations of the state, such as care coordination, home visiting services, and grief support to families that experience infant deaths. In addition, the limited numbers of Spanish-speaking public health nurses employed by the local health departments is a barrier to serving more Spanish-only speaking families. Local health departments have worked hard to bring on Spanish-speaking staff however; they are limited in this area due to budget constraints and limited numbers of individuals who are able to fill the positions when available.

In the past, the Utah WIC Program has had difficulty in recruiting and retaining registered dietitians in the rural clinics and in some of the urban sites as well. In rural areas, Registered Dietitians (RD) cover more than one clinic site due to shortages of registered dietitians and low salaries in public health. In the past some WIC clinic sites have had positions open for long periods. However, at present there are no vacancies for RDs in the Utah WIC Program as a result of broader and more effective recruitment and retention practices. However, recruiting a registered dietitian for rural clinics is very difficult given the low salaries and the availability of RDs. Recently, utilizing state and national salary data for RDs, the WIC Director of the largest urban district (Salt Lake)

was able to negotiate an increase in salaries for the registered dietitians in the local WIC Program. Two rural WIC Directors for TriCounty and Central Utah were able to negotiate hiring registered dietitians on a contractual basis at a higher hourly rate than that of a full time employee. In addition, the salaries for RDs were examined in 2007 by the Utah Department of Health in conjunction with the Human Resources Office to determine if a market adjustment was needed after an extended search for an RD in the state program office. Upon successful market adjustments for the open position, the program was able to successfully recruit a RD.

Remote or rural areas of the state suffer from a notable shortage in physical, occupational, and speech therapists. The Baby Watch/Early Intervention Program (BWEIP) oversees a statewide credentialing program for professionals in the early intervention field working with children to 3 years. BWEIP has agreements with the University of Utah and Utah State University for pre-approved programs of study that will allow graduates in early childhood education to receive the state early intervention credentials.

Preventive and Primary Care for Pregnant Women and Mothers and Infants

The Department of Health toll-free Baby Your Baby Hotline continues to provide information and referrals to callers seeking providers and/or financial assistance for prenatal care, family planning, well childcare, nutrition services, or other MCH-related services. The hotline staff collaborates well with community resources in order to promote these and ensure that information is current. The hotline is viewed as a valuable resource for both callers, as well as community resources. The Department sponsors numerous other hotlines that serve the MCH populations. A recent review of Title V Hotlines by the Commonwealth Fund and the Association of Maternal and Child Health Programs highlighted the Baby Your Baby Hotline in an article in press ranking the Hotline as one of the best in the nation.

Some prenatal services, including Presumptive Eligibility (PE) determination, are offered by all local health departments (LHDs). One urban LHDs (Salt Lake Valley Health Departments) serves as a site for direct prenatal services that are actually provided by the University of Utah Health Department of Obstetrics and Gynecology. This same health department also serves as a site for children's health care, provided by the University of Utah Department of Pediatrics.

Federal MCH funding has been allocated to the Salt Lake City Community Health Centers, Inc., to support prenatal services to uninsured women. Depending on a woman's payer, all or a portion of the enhanced prenatal services (perinatal care coordination and pre/postnatal home visiting, nutritional counseling, psychosocial counseling and group pre/postnatal education) are available directly or by referral to other agencies.

All twelve LHDs obtain a prenatal history, including obstetrical, nutritional, and brief socioeconomic and psychosocial review. Risk factors are identified and a plan of action developed. The woman is assisted in finding a provider and referrals to other resources

are made based on her need. Availability of enhanced prenatal services varies among the health districts and even among an individual health district's sites.

The University of Utah Health Sciences Center has a comprehensive program for pregnant teens in the Salt Lake City area. This program includes Presumptive Eligibility (PE) screening, prenatal care for the teen and a prolonged period of intensive follow-up for the mothers to prevent rapid repeat pregnancies and well child care for her infant. Four University of Utah Health Centers in Salt Lake City also provide presumptive eligibility for women enrolling in their prenatal programs.

Low cost perinatal and family planning services, utilizing a sliding fee scale, are available in community health centers in the state, including four rural sites. Family planning services based on a sliding fee scale are available through Planned Parenthood Association of Utah (PPAU), the state Title X grantee. PPAU is currently collaborating with the LHDs to provide emergency contraception supplies for qualifying women. MCH has developed a strong relationship with PPAU over the years with much collaboration between the two agencies on a number of common issues.

A clinic for comprehensive health care for homeless individuals is located in Salt Lake City. Presumptive eligibility is available as well as family planning through this agency's contract with Planned Parenthood Association of Utah. A migrant health center in northern Utah, Centro de Buena Salud, in Brigham City, provides presumptive eligibility (PE) screening and antenatal care to eligible women. Prenatal care and family planning services are available to Native American women at Ft. Duchesne in northwestern Utah and at Montezuma Creek and Monument Valley Medical Clinics on the Navajo Indian Reservation in southeastern Utah. Both sites on the Navajo Indian Reservation provide presumptive eligibility screening. Presumptive Eligibility screening is also available through two hospitals located in Salt Lake City.

The Utah WIC Program has an effective referral process, which is a component of its program for pregnant women and mothers and infants. Current listings and information about other nutritional support and related health agencies are maintained in every WIC clinic and distributed to every participant. Referral agencies on the list include Baby Your Baby, Medicaid, Food Stamp Program, family planning clinics, hospitals, dental clinics. These health-related programs receive outreach materials providing information about the Utah WIC Program and the clinic locations with phone numbers on an annual basis. Local WIC clinics also use routine in-service programs to schedule representatives of other health-related programs to present information that can be used by WIC staff as part of the referral process in working with WIC participants.

Community-based injury prevention programs are available in each of the twelve local health departments through contracts from the Violence and Injury Prevention Program. Community-based injury prevention programs targeting pregnant women, mothers, and infants have included infant and child car seat promotion, occupant protection, water safety, drowning prevention, fire safety, and home safety.

Preventive and Primary Care for Children and Youth

For immunizations, more than 300 sites in the state are currently VFC providers, including local health departments, private providers, and community health centers making low cost immunizations available in most communities. The majority of the VFC providers are in the private sector. Some areas of the state may have few VFC providers, which may pose a barrier to eligible children receiving needed immunizations. The Immunization Program has been working to expand its VFC provider network to most Medicaid providers, as well as with other providers in the state. The Immunization Program provider relations staff promote enrollment in the state immunization registry, USIIS, when they are visiting provider offices for VFC follow-up. Having the same staff enroll providers in VFC and USIIS has been very effective.

WIC Program clinics throughout the state provide information to parents whose children are WIC participants on other health-related preventive and primary care services for children, including referrals to primary care providers or medical home for well child examinations and immunizations, dental care, and Medicaid and CHIP.

The Oral Health Program has applied for a CDC grant that would assist Utah in fluoridation, sealants and other preventive activities. We hope to expand our capacity to address oral health needs in the state. The State Dental Director has worked to assist LHDs in developing local coalitions formed around the need for improved access to dental care.

The Oral Health Program has supported fluoridation of community water systems through provision of information and participation in local meetings. The 2000 Utah Legislature passed a bill allowing counties of the second class to present a referendum to its residents to vote on fluoridation. At that time, only two communities in the state (other than military installations and Indian reservations) had added fluoride in their water supply: Brigham City in Box Elder County and Helper in Carbon County. Voters in Davis and Salt Lake Counties approved fluoridation in November 2000; implementation was completed for the most part by October 2003. Legislation to restrict water fluoridation has continued to appear in proposed bills in each of the Legislative Sessions since 2003, although they have failed to pass. Davis County held a revote on water fluoridation in November 2004, despite the fact that most communities in the county had implemented the fluoridation of the water systems; residents voted by a narrow margin to continue fluoridating their public water.

Since only one of the local health departments has a dental program to provide for community needs, it is vital for the state to continue to expand its efforts to promote better dental health care and access, especially for disadvantaged populations. The state staff plays a key role in assisting communities, provider and advocacy groups, insurers, and other partners to improve the oral health status of Utah children by developing effective strategies to promote and implement prevention-focused activities and by seeking ways to improve access to oral health care services. The Oral Health Program is committed to promoting oral health as a priority for a broader population of Utahns, i.e.,

pregnant women whose poor oral health may affect their pregnancy. Additionally, the state needs to continue to advocate for addressing dental needs among MCH populations by developing strategies to improve oral health status.

Using the Oral Health Task Force model implemented in Salt Lake County, an Oral Health Initiative needs to be expanded to include selected communities to build an integrated system of oral health care for underserved children. Collaboration among many players in these communities must be accomplished in order to coordinate growth of the system, outreach and referral, volunteer services, special needs services and public awareness. Prevention must be maximized to reduce the demand upon the system.

The State Dental Director is a member of Utahns for Better Dental Health, a group organized to promote community water fluoridation in Salt Lake County, serves as a consultant to county boards of health throughout the state, which are involved in water fluoridation activities, and also serves as a member of the Utah Dental Association Dental Access Committee. The issue of dental health services for pregnant women and mothers is an area that the Division hopes to expand and to oversee, as well as oral health among other populations. Activities undertaken by the Salt Lake Valley Health Department Oral Health Task Force, the HRSA grant funded Coordinated Dental Access System and the Health Access Project (HAP) have resulted in increased access to preventive and treatment care among children residing in Salt Lake County. Collaboration among community health center dental clinics, Medicaid dental clinics and school nurses has resulted in a referral system which guarantees children identified with emergency dental needs timely access to care. A similar collaboration among public dental clinics and volunteers examining Head Start children has resulted in more children being identified in need of dental treatment and accessing care. Children are referred to the appropriate facility based upon the type of treatment required as well as the child's economic or insurance status. Sealant Saturday projects provide occlusal sealants for many uninsured or underinsured children. Collaboration among the Oral Health Task Force Prevention subgroup, Utahns for Better Dental Health and the local sections of the Utah Dental Association Utah Oral Health Coalition and the Utah Dental Hygienists Association has made it possible for Salt Lake County residents to vote on community water fluoridation in the November 2000 general election. Implementation of water fluoridation in Salt Lake County began in October 2003.

Substantial numbers of low-income children still remain without dental insurance, and do not qualify for CHIP because they have some medical insurance. In order to address this concern, FHP has worked with the Regence Blue Cross/Blue Shield (BC/BS) Caring Foundation, which has established a program for low income children to receive services from a BC/BS dentist. The scope of services provided through the Caring Foundation is identical to those provided by PEHP dentists to children enrolled in CHIP and is available statewide. In 2004, the Caring Foundation was able to provide dental services to over 1000, uninsured children in Utah. Then in 2006, Sealant for Smiles, a non-profit organization, began providing free sealants for children in Title I schools. Since it began more than 15,000 children have received sealants.

Utah CHIP began enrollment in August 1998. The program provides coverage for dental services through Public Employees Health Program (PEHP). The program has been successful in providing access to needed dental care for CHIP-enrolled children. Although Utah CHIP has proven a valuable resource to enrolled children, the scope of CHIP dental benefits is not as broad as that for children enrolled in CHEC/EPSDT. While the dental benefits in Medicaid for children may be more expansive than those covered by CHIP, the low reimbursement rates for Medicaid dental services is a major barrier to dentists providing services to children on Medicaid. The CHIP dental reimbursement rates are much higher, perhaps accounting for a larger percentage of CHIP children receiving dental services.

In 2010, the Violence and Injury Prevention program was awarded a three year MCHB TBI systems development grant. One of only three awarded in the country, this project will build the infrastructure to support children and adults in Utah with Traumatic Brain Injury. The target populations for this project will be children under age four, military veterans served through VA Hospital and Native Americans with TBI.

Availability of Specialty Care Services for Children with Special Health Care Needs

The Bureau of Children with Special Health Care Needs in collaboration with the University of Utah, Division of Pediatrics continues to provide direct and enabling services to children with special needs who are unable to access services through other sources. Due to funding constraints, the Bureau's direct and enabling services are focused on children in three groups: 1) young children birth to age 8 years with suspected developmental/genetic/hearing disorders; 2) children to age 18 needing developmental evaluation in rural Utah; and 3) newborn ICU graduates, birth to 6, whose birth weight is less than 1200 grams, who have had ECMO, or who have known disabling conditions. These direct services include multi-disciplinary developmental evaluation clinics in Salt Lake City and in 7 satellite sites; early intervention services in 12 rural and 7 urban centers (Baby Watch Early Intervention Program); and newborn follow-up multi-disciplinary developmental evaluation clinics for newborn ICU graduates in Salt Lake, Provo and Ogden through the Neonatal Follow-up Program). Information and care coordination are provided by CSHCN staff to improve access to SSI services and for Spanish speaking families. Care coordination is provided for children who are followed in CSHCN clinics or early intervention centers and to children served by dedicated case management programs such as the Fostering Healthy Children Program and the Technology Dependent Waiver. These direct and enabling services are described in more detail in the Overview section.

The CSHCN Bureau Collaborative Medical Home program has been working with pediatric offices and dental offices throughout Utah to enhance their capacity to provide medical homes for children with special needs and their families. There are currently 23 trained Medical Home teams and 6 Dental Home teams in Utah, who continue to participate in the Collaborative Medical Home project. Eleven more practices are being trained this summer (2010). Division staff members provide technical assistance, consultation (administrative and clinical), training and/or mentoring as needed to local

health departments, contracted private providers, medical homes and community health centers that provide services to mothers and children.

Through the Utah Collaborative Medical Home Project, CSHCN, in collaboration with the University of Utah, has implemented a statewide system to support primary care physicians in providing medical homes for children with special health care needs. As part of this system, a website was developed to meet the needs of the practices to provide coordinated, comprehensive and family centered care. The Medical Home Website, <http://www.medicalhomeportal.org>, provides users with up-to-date information on chronic diagnosis, practice guidelines, care coordination, and statewide resources. The site also includes a module directed at families, a transition module with resources, and an education module directed at physicians, care coordinators and families. The website is a work in progress as the site is continually updated with information and new modules. Information is primarily directed toward primary care physicians however it is readily accessible to families of children and youth with special health care needs and other health care or educational providers.

CSHCN supports a part time Coordinator and a part time Family Advocate for the Medical Home Project and now serves twenty three primary care medical home practices and six dental homes around the state through technical support, site visits email broadcast resource information, office trainings, community presentations, and family advocate support. A biannual medical home newsletter, which is sent out to all pediatricians and family practitioners in the state, is topic oriented and includes local, state, and national resources pertaining to each topic. Columns for the Utah Chapter of the American Academy of Pediatrics and the Utah Family Practice organization are submitted quarterly

The Bureau of CSHCN developed a consultant committee with representatives from the community including families, educators, mental health providers, ethnic groups, and physician specialists to advise the project staff on activities and spread of the medical home model of care.

Through a state/local partnership in seven rural areas, the CSHCN Bureau conducts local developmental evaluation clinics. In the five sites of Moab, Blanding, Price, Montezuma Creek and Richfield, CSHCN continues to contract with local health departments for nurse care coordination and clinic management. However, due to cuts in funding and lack of nursing availability in Vernal, the TriCounty Health Department contract was cancelled; but, the Ogden CSHCN staff now provides the clinic coordination in Vernal. Similarly, the St. George local health department was no longer able to support the CSHCN clinic, but through collaboration with Intermountain Women's and Children's Center in St. George, space is donated to CSHCN to continue to provide local clinics. In a nearby community, CSHCN closed the Cedar City clinic and now sees them in the St. George traveling clinic, 40 miles away (see Appendix D).

The CSHCN Bureau provides a number of clinical services for children and youth with special health care needs in the state. Eight clinical programs in addition to the Baby Watch Early Intervention Program provide services to children and families in the state:

Birth Defects and Genetics Program; Child Development Clinic; Hearing, Speech, and Vision Services Program; The Neonatal Follow-up Program; School Age and Specialty Services Program; Community-Based Services Program; Fostering Healthy Children Program; and Newborn Screening Program. Direct services are also provided in the CSHCN Bureau itinerant clinic staffing held with local providers, such as pediatricians, public health or mental health workers, human service workers and families/ family advocates, after the child has been evaluated in the multi-disciplinary CSHCN Bureau clinics, during which a multi-agency care plan is developed for each child. Telehealth is utilized in the itinerant sites, which facilitates ongoing communication between the CSHCN staff, local health department and the schools.

In Utah, children who have SSI are generally eligible for Medicaid, although they must apply for the services. The SSI Specialist in CSHCN works with the Office of Disability Determination Services (DDS) that evaluates disability claims for SSI eligibility. The specialist reviews the claims and provides outreach and referral for appropriate families to Medicaid, which requires a separate application. The specialist also provides information, referral and enabling services to families having difficulty accessing or utilizing services, such as Utah Legal Services, Disability Law Center or consultant staff in DDS. A CHSCN Bureau staff member participates on the DDS Advisory Committee that has fostered cross training of CSHCN Bureau and DDS staff. It also provides the development of professional relationships between SSI, DDS and CSHCN Bureau staff so that conflicts over individual applicants can be resolved. Preschool children who are deaf, blind or otherwise disabled receive early intervention services from Utah School for the Deaf and Blind, Parent Infant Program in collaboration with the Bureau of CSHCN BabyWatch/Early Intervention Program. Rehabilitation services for older children are usually provided by one of three tertiary care facilities, Primary Children's Medical Center, Shriners' Hospital and the University of Utah Health Science Center or private community providers. If the child is SSI eligible, they may access these services through Medicaid in combination with any private health insurance the family may have. CSHCN clinical staff often provides an initial rehabilitation evaluation (especially in rural Utah) and then assists families of these children with information and referral. Assistive Technology evaluations may be provided by CSHCN staff, but more frequently are provided by local school districts in collaboration with the Utah Center for Assistive Technology.

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In Utah, the BabyWatch Early Intervention Program (BWEIP) is a significant provider of therapy services, especially in rural areas. BWEIP serves over 5,000 children per year and anticipates a growth rate of 10% per year because of identification of eligible children, eligibility changes to include very low birth weight (<1000 grams), the program's excellent reputation, and increased collaboration with physicians.

Each of the six specialty care centers is equipped with air transport teams to expedite transfer of high- risk patients emergently. The rates of very low birth weight births (VLBW) occurring in tertiary hospitals equipped for high-risk deliveries and neonates is gradually improving from 79.2% in 1999 to 81.4% in 2008. We have made progress in this area with an increase in maternal fetal medicine specialists being hired for most hospitals with a NICU.

As stated earlier, because of continued access barriers to developmental evaluation of children in rural Utah by pediatric subspecialists, including pediatricians, CSHCN continues to provide direct and enabling services through satellite clinics, the Fostering Healthy Children program, the Baby Watch Early Intervention program and the Technology Dependent Care Waiver. CSHCN is also updating its' telehealth capacity and the CSHCN Medical Director will oversee a pilot project to provide subspecialty follow from the SLC office for rural CSHCN patients and families.

Increased efforts to promote Medical Home in new settings for all children came about due to loss of grant funding for the Utah Collaborative Medical Home Project and the planning through the State Early Childhood Comprehensive Systems grant. Methods to educate community service providers on the concept have been explored including providing links to the Project website through other websites. Work with the Utah Pediatric Partnership to Improve Healthcare Quality (UPIQ) is expected to assist pediatric primary care providers in moving toward a Medical Home model through the continuous quality improvement process. Contracts with local health departments include the provision that public health support a child's medical home. It has not been without controversy as the local health departments view this perspective as undermining what they are doing for children. This perspective has been included in the MCH Block grant contracts as well as the Immunization contracts.

Throughout Utah, a combination of State CSHCN programs, rural or local health department clinics, private providers and medical homes provide "safety net" services for Utah's children and youth with special health care needs. CSHCN is continuing to provide direct pediatric developmental team evaluations for children in the Salt Lake office and in 9 satellite clinics. The CSHCN's Transition Specialist, in collaboration with Utah's Work Ability and the Becoming Leaders for Tomorrow Project, provides transition training and information to medical providers in rural sites including Blanding, Moab, Richfield, and Vernal. Training includes tips to support transition, ways to improve office processes, and community resources to support families.

Information is primarily directed toward primary care physicians however it is readily accessible to families of children and youth with special health care needs and other

health care or educational providers. Project staff continue to outreach to all pediatricians with information on local services through periodic newsletters, columns posted in local professional newsletters, practice site visits and community presentations.

Thirty-two Fostering Healthy Children nurses work in local DCFS offices with Human Service workers to insure that children in Foster care receive optimal medical, mental health and dental care through case management. The nurses work with foster and biological parents, health care providers, as well as providers of health related services, such as early intervention and Head Start.

Impact of Emerging Issues on State's Ability to Provide Direct and Enabling Services

The “emerging issue” for the state is the drastic cuts in state general funds for the Department of Health, especially in the CSHCN Bureau which lost \$1 million for the SFY11. These cuts have required careful review of available funds and priority services to continue for children and youth with special health care needs. As a result of the cuts, staff has been reduced due to program closure, clinics have been reduced or eliminated and contracts with outside providers have been reduced or cut. We hope that as the economy stabilizes, we will be able to get more funding to support the services needed.

The most concerning emerging issue impacting the ability for CSHCN to continue direct services has been the national and state economic recession. Over the past two years, the bureau of CSHCN has lost \$1.5 million in state general fund, which directly affected the ability to continue the clinics and care coordination provided to Utah children with special needs. The bureau lost over 15 FTEs of staff, through attrition and reduction in force, has closed two Hearing and Speech offices in Price and Cedar City, and has restructured clinic delivery and contracts for Salt Lake and rural CSHCN clinic sites. The bureau has been able to maintain most of the basic developmental evaluation services to children less than 8 years of age and to graduates of Utah newborn intensive care units (for children born 1200 grams or less). Clinic and care coordination services for children over 8 years of age living in the Wasatch front has been eliminated (ABLE program) or transferred to the University of Utah Department of Pediatric Developmental clinics, where possible.

Utah has experienced an influx of Spanish-speaking immigrants many of whom are of undocumented status. From 1999 to 2008, the number of live births to Hispanic women rose 45%; from 5,455 (11.8% of live births) to 9,493 (17.1% of live births). According to the 2008 UHAS, the last year for which data are available, 36.5% of Hispanics had no health insurance compared to 7.0% of non-Hispanic residents, showing an increase in non-insured Hispanics and a decrease for non-Hispanics. The 2005 Legislature passed a law that no longer allows anyone of undocumented citizenship status to be issued a driver's license; rather, they are issued a driving permit, which cannot be used by any government entity in the state as a form of identification. This restriction may serve as a barrier for undocumented workers in obtaining services regardless of the funding source, i.e., WIC. Another state law affects some public benefits for people over the age of 18

who will be denied certain benefits because they lack U.S. Citizenship. Most public health programs, including WIC and other public health services for children under age 18, will not be affected. Medicaid and the Children's Health Insurance Program, which already require proof of legal status, will continue to do so.

The low rate of children's access to dental care, especially those on Medicaid, has been very concerning. Utah continues to have one of the lowest Medicaid dental reimbursement rate in the nation, making it difficult to engage dentists to see Medicaid children for care. It is anticipated that problems of access to routine preventive dental care for children, youth and adults with special health care needs will persist over the next five years. Some of the barriers include: many dentists are reluctant and/or not trained to treat children and youth with disabilities in the traditional office setting; and, many children and youth with disabilities are Medicaid participants. The Utah Department of Health has been well aware of the poor reimbursement rate for dental care.

The federal language under the Child Abuse Prevention Treatment Act (CAPTA) requires that all preschool children with substantiated cases of abuse and neglect be referred to the Early Intervention Programs for screening and treatment. This federal requirement could potentially have a great impact on the volume of referrals and number of children who are served by the Baby Watch/Early Intervention (BWEIP) Program. BWEIP has collaborated with the Department of Human Services, Division of Child and Family Services (DCFS) to develop screening plans as well as policies and procedures for the referrals. The policy includes DCFS procedures for child protective personnel to utilize the Ages and Stages Questionnaire (ASQ) for children birth to three at their initial home visit. Fostering Healthy Children program staff score and track ASQ results in the DCFS SAFE database. Children who show potential problems on the ASQ are referred to the BWEIP. Thus far, this system of referral has been effective in identifying children with developmental delays, and has resulted in a moderate, but improve increase in accurate referrals to early intervention programs.

Another emerging issue for Early Intervention is the need for improved, earlier identification of children who may have Autism Spectrum Disorder/Developmental Delays (ASD/DD). Through the Utah ASD/DD Infrastructure grant, a pilot project is being implemented to examine methods of earlier and more accurate identification and referral of children to Early Intervention who have or may have ASD/DD. Additionally, the ASD/DD grant is providing funds to develop training for early screening and referral for diagnosis to Medical Homes and Dental Homes.

A potentially large issue is the re-authorization of the Early Hearing Detection and Intervention Act that provides the bulk of the funding for grants nationwide. This Bill was recently passed in the House and is awaiting a vote in the senate. Loss of these funds would essentially dismantle newborn hearing screening efforts nationwide as well as put undue pressure on already stretched Title V funds. Newborn Hearing Screening, due in large part because of legislative mandates in most states, has dramatically reduced the age of identification for children born with an educationally significant hearing loss. Early

identification and appropriate early intervention services can reduce the cost of special education services by \$400,000 by the time a child reaches the 12th grade.

Cultural Acceptability

The 2000 Census revealed that the largest proportion of ethnic minorities in Utah to be of Hispanic or Latino origin (9.0%), followed by Asian (1.7%), Native American (1.3%) and other minorities (<1%). Since 2000, there has been a 14.3% increase in the Hispanic population (from 204,254 to 233,425). By 2003, Hispanics accounted 10% of state's total population. Currently, one out of every ten Utahns belongs to an ethnic or racial minority group and these populations are growing more than twice as fast as the state population as a whole. The challenges become even greater in establishing and maintaining family-professional partnerships when the family is not from the predominate culture.

During 2008, the Center for Multicultural Health, along with numerous UDOH partners produced a Qualitative Report that summarized the results of 17 community discussion with 180 members of four Utah racial and ethnic minority communities. The report highlighted eight common themes from the groups including: Health Messaging Advice-teaching skills, being concise, use native languages, show minority faces, emphasize in-person communication; Health Program Planning Advice-involve minority community members, pay volunteers, support community-based organizations; and Broad Messages-minorities believe they face greater challenges than other Utahns, lack of health insurance is their greatest concern, cultural barriers interfere with healthy lifestyles and racism in health care settings is a barrier to preventive care. This information will be very valuable in addressing the health disparities that are present among our Utah minority populations.

Utah's predominantly white, non-Hispanic population distribution creates difficulties for our racial and ethnic minority populations as health care providers often lack knowledge and sensitivity to their cultural differences and beliefs about health care and needs. For example, in the Tongan language, there is no word for "prevention", making it difficult to convey the value of prevention versus treatment. Advocates for racial and ethnic minorities promoted and passed legislation in 2004, which provided state funding for a Center for Multicultural Health, which is housed within the Utah Department of Health's Division of Family Health and Preparedness. The 2005 Legislature appropriated additional ongoing funding for the Center. This Center is currently developing strategies to address needs and improve health care for our racial and ethnic minority populations. Additionally, the Department's Ethnic Health Advisory Committee provides input to programs on concerns of communities that are beneficial in program planning efforts.

The Department of Health has a Native American Liaison, housed in the Division of Family Health and Preparedness. The Liaison has established relationships with program staff in the Division of Family Health and Preparedness and is working with staff to identify strategies to improve the health care status and need of the Native American population in Utah. The Department of Health strives to make data available on health status of ethnic and minority populations as much as possible. Small numbers often pose

a barrier to publishing the data due to concerns regarding its reliability and confidentiality. The Department's Center for Health Data staff has been working with the Director of the Center for Multicultural Health and the Native American Liaison to publish an updated report on the health status of ethnic and minority populations.

Utah has a unique population whose health care needs is challenging to address, the families living in polygamous communities around the state. Some programs run into barriers, such as home births and lack of compliance with state mandated newborn blood screening and newborn hearing screening. The Department is working closely with this community to assist them in performing the needed screenings. Programs providing services to the Hispanic population are increasingly developing resources for Spanish-speaking families so that they have the same access to information that English-speaking families do. Programs have expanded websites to include pages for Spanish speaking individuals. Print materials and other resources have been developed in Spanish. While we recognize that cultural differences extend beyond language, programs are continuing to evaluate methods in which they can outreach to disadvantaged populations, including those of ethnic or racial minority. With the Department's Center for Multicultural Health and the Native American Liaison staff programs have greatly benefited from working with them to improve cultural sensitivity and appropriateness. A number of Department websites has material posted in both Spanish and English, including the Maternal and Infant Health Program and Children with Special Health Care Needs. The Center for Multicultural Health's website allows for information in a number of different languages. Other programs have also developed Spanish-language materials. With the ever increasing growth in numbers of individuals who speak a language other than English or Spanish, it is challenging to ensure that interpreters are available for the wide range of languages used among individuals moving into the state.

CSHCN strives to hire Spanish speaking staff, whenever possible, as most of the non-English speaking families, speak Spanish. For families who speak a language other than English or Spanish, CSHCN has a contract with the AT&T language line for brief translation, such as informational calls. Additionally, CSHCN hires contracted medical translators for families whose children are seen in clinics. The CSHCN website and the Utah Clicks sites have text in Spanish and English, and many of the CSHCN program brochures are also translated.

Utah data from the National CSHCN Survey (2005/06) notes significant disparities between Hispanic families and white families in several categories. When asked whether Utah CSHCN usually or always have family-centered care, 66% of the white non-Hispanic families responded positively compared to only 56.5% of Hispanic families. When these two populations are compared in the area of having a usual source of care for both sick and well child care and the area of having a personal doctor or nurse (Medical Home)-there are no significant discrepancies in responses. Although these areas show improvement, Hispanic parents report a lower satisfaction rate as partners in decision making and satisfaction with services, compared to their white non-Hispanic counterparts (34.4% vs. 57.7%). This is a significant downward trend when compared to the CSHCN 2001 survey. In 2001, 66.2% of Hispanic parents reported being satisfied as partners in

decision making and satisfaction with services compared to only 34.4% in 2005/06. These demographics simply underscore the increasing need for continued and improved education and resources to provide optimum health care for children and youth with special health care needs from minority populations.

The Bureau provides cultural awareness training for staff and contract providers, in addition to providing written training and resource materials. Bureau staff has met with the Ethnic Health Advisory Board and the DOH Native American liaison to open dialogue about improving outreach and services to children and youth with special health care needs and families from the different Utah cultural populations. The Bureau's largest minority population served is children from Spanish-speaking families. CSHCN has made an effort to hire Spanish-speaking staff, to translate training materials and application forms into Spanish and to have Spanish signage in clinic areas. Two of the nine medical home teams established with the Bureau's support over the past five years serve predominantly low income and Spanish-speaking families and children. CSHCN clinics along the Wasatch Front have access to interpreters and translation services through state contract, and the AT&T language line is available in all clinics.

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Another notable disparity from the 2005/06 CSHCN Survey is that the Hispanic population is significantly more likely to experience a gap in insurance coverage (29%) compared to the white non-Hispanic population (10%). The rate for Utah Hispanic population with lapses in insurance is almost double that of the national rate (29% vs. 15.1%).

Staff working on the Medical Home Portal web site continued to explore ways to improve the cultural accessibility of the web site. In 2007 the Medical Home Portal staff submitted a proposal to the Mountain States Genetic Regional Collaborative Center (MSGRCC) for funding to translate the "For Parents & Families" and the "Newborn Disorders" sections of the portal into Spanish. Since the proposal was not funded, the portal staff continued the practice of providing links to other web sites that contain Spanish materials including newborn conditions, other diagnoses, and health promotion information. The Medical Home Portal director, authors, and advisory committee

members serve on committees that work to improve access to health care for minority populations.

Other web sites within or affiliated with the CSHCN Bureau have promoted accessibility to culturally appropriate information. The Pregnancy Risk Line contains a page with content in Spanish and regularly distributes, to pregnant and breastfeeding women, several brochures and outreach materials translated into Spanish. Spanish-speaking callers to the Pregnancy Risk Line are served through a telephone-operator translation service. The Becoming Leaders for Tomorrow Project provides links to transition and self-advocacy information for youth, young adults, and families in Hmong, Somali, and Spanish.

More local health departments and community health centers have worked to hire bilingual health professionals to better meet the needs of the increasing non-English speaking population. Since the major ethnic group in Utah is Hispanic, clinics have attempted to address the needs of the Hispanic population by hiring bilingual staff. However, other groups in the state, such as Somali refugees, Russian immigrants, are growing in numbers that are also hard to reach due to language barriers, cultural barriers, and provider acceptability.

Linkages to Promote Provision of Services and Referrals between Levels of Care

In Utah, there are seven tertiary centers for perinatal health care and three tertiary centers for children's health care. Each center has University of Utah College of Medicine faculty assigned and is well recognized throughout the state and the Intermountain West as premier consultation and referral centers for obstetrical and/or pediatric cases. These centers work with hospitals within their referral areas to encourage consultation and referral as needed, depending on the condition of the mother, infant or child.

The Maternal and Infant Health Program has worked to implement a variety of strategies in an attempt to reverse the trend of increased percentages of very low birth weight infants delivered outside Level III perinatal centers. One of the issues related to classification is that the traditional definition of a tertiary center does not include provision of high-risk specialty services for the mother which should go hand in hand with the neonatal high risk specialty care. We have been watching this carefully as we have seen newborn intensive care units develop in hospitals without the accompanying maternal fetal medicine specialists to ensure that the mother is getting the best possible care to improve pregnancy outcome for her and her baby. Changing hospital services, including several Level II hospitals hiring neonatologists to care for VLBW infants born in their facility without the benefit of a maternal fetal medicine specialist to ensure that the mother's care is optimal for her and her baby prior to delivery, have played a role in this trend.

Medical records case review work was done a number of years ago and indicated that infants in the upper weight ranges (1,000 to 1,500 grams) of the VLBW category are receiving acceptable neonatal care equivalent to a level III standard in several level II

nurseries in the state where the majority of these VLBW births are occurring. In order to promote compliance with the ACOG/AAP *Guidelines for Perinatal Care*, the Maternal and Infant Health Program worked with the Department's Bureau of Licensing to rewrite the Utah Administrative code related to hospital perinatal services. The code changes included specific details regarding the standard of care required for labor and delivery services, which had previously not been included in the code. Intermountain Healthcare (formerly known as IHC), the largest integrated health care system in Utah, owns almost half of the delivery hospitals in the state with a network of over 3,000 health care providers. As a result of the Utah Code amendment of rule 432-100-17, the Director of Intermountain's Women and Infant Services has been collaborating with the UDOH MCH Bureau Director and the Maternal and Infant Health Program Manager for input into revising Intermountain's Perinatal Program Standards for obstetric and neonatal hospital care to better reflect the new rule requirements. Although these revised standards will still most likely result in some VLBW babies being delivered at level IIB hospitals, the standards should go a long way toward improving the hospital standards for the VLBW infants born in Intermountain facilities. Continued collaboration to assess the impact of these revised standards will be ongoing. Because the other half of the delivery hospitals throughout the state are owned by other corporations or a government entity, the amended Perinatal Services rule needs to be disseminated to these facilities. Although the rule change should help to clarify expected standards of perinatal care for delivery hospitals through-out the state, market factors exist that may influence hospitals' decisions regarding delivery of VLBW infants in non-tertiary care facilities.

Staff from DFHP interfaces with health providers from these centers through various MCH efforts, including Perinatal Mortality Review, Child Fatality Review, Youth Suicide Prevention Task Force, clinical services, joint projects, and other committee work. Staff participates in a number of efforts led by University of Utah School of Medicine faculty, such as the perinatal Epidemiology workgroup. Through these efforts, the need and importance for consultation and referrals between levels of service are emphasized in reports of mortality review findings or reports on specific topics, such as low birth weight. For example, if through infant death review it is discovered that appropriate consultation and referral were not sought, the coordinator will contact the appropriate referral center to increase their awareness of the need for outreach to community providers and hospitals in their referral area.

The CSHCN Bureau continues to jointly conduct orthopedic clinics with contract University of Utah pediatric orthopedists. Orthopedic clinics are conducted weekly in the Salt Lake area and three or more times per year in the nine rural satellite clinic sites. CSHCN provides physical therapy, occupational therapy, social work and resource specialist support (a specialist who supports families in accessing community resources) to all the clinics. CSHCN staff provides follow up care coordination for the children and families.

The CSHCN Bureau also continues to provide local multidisciplinary developmental evaluation clinics in rural Utah, Salt Lake, Ogden and Provo, so that families and local

health care providers can coordinate through the teams with tertiary health providers to bring subspecialty care to underserved children and youth with special health care needs..

CSHCN and Shriners Hospital continue to collaborate to help children and families with special needs. CSHCN staff works directly with the Shriners' care coordinators to follow common patients and to make direct referrals to Shriners or from Shriners to CSHCN.

In response to Medical Homes/local care providers' request to improve communication on results of CSHCN clinic evaluations, the CSHCN Medical Director has piloted a referral system between CSHCN clinical staff and primary care providers. Using a newly developed referral form (available on our website), local clinic staff, with permission from patients' parents, are making contact with medical homes and local care providers notifying them of upcoming clinics and appointments scheduled for their patients. This contact allows the local providers and primary care doctors to give input and request specific consultations based on their concerns and knowledge of a child's needs. The information from the form is provided to local clinic staff and is accessible to the specialists at the time of the clinic consultations. In return, the specialists provide their findings and recommendations on the form, which is then copied to the local primary care providers within 48-72 hours of the clinic visit. This strategy has proven to be a valuable asset in increasing communication and providing more timely support and information for local care providers.

Relationship of Title V with Others in the State Who Address Health Care Resources

The state Title V agency works well with the state Primary Care Organization (PCO) and Primary Care Association. Through efforts of the State Dental Director, the Department's loan repayment program was expanded to include dentists in an effort to attract dentists to the rural areas of the state. The State Dental Director and the program manager of Maternal and Infant Health Program serve on the PCO's grant review committee.

The Bureau of Children with Special Health Care Needs is a member of the Utah Telehealth Network, a collaboration of telemedicine networks. The University of Utah is a leader in this Network, which strives to provide educational and health access to Utahns, especially in the rural and frontier areas of the state.

Program staff in the Division often serves as mentors or faculty for students desiring public health experience or internships. These opportunities are a good mechanism to promote the work of the State, promote issues for mothers and children in the state, and at times a mechanism to fill vacant positions. Student efforts have by and large been very positive experiences for both the student and state staff. It is not uncommon for students to gain a better sense of future employment goals and content areas. Students represent nursing, medicine and health education fields and staff enjoys working with them to promote the importance of the work done at a state level in public health.

Many staff members are faculty at the University of Utah, Brigham Young University, Salt Lake Community College and other academic settings that allow them to promote their work and dedication to public health. The State Dental Director is frequently invited to present to pre-dental students on the role of the dentist, especially related to the needs of underserved populations.

Population-based Services

Need for Population-Based Services

The award winning Baby Your Baby Program has promoted early prenatal care since 1988. During the initial seven years of the program, the percentage of women starting early prenatal care steadily increased. However, this trend began to reverse in 1995 and 2008 data indicate that only 79.1% of women are entering prenatal care during the first trimester. During 2001, Utah's adequacy of prenatal care as measured by the Kotelchuck Index rank declined to last in the nation in adequacy of prenatal care with only 61.2% of Utah women receiving adequate care. The Maternal Child Health Bureau's Maternal and Infant Health Program conducted research to determine contributing factors to the continued decline in adequacy of prenatal care. Focus group testing of women who received inadequate care helped to elucidate barriers and strategies to improve prenatal care rates. The Department, working with the Baby Your Baby Program, developed the message "13 by 13", encouraging women to enter prenatal care before 13 weeks and get 13 visits throughout their pregnancy. Since implementation of this campaign, Utah's prenatal care adequacy rates rose to 80.4% in 2008.

Division staff has met with Medicaid staff and provider representatives to discuss low reimbursement issues for prenatal care. These low rates have resulted in fewer prenatal care providers seeing Medicaid participants for prenatal care. With increasing liability insurance premiums and steady or declining rates of reimbursement, providers have joined forces with a union to help negotiate higher reimbursement rates to cover increasing overhead costs.

Women of undocumented status are referred to the Department of Workforce Services to obtain coverage for delivery expenses through Medicaid's emergency medical program. Despite this, obtaining adequate care is problematic, as emergency services will not cover outpatient prenatal or postpartum care. Women who are without insurance may receive care at a reduced fee through community health centers or the University of Utah Health Sciences Center OB clinics located in two Wasatch Front health district facilities or from private providers willing to accept self-pay.

The BYB program continued to accept Presumptive Eligibility applications via phone. The UtahClicks on-line eligibility application system was utilized. Training of local health department staff and other Presumptive Eligibility sites on use of the UtahClicks system was conducted. In FY 2009, 7,679 Baby Your Baby applications were made through UtahClicks, an increase of almost 1,800 applications from the year before.

To promote early prenatal care, the Baby Your Baby Campaign (BYB) continues to employ various outreach strategies, such as billboards, public service announcements, brochures, and newsletters. BYB has had high visibility in the state through its ongoing television coverage. The Program continues to provide hotline services which allow the public to call for information about financial and other resources for pregnancy-related and child health care. The BYB staff provide hotline services for numerous maternal and child health areas, such as immunizations, breastfeeding, or questions about specific conditions related to pregnancy or childhood.

As data have become available about women who don't receive early prenatal care, the BYB Program has developed strategies, such as targeting public service announcements to women less likely to enter prenatal care (i.e., mothers who have had several previous children). It is clear that current public outreach and education must be continued along with messages targeted to hard-to-reach populations, based on specific data that identify barriers to early prenatal care. Ads encouraging planning for pregnancy and financial help for prenatal care are being run in several college newspapers throughout the state. The Maternal and Infant Health Program (MIHP) has participated in the promotion of the March of Dimes' Teddy Bear Den Project. This project seeks to improve prenatal care of low-income women by offering incentives such as infant car seats and infant supplies to women engaging in healthy behaviors during pregnancy. Division staff has participated in health fairs targeting high-risk populations such as single mothers, uninsured families or those targeting areas of the Wasatch Front with high percentages of racial and ethnic minorities attending.

In an effort to improve adequacy of prenatal care among Hispanic women, KUTV, the local CBS affiliate and one of the partners sponsoring the Baby Your Baby campaign, has contracted for the second year with Univision, the top-rated local Spanish television station in the Salt Lake Valley. Univision carries Spanish Baby Your Baby PSAs airing them during the 5:00 and 10:00 PM news shows and during their highly rated novellas. Baby Your Baby will also have four segments lasting 3 to 4 minutes each on the station's Saturday morning community talk show. These slots will be utilized to promote the importance of prenatal care, the availability of care and healthy behaviors before and during pregnancy. KUTV has also contracted with Busto Media, a major Spanish broadcaster in Utah. Busto stations run Baby Your Baby ads regarding the importance of early and continuous prenatal care. The campaign message of having the first prenatal visit by week 13 and making 13 prenatal visits prior to delivery is also being disseminated through a new Spanish newspaper in the Ogden area. The Baby Your Baby website has been translated into Spanish.

In 2004, the BYB Advisory Committee conducted a formal evaluation of the new campaign and found that the majority of women knew about the Baby Your Baby program (88.6%), 70.5% of respondents had seen a Baby Your Baby ad on television, 34.4% had heard an ad on the radio, and 39.1% had seen a billboard. While women agreed the ads were motivating, and first trimester entry was significantly different among women who had seen an ad, there was no difference in prenatal care adequacy rates by viewing.

Local WIC staff analyze the CDC Pediatric (PedNSS) and Pregnancy (PNSS) Surveillance data annually to identify specific areas of declining nutrition and health-related indicators, such as increasing rates of anemia, obesity and / or malnutrition as reflected in inadequate weight gain or growth patterns. Following the analysis, local WIC staff develops goals and action plans to reduce the prevalence of any increasing rates of adverse health indicators. In the Utah WIC Program, two new effective nutrition intervention strategies, Family Centered Education and Facilitated Group Discussion, have been implemented to increase family involvement and interaction. Many WIC mothers lead very busy lives and find that our new offering of online nutrition education classes that can be taken on computers in the clinics or libraries or in participants' homes to be very convenient. These strategies have resulted in positive behavior changes related to improved nutritional consumption and greater physical activity among WIC participants.

Since SFY01, the Utah Department of Health has received an annual appropriation of \$4 million for tobacco control programs from the Tobacco Master Settlement Agreement. Additionally, in SFY03, the UDOH received a \$3 million allocation of tobacco excise tax revenue resulting from a cigarette tax increase. Services offered through the Tobacco Prevention and Control Program (TPCP) are available statewide, through a variety of mechanisms, including local health department contracts with staff designated to coordinate local services. Since 80% of adult tobacco users become addicted to tobacco in their teens, local and statewide tobacco use prevention efforts focus on youth. Mini-grants to community organizations, particularly those who serve population groups at higher risk for tobacco use, are disseminated based on their potential to promote positive health practices that aim at preventing underage tobacco use and providing information and programs that enable target audiences to quit tobacco use.

A primary goal of the Tobacco Prevention and Control Program (TPCP) is to provide leadership and guidance to build capacity for comprehensive, science-based tobacco prevention and cessation programs at the community level. By means of collecting and summarizing tobacco related data, the TPCP identifies the extent of youth-specific, tobacco-related issues and problems. This information is used by state/local health departments and other partnering agencies to develop and carry out targeted interventions. The TPCP is comprised of program specialists who primarily focus on: prevention; youth access; teen and adult tobacco quitting programs; secondhand Smoke and the Utah Indoor Clean Air Act; counter-marketing; tobacco control policy; partnerships with health care providers; and surveillance and evaluation. Besides acquiring or developing specific program materials, specialists promote adoption of strategies, programs, and activities to the public and to collaborating agencies.

Partnering agencies promote changes in tobacco-related policies and provide services and activities to prevent Utah's youth from becoming dependent or addicted to tobacco. The Tobacco Prevention and Control Program collaborates with many partners including: local health departments; State Office of Education and local school districts; the Utah Tobacco Quit Line and Utah QuitNet; the Utah Juvenile Court System; American Cancer Society, American Heart Association, and American Lung Association, Utah Medical

Association, Utah Dental Association, Utah Dental Hygienists' Association; Chiefs of Police Association and Utah Sheriff', Association; Utah Substance Abuse and Anti-Violence Coordinating Council; the Utah Department of Human Services Division of Substance Abuse and Mental Health; the Coalition for a Tobacco Free Utah; and many others. While it takes extra time and effort to activate collaborations with "sister" agencies, the payoff in terms of results, quality, and effectiveness of youth-related tobacco programs is great.

A multidisciplinary advisory committee with representation from community agencies, educational institutions, and other state agencies advises the TPCP on how to use the funds. The Tobacco Prevention and Control Program allocates funds through a competitive process in the following areas: media and marketing; local interventions focused on comprehensive tobacco prevention education, policy change, and referral to quit services; projects focused on reducing tobacco-related disparities; telephone and web-based quit services; partnerships with health care providers; and evaluation of efforts.

The Tobacco Prevention and Control Program (TPCP) works with Medicaid in the coordination of media campaign efforts. Utah Medicaid provides tobacco cessation counseling and medications for clients, including pregnant and postpartum women. The TPCP collaborates with school districts to implement the CDC's Guidelines for Comprehensive School Tobacco Policies; One Good Reason, Utah's youth movement against tobacco, trains youth advocates across the state in street marketing techniques; local health departments provide community-based prevention education, engage youth in efforts to increase the number of tobacco-free recreational sites, and collaborate with courts to provide tobacco cessation programs ("Ending Nicotine Dependence") to youth who violate Utah tobacco possession laws. In addition, the TPCP works with local health departments to develop and offer telephone or group-based tobacco cessation programs ("First Step") for pregnant women. Further efforts to provide comprehensive quit services to pregnant women include partnerships with Medicaid, Utah's Primary Care Network (PCN) and the Association for Utah Community Health (AUCH).

With approximately 50,000 live births per year, over 1,000 infants are born with medically significant birth defects, a major contributor to fetal deaths and neonatal and infant mortality in Utah. Live born infants with birth defects have increased morbidity and for some, mortality. Certain birth defects are more prevalent among different racial groups, higher in Utah than other states or countries and may occur in the first or later pregnancy. In addition, young maternal age is a strong risk factor for some birth defects.

The Pregnancy Risk Line, with its statewide toll-free phone service, was established in 1984 as a joint effort by the Utah Department of Health and the University of Utah Health Sciences Center to address the growing need for accurate information about teratogens in pregnancy and lactation. The Pregnancy Risk Line provides up-to-date, accurate information to consumers and health care providers regarding potential risk to a fetus or an infant due to various exposures whether they are medications, illicit drugs, chemicals, viruses, etc. This information is often not easily accessible to health care

practitioners or consumers. Since it is common for pregnant and lactating women to be exposed to medications/drugs, chemicals, infectious agents and other potentially harmful situations, misinformation is common. Although there is an increased sensitivity during pregnancy to the possibility of having a child with a birth defect, women often feel their risk of having an affected child is higher than the actual risk posed by the exposure because of the poor quality of available information. These perceptions of heightened risk have too often led to termination of otherwise wanted pregnancies, increased anxiety, requests for unnecessary and costly prenatal diagnostic procedures as well as repeated screening and testing of the in utero exposed fetus. Since its inception, demand for Risk Line services has steadily increased from just over 2,000 calls in its first year to nearly 10,000 calls in 2004.

The Pregnancy Risk Line provides counseling and appropriate referrals for pregnant women who abuse substances. Staff for this statewide, toll-free telephone resource counsels and educates nearly 10,000 pregnant women, care providers, families and other professionals each year. Approximately 1,000 pregnant women who abuse substances are counseled and referred to prenatal care and drug treatment services each year.

Utah's immunization rates have been one of the lowest in the nation for the past ten years. In 1999, Utah ranked 25th in the nation, up from 44th in 1998, and 51st in 1997. Previously the reported immunization rates in Utah had been for 4:3:1, however, the reporting for the block grant and CDC are now concentrating on the rates for 4:3:1:3:3. In 2000 68.2% of Utah children were immunized for 4:3:1:3:3 which is below the national average of 72.8%. The coverage levels for two year-old children increased from 64% in 1996 to 82% in 1999. The most recent data for 2008 show that for 4:3:1:3:3 Utah children are immunized at 78.1% which is just lower than the national rate of 78.2%. The Utah Immunization Program provides statewide coordination for childhood, adolescent, and adult immunization efforts, as well as other needed technical assistance and support through a variety of mechanisms. Rates have improved based on the most recent NIS data. Utah's ranking has improved. We continue to develop a variety of strategies to address the rates among Utah children.

The Utah Immunization Information System (USIIS), a statewide immunization electronic information system was developed through partnerships with professional organizations, insurance companies, managed care organizations, and public health agencies. USIIS is a central registry to maintain current immunization information for children and adults in Utah, available to authorized public and private providers. Local health department clinics, many private provider offices, schools and others have been enrolled in USIIS. As part of data integration efforts, Vital Records exchanges immunization information with USIIS to make immunization records more complete. USIIS enables the Immunization Program and health care providers to track immunization rates in an efficient manner. The Registry serves as a tool to prevent unneeded repeat immunizations due to poor record keeping, and will enable providers to easily track the immunization status of children in their practices.

The Immunization Program has worked to enroll school districts in USIIS to help them assess a student's immunization status for school entry rules. USIIS has become a convenient tool for providers to validate immunization records so they will easily know if a child needs an immunization and which one is needed.

The Oral Health Program has been diligent in establishing and maintaining working relationships with private and public partners. The Utah Oral Health Coalition is the cornerstone of that effort. The coalition provides a forum for sharing ideas and developing priorities and projects to improve the oral health of all Utah residents. The State Dental Plan entitled "Utah's Plan of Action to Promote Oral Health: A Public-Private Partnership" is a product of collaborative labors with the Utah Oral Health Coalition. The Coalition generally holds a day-long meeting once a year to discuss future directions and priorities for the Coalition to address over the next 12 months. Often the Coalition will identify legislative issues they want to support. Coalition members who are not state employees are free to advocate and promote oral health legislative issues.

Need for State's involvement in direct management of services and programs

Over the past several years, coordination of the BYB media campaign has been shared between the Department and KUTV, with a full-time media coordinator supported jointly by the two agencies. This media coordinator was let go in 2009 due to budget constraints from KUTV. Baby Your Baby has existed more than 20 years.

The Maternal and Infant Health Program makes information available on its website. Public information on the website includes topics such as preconception care, family planning, pregnancy, and postpartum. Most of this information is available in English and Spanish and is also available in printer friendly formats for downloading. A provider and researcher part of the site provides information on publications, data, and trainings. The website averages over 5,000 unique visitors per month. The Maternal and Infant Health Program purchases brochures on various subjects as well as producing its own information brochures. The materials are distributed free of charge to local health departments, community health centers, the AIDS training center, various promotora programs, as well as to individuals at health fairs.

In 1979, the statewide Newborn Screening Program was established to oversee and coordinate newborn heelstick testing of all infants born in the state. The program now screens for over 37 different disorders. These disorders include amino acid metabolism (including PKU), acylcarnitine (fatty acid oxidation and organic acid metabolism disorders), biotinidase, congenital adrenal hyperplasia, congenital hypothyroidism, cystic fibrosis, galactosemia, and hemoglobinopathies. The cost effectiveness of screening has been well established, with screening for PKU and congenital hypothyroidism saving \$3.3 million for every 100,000 infants screened and \$93,000 for each identified and treated child. The Newborn Screening Program has identified needs including medical translation services and access to a genetic counselor in the rural areas. The Newborn Screening Advisory Subcommittee has developed criteria for adding or deleting a disorder from the Utah Newborn Screening panel of tests. Using these criteria, the committee reviews disorders for possible inclusion in the screening battery.

Identification of missing newborns in one or more databases will provide information for targeted education about our services and how to successfully incorporate the BRN assignment in hospitals that are having difficulty with compliance. Hearing screening staff and heelstick screening staff have compared their databases for babies who did not have a normal hearing screen. The comparison identified a problem with the BRN assignment in that there have been several babies with unmatching BRNs. Ongoing evaluation of the BRN assignment system will include validation among the three databases to determine if the BRN in each database is identifying the same unique newborn.

The Newborn Screening Advisory Subcommittee has developed criteria for adding or deleting a disorder from the Utah Newborn Screening panel of tests. Using these criteria, the committee has reviewed biotinidase, congenital adrenal hyperplasia (CAH), and Medium-chain Acyl-CoA Dehydrogenase Deficiency (MCADD), and recommended to the Department that they be added to the screening battery. This expanded screening plan will require statewide coordination of efforts to ensure successful implementation and follow through on screens that are positive.

The Utah Birth Defect Network (UBDN) is a statewide population-based surveillance program that monitors the occurrence of all major structural birth defects in recognized pregnancies among Utah resident women or their live born infants. The UBDN is an integrated co-agency program between the Utah Department of Health and the University of Utah Health Sciences Center's Department of Pediatrics. In addition to the Department of Pediatrics, another integral aspect of the UBDN's infrastructure is its close working relationship with the University of Utah's Maternal Fetal Medicine perinatologists which provide prenatal diagnostic care throughout the state. The infrastructure of this integrated program provides the necessary expertise of epidemiologists and clinicians in addition to the trained staff performing data collection in order to obtain the highest quality of data for monitoring. With well over 50,000 live births per year in Utah resulting in more than 1,500 fetuses/infants diagnosed or born with at least one major structural birth defect such a dynamic system is important. Birth defects are a major contributor to fetal deaths and neonatal and infant mortality in Utah. Those infants that survive the first year of life will often have related childhood and adult co-morbidities.

The UBDN collects data on the prevalence and distribution of pregnancies and births that are affected by a major birth defect. The UBDN began surveillance activities in 1994 tracking only neural tube defects (NTD). In 1995, oral facial clefts and the common trisomy disorders were included, with expansion to other birth defects, including cardiac anomalies, until 1999 when the UBDN became a full surveillance system collecting all major structural malformations, except ventricular septal defects. All potential cases are reviewed for classification of isolated, multiple or syndromic (i.e., known etiology) defects either by the Director, a geneticist or pediatric cardiologist. Though a relatively young program, the UBDN is now recognized, both nationally and internationally, as a highly regarded and efficient program with a focus on quality data.

The UBDN is one of eight Centers for Birth Defects Research and Prevention, along with CDC, participating in the National Birth Defects Prevention Study, the largest and most robust population-based case control study investigating risk factors (i.e., environmental and genetic) involved in birth defects with unknown etiology.

The UBDN developed and continues to lead the efforts of educating childbearing aged women about the need to consume a daily multivitamin with folic acid before a pregnancy occurs to prevent neural tube defects (NTDs). The UBDN is charged with both primary prevention, as well as recurrence prevention of NTDs.

After linking the UBDN case data with Medicaid files, we determined that over 50% of infants born with a major structural malformation have been on Medicaid sometime during their first year of life. In a focus group conducted with the Utah Chapter of the March of Dimes, the UBDN met with families to identify issues and barriers of having a child with a birth defect. All families stated that there was an information gap for their particular situation, both prior to delivery and after birth of a child with a birth defect. Families would prefer to discuss pertinent issues or ask questions they may have with another family that has experienced similar challenges. Information provided to them by their health care provider was viewed as inadequate. The Utah Birth Defect Network has the capability to link families to families that share a common bond of having a child with a particular birth defect. This request has come numerous times via focus groups and parents who contact the UBDN. Health care providers are not able to provide the day-to-day information that families would prefer in order to assist their child. Currently, pregnant women or families who contact the UBDN are provided with information and referred, if requested, to the appropriate subspecialists for their child's care. Also to help families, we have posted information on specific birth defects and referral for services on the UDOH IBIS website.

The UBDN provides a training environment for interested graduate and medical students to study birth defects and work on epidemiologic projects. The UBDN has expertise in epidemiology, dysmorphology, genetics, and molecular genetics and nutrition epidemiology with the collaboration of Utah State University. The UBDN Director is a founding member of the National Birth Defect Prevention Network and was the president of this organization in 2005. This group is a collective effort of those individuals and surveillance programs interested in the primary prevention of birth defects and secondary prevention by assisting families with services and research. Recently, the UBDN Director became a member of the steering committee of the Congenital Heart Public Health Consortium, a collaborative effort between the CDC and American Academy of Pediatrics. University of Utah faculty members are members of the database subcommittee and the prevention subcommittee.

The Violence & Injury Prevention Program (VIPPP) promotes the health of all Utah residents by working to reduce the incidence and severity of fatal and non-fatal injuries. This work is done by: 1) data collection and injury epidemiology; 2) education to increase awareness and change behavior; 3) promoting the passage and enforcement of rules, regulations, and legislation to increase safety, e.g., primary seat belt law, graduated

driver licensing, and school zone speed limit enforcement.; 4) promoting the use and improvement of safety systems and equipment to reduce injury incidence and severity, e.g., use of seat belts, bicycle helmets, and smoke detectors.; 5) coordination and collaboration among community agencies and organizations involved in injury prevention; and 6) strengthening local health department injury prevention capacity.

The VIPP is responsible for injury data collection and analysis, and for tracking, developing, and implementing injury prevention strategies for both unintentional and intentional injury. The Program, which began in 1984 with investigation of school-related injuries, and has evolved from a program with one part-time staff member to one with numerous staff addressing many aspects of both un-intentional and intentional injury prevention. The VIPP is funded with MCH Block (in which a majority of the funds are contracted to local health districts), Preventive Block, Rape Prevention Education Grants, Core Injury Surveillance Grant, Traumatic Brain Injury Surveillance Grant, and some categorical grants. Some of the programs and issues addressed by the VIPP include: child fatality review, domestic violence prevention and fatality review, student injury reporting system, traumatic brain injury surveillance and prevention, fall prevention, motor vehicle occupant injury prevention, pedestrian & bicycle safety, Utah SAFE KIDS Coalition prevention activities, rape and sexual assault prevention, and suicide prevention.

In addition to continued education and community-based activities, there is a need for a primary seat belt law, a bicycle helmet use law and increased enforcement of child restraint laws. Program staff, as well as community partners, has found it very difficult to get legislators to pass injury prevention laws. Education of legislators and the public will, in time, change the political climate and attitude toward safety legislation for children. There is need to continue to expand the successful methods which have been demonstrated in communities throughout the state. Education about the importance of and the correct use of occupant restraints, especially child safety seats and booster seats, and bicycle helmets needs to continue to further reduce preventable deaths due to lack of or incorrect use. Since 2008, the program has focused efforts at the state and local level to reduce the number of teens that are killed in motor vehicle accidents in which a teen is driving. We have seen a number of multi-fatality accidents that were preventable.

The Violence and Injury Prevention Program has participated in the Utah Youth Suicide Study and the Utah Youth Suicide Prevention Task Force over the years. Although there have been numerous studies that identify causes and contributing factors as well as treatment and intervention for those who attempt suicide, little has been known about early identification and effective prevention measures for teens that may be at risk for but have not yet attempted suicide. The findings of the Youth Suicide Study indicate that youth who successfully commit suicide have a greater chance of being involved in the juvenile justice system, which could provide an opportunity for early recognition and intervention of depression. The Utah Youth Suicide Task Force, a multi-disciplinary team that addresses the serious problem of youth suicide in Utah, consists of members from the University of Utah, Department of Health, National Alliance on Mental Illness (NAMI) Utah, Mental Health Association of Utah, Division of Youth Corrections, State

Office of Education, State PTA, Brigham Young University, legislative fiscal analyst, Juvenile Court, and other agencies. VIPP staff assists this task force by provision of data analysis, assistance in writing the “Suicide in Utah” report, assistance in planning activities and evaluation of suicide prevention efforts. The youth suicide prevention effort will be transferred to the new children’s mental health specialist position so that VIPP can focus its work on surveillance.

Approximately 80% of all adult tobacco users start smoking before the age of 18. Every day, nearly 4,000 young people under the age of 18 try their first cigarette. More than 6.4 million children living today will die prematurely because of the decision to smoke cigarettes. In 2009, 8.5% of students responding to the Youth Risk Behavior Survey (YRBS) said they had smoked cigarettes in the last 30 days. The 2007 Youth Tobacco survey found similar rates among high school students and also found that among current smokers, approximately 50% of the high school smokers indicated that they wanted to quit and 40% indicated they had tried to quit in the past year. While a variety of effective adult cessation programs were developed and tested during the past decades, addressing nicotine addiction among youth remains a challenge. Through a combination of retailer education, positive recognition and compliance checks, successful tobacco buy attempts by underage youth during compliance checks have been reduced from 60 to 70% in some areas in the mid-1990s, to less than 10% statewide. The 2007 Utah Youth Tobacco Survey found that more than 60% of current high school smokers list social sources as their most frequent way of obtaining cigarettes. Tobacco control programs need to research and carry out interventions that aim at reducing minors’ access to tobacco through buys as well as social sources.

In the past couple of years, the Bureau of Health Promotion now in the Division of Disease Control and Prevention has developed several new programs, which include children’s health needs. The Asthma and the Genomics Programs have been created to provide state-level planning to address needs of Utah’s population including mothers and children. MCH staff members are involved with these programs as they develop strategies to address these areas. In addition, other Bureau of Health Promotion programs provide prevention services that include children, such as Diabetes Program and Heart Disease and Stroke Prevention Program. The Bureau of Health Promotion is launching a major effort to reduce childhood obesity. Title V funding supports some of the Bureau’s efforts in this campaign and Title V staff members, including the Title V Director, MCH Director and CSHCN Director, are actively partnering in their efforts.

In October 2008, the DOH issued a report on childhood obesity that indicated that

- More boys were overweight or obese at every grade.
- The percentage of overweight or obese students increased dramatically between the 3rd and 5th grades.
- 21.5% of elementary school students were at an unhealthy weight. The rate in 2006 was similar at 22.5%.

- 9.7% of elementary school students were obese, similar to 2006 when 10.3% were obese.

In 1994, 16.9% of 3rd graders were at an unhealthy weight. In 2008, it increased to 19.7%, a 17% increase. There was no evidence that the rate of overweight and obesity among elementary school students increased between 2006 and 2008.

Title V staff will join the efforts of the Bureau of Health Promotion in working to reduce obesity in children. While YRBS data indicate the Utah youth are below the national average for obesity, programs within the Division recognize obesity as an emerging issue based on the increasing trend in obese youth. The Bureau of Health Promotion (BHP) through the Gold Medal School initiative has targeted elementary schools across the state. Program staff has started discussions of ways to collect data statewide and expand prevention efforts. The program has enrolled 40% of elementary schools (190) in the program, with 31% (148) currently participating. Another 42 schools have participated and the program staff is working to re-engage them with the Gold Medal Plus program. The program expects to enroll 80% of elementary schools in the Gold Medal Program by 2008, including 90% of Title I schools. Intermountain Healthcare has donated a substantial sum of money to support the expansion of the Gold Medal Schools, however that funding ends in 2010. The Department was awarded a CDC PANO grant (Physical Activity, Nutrition and Obesity) which is in its 2nd year of funding. The purpose of the grant is to develop a state plan to promote physical activity and good nutrition and reduce or prevent obesity.

One of the issues that the MCH Bureau pushes is the recognition of the importance of health weight in women of childbearing ages, before pregnancy, during pregnancy and after pregnancy. The Maternal and Infant Health Program (MIHP) has conducted analysis of PRAMS data to establish baselines for where Utah women who give birth are with weight. The PRAMS phase VI survey added questions on provider advice on pregnancy weight gain and data will be analyzed to determine if women are being given appropriate instruction. The Maternal and Infant Health and WIC programs work closely with the Bureau of Health Promotion in its efforts. The Program has developed online weight graphs to assist pregnant women in tracking their weight gain during pregnancy. These graphs were designed to help pregnant women to keep their weight gain within normal limits.

State's coordination with other agencies and organizations in the provision of population-based services

Baby Your Baby coordinates with many different groups through partnerships with representatives from Intermountain Healthcare, the state's largest health care system, KUTV, the local CBS affiliate, and community based organization. Baby Your Baby staff provides coverage for the Baby Your Baby Hotline as well as 20 other Department of Health hotlines, such as the Immunization Resource Hotline, Health Resource Line (which is a general health resource for information about community resources), Cancer Control hotline, and the Children's Health Insurance Program (CHIP) and Primary Care Network (PCN) hotlines. Each hotline has an advisory committee or board with which

the Department coordinates efforts. In addition, the Department also has a BabyWatch/Early Intervention Hotline that is operated separately from the others.

The Maternal and Child Health Bureau partners with a number of key organizations and institutions to carry out its work, such as the Utah Chapter of the American Academy of Pediatrics' collaborative quality improvement effort, the state Primary Care Association (AUCH: Association for Utah Community Health), March of Dimes on their Prematurity Prevention Campaign, Planned Parenthood Association of Utah around family planning service gaps, local health departments and community health centers, the state Division of Substance Abuse and Mental Health on mental health service gaps, and so on. The Bureau and its programs have a number of committees, advisory committees, councils that address health resources for mothers and children, including those with special needs, including the Intermountain Pediatric Society (Utah Chapter of American Academy of Pediatrics, American College of Obstetricians and Gynecologists, Association of Women Health Obstetric and Neonatal Nurses, and American Academy of Family Physicians.

The Division has been heavily involved in the effort to develop a statewide system of comprehensive services for young children and their families that includes early childhood development and education, parent support and health and well being. The ECC (Early Childhood Council) is composed of a diverse group of individuals representing all aspects of the spectrum of early childhood needs. However, the ECC has not really functioned after former Governor Huntsman left office in 2009. We hope that when we have an elected Governor in place, that the ECC will be renewed with support from the new Governor.

The Maternal and Infant Health Program collaborates with perinatal healthcare providers through its work in the Perinatal Mortality Review (PMR) Program. The PMR Committee is comprised of an obstetrician, a perinatologist, a pediatrician, two neonatologists, several Certified Nurse Midwives and perinatal quality nursing staff. The input provided by this group of providers is invaluable in the review of infant deaths due to perinatal conditions and pregnancy related deaths.

MCH Bureau staff worked with the Office of Vital Records and Statistics to provide input in the development of the new 2003 birth certificate which was implemented in January 2009. MCH Bureau staff sought input from outside partners to ensure that the new birth certificate included data fields that are used to identify factors associated with pregnancy outcomes and to develop program strategies to improve them. With new leadership in the Office of Vital Records, we hope to engage them in our work much more closely than in the past.

Division staff has participated in a number of activities with the Bureau of Communicable Disease to support their work on issues related to STDs, HIV/AIDS, and teen pregnancy prevention. The Adolescent Health Network includes representatives from the programs in this Bureau so that we can work collaboratively on similar issues. The Bureau of Communicable Disease is in a sister division of the state, thus

collaboration is important in moving forward on these areas that impact women of reproductive age and youth.

The Utah Immunization Program regularly coordinates and collaborates with programs in the Division. Since the Immunization Program was moved to another Division as a result of the Department reorganization, we continue our joint efforts. Since WIC linkage activities are mandated on a federal level, coordination with WIC allows immunization education, outreach and access activities at WIC clinics statewide. In 2008 one local WIC program participated in a pilot project to increase immunization rates among children enrolled in WIC. For those children not up to date on immunizations, parents were offered to get the child's immunizations at the clinic or to go to their child's health care provider to do so. For those who did not get the immunizations on site, one month of vouchers was issued rather than the regular three months. Once documentation of the immunizations as being up to date, the family was returned to three month vouchering. The pilot has been successful in increasing immunization rates among children in the pilot. Other district's WIC programs are interested in participating in this approach to increase children's immunizations.

The State Scientific Vaccine Advisory Committee (VAC), first convened in 1999, provides a forum for scientific input to the priorities and policies of the Immunization Program. Members of the committee include representatives of local health departments, state epidemiology, family practice and pediatrics, a medical communicable disease specialty, and Medicaid. The committee meets three times a year to review recommended practices and provide recommendations to the state as to necessary actions. Continued collaboration with these partners is vital to the program, as is the identification of new public/private partnerships to support the immunization registry and outreach and education efforts to improve Utah's immunization rates. As new vaccines are recommended by ACIP, the VAC considers additional school entry requirements. The state does not require HPV for school attendance.

CSHCN collaborates with other state agencies through numerous initiatives and grants. The Bureau of CSHCN was awarded and has maintained CDC grants for Early Hearing Detection and Intervention (EHDI) tracking, research activities, and integration with other newborn screening programs. The Bureau also has on-going grants for maintaining the newborn hearing screening program (HRSA) and reducing the number of infants lost to follow-up after newborn hearing screening (HRSA). Development of the statewide clinical health information exchange (cHIE) also relies on HRSA funding through a cooperative agreement. Development of infant and pediatric audiology providers is also supported through a HRSA / AUCD three-year grant.

The Utah Birth Defect Network is well integrated with perinatal providers, genetic counselors, and specialty pediatric providers throughout the state. The UBDN works closely with the University of Utah Health Sciences Center, Intermountain Healthcare, Primary Children's Medical Center, the Utah Chapter of the March of Dimes, and the Utah Perinatal Association.

The Pregnancy RiskLine has a close relationship, in fact, a partnership, with health care professionals at the University of Utah Health Sciences Center. For example, one of the leading supports for the RiskLine and its work is a medical geneticist at the University. In addition, there is a strong collaborative relationship with a medical bioethicist. It is anticipated that this relationship will be strengthened with the recently awarded Genetic Services and Data Integration Grant from the Maternal and Child Health Genetic Services Branch grant and the reconstitution of the Department's Genetics Advisory Committee.

The Pregnancy Risk Line collaborates on projects with state and county agencies and has a close relationship with health care professionals throughout Utah. Continuing education for physicians, mid-level practitioners, pharmacists, genetic counselors, nurses and other medical care providers is on-going from the Pregnancy Risk Line. Relationships with the University of Utah's Divisions of Medical Genetics, Perinatology and School of Pharmacy result in 24 student rotations per year through the Pregnancy Risk Line.

Collaboration with community-based organizations, non-profit clinics and other providers of services including Utah's largest non-profit insurance and hospital provider, Intermountain Health Care, result in referral of clients. In return Pregnancy Risk line provides in-service and other trainings. Agencies such as adoption service providers, teen pregnancy services, family advocacy programs and projects supporting Utah's ethnic and Medicaid's low-income populations partner with the Pregnancy Risk Line to make certain services are equitably delivered and appropriate for these underserved populations.

Pregnancy Risk Line leads activities to reduce fetal exposure to alcohol, tobacco and other drugs of abuse and educates mothers on the availability of substance abuse treatment programs. Agencies that collaborate with the Pregnancy Risk Line are the Utah Indian Health Advisory Board, Utah Substance Abuse Advisory Council, Drug Exposed Newborn Committee, Utah Fetal Alcohol Coalition, Utah Alliance for Drug Endangered Children, Utah Association of Counties, League of Cities and Towns and state Departments of Human Services, Alcoholic Beverage Control and Corrections. As a founding member of the Organization of Teratology Information Services, the Pregnancy Risk Line collaborates with other teratology education and research centers across the US and Canada to increase knowledge that is then provided to agencies, health care practitioners and the public throughout Utah.

To reduce injuries among Utah children, the Violence and Injury Prevention Program (VIPP) has formed working partnerships with numerous agencies, including hospitals, community based organizations, local health departments, PTA, Utah Safe Kids Coalition, other state departments, such as Utah Department of Public Safety (UDPS), Department of Transportation (UDOT) and others. VIPP contracts with LHDs to provide most of the community level injury prevention activities.

The interagency Child Fatality Review Committee (CFRC) has been operational for more than 17 years and functions under the auspices of the Utah Department of Health. CFRC

brings together representatives of the many diverse agencies and organizations that serve Utah children and families, with the goal of better understanding of the causes and circumstances of child fatalities to prevent future deaths. Committee representation includes the Medical Examiner's Office, EMS, State Office of Education, Attorney General's Office, Criminal Justice, Courts, Division of Children and Family Services, community mental health center, local law enforcement, health care providers and hospitals.

The multi-disciplinary committee reviews all available information on child deaths in order to identify and describe: 1) prevalence of risk factors among deceased children; 2) trends and patterns of child deaths; 3) service systems response to high-risk children; 4) preventable deaths and strategies to reduce them; 5) accurate and complete information on death certificates; and 6) strategies to improve the care quality to children and families through professional and community education. The CFRC also works to make policy recommendations to improve the system response.

CSHCN collaborates with other state agencies through numerous initiatives and grants. The Bureau of CSHCN was awarded and has maintained CDC grants for Early Hearing Detection and Intervention (EHDI) tracking, research activities, and integration with other newborn screening programs. The Bureau also has on-going grants for maintaining the newborn hearing screening program (HRSA) and reducing the number of infants lost to follow-up after newborn hearing screening (HRSA). Development of the statewide clinical health information exchange (cHIE) also relies on HRSA funding through a cooperative agreement. Development of infant and pediatric audiology providers is also supported through a HRSA / AUCD three-year grant.

Currently, Utah screens for over 37 diseases in newborns and newborn hearing loss. This testing is facilitated by a successful collaboration with the University of Utah Health Sciences Center, Department of Health (laboratory and follow-up) and a private laboratory, Associated Regional and University Pathologists, Inc. (ARUP).

Geographic availability/distribution and funding of population-based services

Newborn heelstick screening is available in every birth institution (including hospitals and birthing centers) in the state and through providers who do home deliveries and medical home providers. Identification of abnormal results and the arrangements for further testing if needed is coordinated with the medical home providers and medical specialists. Program funding is generated through the purchase of screening kits by the birth institutions and providers.

In July 1999, the Utah State Legislature enacted a law requiring all birthing facilities to implement Universal Newborn Hearing Screening (NHS) programs. UDOH, in collaboration with the National Center for Hearing Assessment and Management (NCHAM) housed at Utah State University, implemented a computer-based tracking and data management system. The "Hearing Impaired Tracking" (HI*TRACK) system has fields for over 200 variables related to demographic, medical, and contact information for

the baby and mother, results of screening and diagnostic measures, and status relative to diagnosis and intervention. The UDOH CSHCN Bureau collects the results of screenings and specific demographic data from all 43 Utah birthing hospitals and birthing centers, and Primary Children's Medical Center. These data are collected on a monthly basis for each baby born. The HI*TRACK system allows case management and follow-up on all babies and supports the national EHDI 1-3-6 guidelines for screening before one month, diagnosis before three months for those babies who fail the screening, and early intervention services - including appropriate amplification - prior to six months. CSHCN provides training and support to all of the NHS programs and the birthing hospitals through training and monitoring of quality of the screening process. Recently, a concerted effort has been made to include midwives into our training and educational efforts to improve the number of home births that receive newborn hearing screening and to reduce the number of infants that are lost to follow up or lost to documentation.

Access to services provided by the Pregnancy Risk Line is facilitated state-wide through the program's toll-free telephone service. Consumers, as well as health care professionals, call Pregnancy Risk Line staff if they have questions about the potential impact of an exposure on a pregnancy and the side effects of exposures for the breast fed baby. These services are available to callers during regular business hours; however, the program has an answering machine that enables program staff to return calls to callers who have accessed the program during non-business hours. Pregnancy Risk Line staff also provides many educational presentations to community and health care provider groups across the state. The program is developing a secure web-based application for health care professionals to access risk statements about individual medications and other exposures. These risk statements contain details from medical research that the Pregnancy Risk Line staff uses to assess individual risks factors that can lead to fetal death, premature delivery, birth defects and other health concerns for children.

WIC services are available statewide through local health departments. Over the past several years, several clinics have been closed due to low participation numbers or proximity to services available in close proximity. The availability of WIC clinics in rural and urban areas is considered adequate, although WIC has been requested to consider the possibility of opening a couple of additional clinics.

The funding stream for the federal Abstinence-only Education Program was eliminated this past year however, healthcare reform legislation allocates a significant amount of funds to continue teen pregnancy prevention efforts. Communities have expressed great interest in applying for these funds to bring programs into their areas.

Community-based injury prevention programs are available in each of the twelve local health departments (LHDs) through contracts from the Maternal and Child Health Bureau and also from the Violence and Injury Prevention Program (VIPPP). These funds are used by LHDs to provide clinical services and programs to address injury prevention throughout the State. While individual LHDs are encouraged to base their injury prevention plans on the unique needs of their local communities, all are required to include at least one major component that addresses motor vehicle crash injury

prevention including occupant protection, bicycle safety, or pedestrian safety. LHDs have been participating in the implementation of a statewide effort to survey and improve booster seat use among children age 4-8 years.

Funding mechanisms for population-based services

The MCH Block grant provides the bulk of funding for population-based services provided for mothers and infants. Numerous programs, as mentioned in the State Overview section, are funded with MCH Block Grant dollars, enabling the state to address the health care needs for mothers and children. Programs usually have more than one funding source, such as state general funds, Preventive Block Grant, other CDC grants (PRAMS), other HRSA grants (SSDI, SECCS, etc.), USDA, the Administration for Children and Families (Head Start State Collaboration Project) the tobacco master settlement fund, private grants, and so on. The blending of funding from various sources maximizes the state's ability to develop population-based services. Few state dollars go into programs in the Division of Family Health and Preparedness. Most programs are funded only or primarily with federal dollars.

The Newborn Hearing and Newborn (blood) Screening population based screening are now completely funded by collections from hospitals for heelstick blood collection kits. This change has occurred gradually through yearly legislative approval of increase in kit fees. As demand for and cost of these screening programs increases, CSHCN will continue to work with the legislature to identify adequate collection fees to fund the programs

In 2008, six UDOH programs collaborated to apply for the First-time Motherhood/New Parent Initiative (FTM/NPI) funding from HRSA's MCHB. These programs include Maternal and Infant Health, Birth Defects Network, Baby Your Baby, Pregnancy RiskLine, Tobacco Prevention and Control and the WIC programs. They had collaborated to identify needs and priorities among the same target audience prior to the grant. Preconception health was identified as a high priority for population based interventions and when the FTM/NPI funding was announced the group applied and was funded. A major social marketing campaign was launched early June 2010 with a new website Power Your Life, print materials, including a Reproductive Life Plan for teens and for adults.

Infrastructure Building Services

The Utah Department of Health has made great strides in infrastructure building services for addressing health issues for women of childbearing ages, children and youth, and children and youth with special health care needs. Data analytic capacity, database integration, adolescent health, medical home, collaborative efforts on key issues for mothers and children have been enhanced during the previous five years. With the formal five-year needs assessment coming to a culmination, the Department has identified new priorities for the upcoming years and has reallocated some of its Title V block grant funding and staff time to address the priorities.

The MCH Bureau, along with the Maternal and Infant Health Program, utilizes the Perinatal Task Force (described later) to advise on issues related to pregnancy, pregnancy outcomes and reproductive care. The Taskforce meets several times a year to learn about recent and emerging trends and then helps with prioritization of work.

PRAMS data have been instrumental in providing insight to gaps in comprehensive systems of service in Utah. We currently have ten years of data from which to analyze questions related to MCH issues of concern. To date, we have published numerous reports that have been widely disseminated through-out the state to healthcare providers, community health and non-profit partners; topics include adequacy of prenatal care, breastfeeding, prematurity, unintended pregnancy, pregnancy spacing, STIs, infertility, HIV testing, prenatal education, maternal obesity, domestic violence, and preconception health. Utah PRAMS data are available on the “Indicator Based Information System” (IBIS) in a queryable format. In addition, a comprehensive data book containing most of the data collected by PRAMS has been published and disseminated to appropriate individuals and organizations throughout the state. Utah has the reputation as having an exceptional PRAMS programs. PRAMS data are used on a regular basis for reports, identification of variables related to a specific health issue, and so on.

The Department of Health has been integrally involved in a state level coalition targeted to build infrastructure for an early childhood service system, the Early Childhood Council. The Council included over thirty state and local programs and advocacy and non-profit organizations interested in promoting an early childhood services. As mentioned earlier, the future of a state level Council is unknown and won't be until after the gubernatorial election in the fall. The Division continues its work on early childhood systems building. Having all the early childhood programs together in one Bureau will promote better and stronger working relationships.

The MCH needs assessment process has provided another mechanism for gathering and confirming information related to gaps and needs for the system of services for young children. SECCS grant funding allocation is under review to determine the best use of the grant funds. With the release of the Home Visiting guidance, we plan to incorporate the findings of the 2011 MCH Needs Assessment, with some possible supplementation focusing on the early childhood population in the state.

Infrastructure building for the system of services for young children extends beyond state level initiatives. The Head Start-State Collaboration Office provides funding for six local early childhood councils that cover all regions of the state. These councils are addressing local issues including literacy, provider training, and service coordination for local providers. One local council is assisting in the coordination of services among pediatric practices, Early Head Start, Early Intervention, and other service providers for children with developmental delays. The members of this local council have provided technical assistance to pediatric practices on identifying developmental delays and have gathered information about ways other service providers can better meet the needs of pediatric practices.

The Adolescent Health Coordinator who works in the Maternal and Infant Health Program depends heavily on direction from the Adolescent Health Taskforce, a group of stakeholders in Adolescent Health from a wide variety of agencies and organizations. Several members of the Taskforce collaborated this year to participate in AMCHP's Adolescent Preconception Health Action Learning Collaborative. The team consisted of UDOH, Utah State Office of Education, Salt Lake School District and Planned Parenthood of Utah staff who worked together to promote the inclusion of preconception health into the state's secondary core curriculum. In addition, select members of the Taskforce contributed to a comprehensive report on Adolescent Reproductive Health that is due for release this summer.

The Presumptive Eligibility Program for Prenatal Medicaid continues to screen pregnant women throughout the state. To increase access to presumptive eligibility for pregnant women, several new eligibility sites have been added over the past couple of years. To promote more widespread access, DFHP continues to contract to support UtahClicks, the online universal application system (available in English and Spanish) has improved access to multiple services essential for low-income families and has expedited the application process for the programs included.

The UDOH is working to improve application for statewide services for families through a contract with Utah State University in establishing UtahClicks, a web-based universal application initiative. The program has been operational since the summer of 2005, originally enabling families to apply online to five different programs including Medicaid, Baby-Your-Baby, BabyWatch/Early Intervention, CSHCN clinical services and WIC. UtahClicks is operating and serving families interested in applying for services that they may be eligible for. Unfortunately, the Department of Workforce Services has developed a new electronic system for eligibility determination, E-Rep, and UtahClicks is not compatible with the new program. Medicaid and all DWS services will now be available through E-Rep, and Medicaid is no longer accessible through UtahClicks. The change has resulted in a decrease in usage of UtahClicks since anyone wanting to apply for Medicaid now goes through the new system.

Perinatal care coordination for presumptively eligible pregnant women is available through Medicaid qualified providers (QP) who assess possible risks that may impact pregnancy outcomes. The QPs determine women's risk status by medical and obstetrical history, including lifestyle behaviors, and psychosocial stressors, with appropriate referrals to Medicaid-covered services for home visiting, psychosocial and nutritional counseling and childbirth education classes. Local health departments in the Wasatch Front are encouraged to work with the Managed Care Organization care coordinators. Two RN case managers in the Maternal and Infant Health Program provide case management for high-risk prenatal women in Salt Lake County for Intermountain Healthcare's Medicaid product, Select Access. Local health departments are encouraged to provide services to women who are not Medicaid eligible through the Prenatal to Five Home Visiting Program funded with Title V contracts to the local agencies.

The Utah Pediatric Partnership to Improve Healthcare Quality (UPIQ), sponsored by the Intermountain Pediatric Society, Utah's chapter of the American Academy of Pediatrics, the state Title V and Title XX agencies, the University of Utah Pediatrics Department, and other key health organizations are providing training to pediatric practices to improve the quality of services delivered in pediatric provider practices. The MCH Director, SECCS Grant Director, and Children's Mental Health Promotion Specialist have been involved in guiding and supporting the work of UPIQ to improve well-child services, developmental screening, and social emotional screening of young children. The Bureau of CSHCN is working with UPIQ on a number of projects to provide training for Medical Homes serving children with special needs, including the ASD/DD project for Medical and Dental Homes (MCHB), the Utah Newborn Screening Clinical Health Exchange (MCHB), and the Child Health Insurance Project awarded to Utah Medicaid, which includes, among other projects, training for Medical Homes about children with special needs.

The Utah Collaborative Medical Home Project is a collaborative effort by the Bureau of Children with Special Health Care Needs with the University of Utah Department of Pediatrics, Utah State University, Medicaid and Utah Family Voices that provides outreach and support to medical homes statewide for children with special health care needs (CSHCN) in primary care settings. Originally funded by an MCHB grant, the project continues to expand throughout the state Pediatric Grand Rounds statewide.

The CSHCN Medical Director serves on the PCMC Pediatric Education Services Continuing Medical Education Committee, the credentialing committee for CME credits for physicians. This Committee identifies the topics to be presented in weekly Pediatric Grand Rounds statewide

Another infrastructure building project, funded through a three year MCHB grant is the Utah Autism Spectrum Disorders (ASD) Systems Development Project will enable the State of Utah to implement key components of "Utah's State Plan for Improving Outcomes for Children with ASD and developmental disabilities (DD)," that improves access to comprehensive, coordinated health care and related services for children and youth with ASD and other DD. Goals of the project are to: 1) Improve identification and health care of children with ASD/DD by training family/pediatric Medical Homes, dentists, and other providers on screening, intervention and community resources; 2) Use www.medicalhomeportal.org to expand ASD/DD evidence-based information available to families and providers; 3) Improve community providers' capacity for early recognition of signs of ASD to improve referral, diagnosis, treatment; and 4) Expand Utah Family Voices' capacity to provide families with support coordination.

The Child Health Advanced Record Management data integration system (CHARM) has begun to help identify gaps in services. This project is an on-going effort to integrate disparate children's databases from CSHCN programs. To link the data sets, CHARM uses the Birth Record Number from the Newborn Screening heel stick kit as part of a matching algorithm and then links records of individual babies in participating program databases, including vital records, heelstick screening, hearing screening, early

intervention, immunizations, and others. This goal was accomplished through in-service training, developing a mechanism for the number to be included with the collection data, and individual targeted education for those hospitals and participating programs and partners within the UDOH.

Currently, there are four on-going statewide e-health quality initiatives that the UDOH CSHCN Bureau is actively involved in. The CHARM Program, mentioned above, the statewide clinical Health Information Exchange (cHIE) initiative, the Medical Home Portal, an on-line information resource to support clinicians and families in improving care for children with chronic special health care issues through the Medical Home model, and the Utah Pediatric Partnership to Improve Healthcare Quality (UPIQ) to help support primary care practices with on-going quality improvement.

Through the Utah Newborn Screening Clinical Health Information Exchange MCHB funded grant, participants from CSHCN, CHARM, University of Utah Department of Pediatrics, Intermountain Healthcare, Utah Health Information Network, and private providers will develop secured electronic information network for exchange of newborn screening results with Medical Homes, assuring confidentiality, privacy, and security policies and procedures are in place. Decision support at point-of-care and training of targeted Medical Homes will be provided to improve short- and long-term follow-up. This grant was one of four awarded in the country.

The Bureau of Children with Special Health Care Needs contracts or coordinates with three local health districts and, in St. George, with Intermountain Health Care to coordinate local pediatric developmental clinical services for children living in rural Utah. State staff meets with local health officers and nursing directors on an as needed or requested basis to coordinate the clinical services at a local level.

Over the past ten years, the UDOH has made substantial progress in developing public health information infrastructure that integrates disparate health data systems. The Child Health Advanced Records Management (CHARM) system will create a virtual health record for every child that allows real-time data sharing across health programs and medical homes. Funds for this data integration initiative have come from the EHDI - CDC Cooperative agreement, the Genetic Services Implementation (MCH - GSDI) grant, the MCH State Systems Development (SSDI) grant and the Title V Block Grant and most recently from a HRSA grant to help develop the statewide clinical health information exchange (cHIE).

This data integration project has successfully linked vital records (birth and death certificates), the Utah Immunization Registry (UHIIS), Early Hearing Detection and Intervention (EHDI), the Newborn Screening (Heelstick) Program, and Baby Watch/ Early Intervention. Additional links are being developed with CSHCN clinical programs, the Utah Schools for the Deaf and Blind, and the Utah Office of Education and (soon) the Fostering Healthy Children Program. Each participating program maintains its own database and controls what data are shared and with whom based on formal Data Sharing Agreements. The goal of integrating health information among these programs is to

improve health care by providing more complete information to the child's medical home. The statewide system is reducing the number of children who are lost to follow-up, reducing duplication of health care services, such as immunizations, allowing more accurate tracking of adoptions, babies with name changes, as well as helping to provide consistent, current, and authoritative information about any child born in Utah or any child who is receiving services from one of the participating health care programs. Access to this system alerts users to exceptional conditions in individual children. Future plans for the system include additional program data integration, integration with the statewide clinical Health Information System (cHIE) and secure access linking and transmission to providers, using the MedHome Portal website.

Efforts are currently ongoing to improve data quality (e.g. accuracy, completeness, timeliness) of the child health information that is used to integrate the health care services provided by UDOH programs, private providers, hospitals, and clinics. Policies for confidentiality, privacy and security are also being developed that will drive the technical and architectural specifications of future data sharing with the UDOH. The Child Health Advanced Records Management system along the statewide cHIE will provide easy to use, technology based ways of providing access to integrated information at the point of service for authorized users. The CHARM system will act as an electronic broker for participating programs, but it will not replace existing databases.

The SSDI Project supports the continuation of the CHARM and related cHIE projects. The SSDI funding is used to support the cost of a DTS programmer who works to tie in programs to the CHARM and cHIE systems. These programs include BabyWatch Early Intervention, Newborn Hearing and Blood Screening, Vital Records and Immunizations. The Annie E. Casey Foundation is planning to provide funding to link the Fostering Healthy Children Program/Department of Human Services to CHARM and cHIE. This will decrease loss to follow up for children who failed second hearing tests, as well as allow integration of all DOH screening information to be added to the SAFE child health records.

Utah CSHCN is in its sixth year of the MCHB-funded Utah Regional Leadership Education in Neurodevelopmental Disabilities (URLEND) Program. The URLEND funding has been granted to the University of Utah, Department of Pediatrics, School of Medicine. Through URLEND, the University of Utah, Department of Pediatrics, School of Medicine is collaborating with CSHCN and the Utah State University, Center for Persons with Disabilities in an MCHB Leadership Grant. URLEND provides opportunities for students and professionals from a variety of health-related disciplines (e.g. pediatrics, physical and occupational therapy, speech-language pathology, psychology, nutrition, social work, audiology, pediatric dentistry, genetics, nursing, business/marketing, special education, and families) to increase their knowledge and skills in providing services and supports to children with neurodevelopmental disabilities. With the growing trend towards collaborative interdisciplinary efforts in the health care field, the demand for persons with enhanced teamwork skills who have had experience working with individuals from a variety of disciplines to provide services to children with disabilities has increased.

CSHCN works to integrate local rural clinic activities into the statewide medical home effort, and works closely with local primary care medical home providers to coordinate the care of children. This year, the CSHCN Bureau plans to begin to update its technology, which was originally purchased over 10 years ago. This upgrade will provide an opportunity to offer follow-up sessions with those not directly involved with the rural clinics, such as local special education representatives. Telehealth has not yet been available as a means for Salt Lake City based pediatric subspecialists to provide remote evaluations for CSHCN children. The CSHCN Medical Director plans to seek funding for and promote subspecialty evaluations for children being seen in rural CSHCN multi-specialty clinics. Building capacity in this area could greatly enhance the reach for CSHCN.

The CSHCN Bureau staff participates in Medicaid's Utilization Review and EPSDT Expanded Services Prior Authorization Committee that meets weekly to determine coverage of non-covered services for Medicaid recipients. The CSHCN Medical Director, a pediatrician, has voting status on the committee. The Bureau's physical therapy supervisor is a consultant to the committee.

University of Utah School of Medicine Department of Pediatric physicians serve on numerous CSHCN advisory committees, including the BabyWatch/Early Intervention Program Interagency Coordinating Council, the CSHCN Executive Council, the Newborn Hearing Screening Advisory Committee and the Genetics Advisory Committee.

The CSHCN Bureau Director serves on numerous multi-agency/multi-advocacy group advisory councils including:

- Utah Developmental Disabilities Council (UDDC)
- Utah State Rehabilitation Council/Utah State Office of Education
- Interagency Outreach Training Initiative/Utah Center State University
- Coordinating Council for People with Disabilities, a state mandated advisory council, comprised of all state agencies serving adults and children with disabilities
- Senator Orrin Hatch Committee on Disabilities
- Children's Health Care Consortium, a multi-agency committee that advises on coordination of health care services for children in Utah Foster Care. This committee includes members from the Drug Endangered Child Medical Alliance Team, Mental Health Providers, DCFS, Medical Partners, the Christmas Box House (SLCO Shelter and public advocates, and Safe and Healthy Families (PCMC), Medicaid, and State Juvenile Justice Courts Improvement Project

The Division is fortunate to have strong Department leadership related to core public health functions and infrastructure to support them. The Department has made a strong commitment to collection, analysis and dissemination of data. Since the 2001 needs assessment, the Department created the Center for Health Data, which includes several offices, including Vital Records and Statistics. Division staff works closely with staff from Vital Records, as well as staff from the other Center Offices. Division staff members contribute to the IBIS website, an Internet query system which includes vital records, hospital discharge, PRAMS, BRFSS and population data sets.

The UDOH has made substantial progress in developing public health information infrastructure that integrates health data systems. The Child Health Advanced Record Management (CHARM) system will create a virtual health record for every child that allows real-time data sharing across health programs and medical homes. CHARM will provide an easy to use, technology based way of providing access to integrated information at the point of service.

Each participating program maintains its own database and controls what data are shared and with whom based on formal Data Sharing Agreements. The goal of integrating health information among these programs is to improve health care by providing more complete information to the medical home and families. The statewide system will reduce the number of children who are lost to follow-up, reduce duplication of health care services, such as immunizations, allow more accurate tracking of adoptions, babies with name changes, and will provide consistent, current, and authoritative information about any child born in Utah or any child who is receiving services from one of the participating health care programs. Access to this system will also alert users to exceptional conditions in individual children. Future plans for the system may include additional program data integration, such as Children with Special Health Care Needs and secure access linking and transmission to providers, using the MedHome Portal website.

The Division has built enhanced data capacity to support MCH and CSHCN programs in their data needs for program planning and evaluation. Since the 2000 needs assessment, the Division hired a MCH Epidemiologist and added additional data staff members that are critical to the work of the Title V agency. The Division has need for additional data analytic capacity; however, recruitment for a vacant position and creation of new positions are not possible even though federal funds are available to do so because the Governor has imposed a soft hiring freeze.

The MCH Epidemiologist has enabled the State Title V agency to conduct higher-level analyses of data, participate with outside partners on studies (fetal death study funded by NIH grant to the University of Utah) develop surveys based on sound survey methodology, develop program evaluation plans that contribution to quality improvement of program strategies. In addition, the MCH Epidemiologist provides oversight of data work that others do within the MCH and CSHCN programs, stimulates research and develops abstracts for meetings like the annual MCH Epidemiology meetings.

The Department of Health has collaborated with the Nevada Department of Health to develop the Great Basin Public Health Leadership Institute which offers public health professionals in the two states an opportunity to participate in a year-long educational program focused on public health leadership. The first class of scholars graduated in March 2005, with the second class beginning its work in May 2005. The Institute provides scholars with educational experiences that are invaluable in enhancing leadership in public health. The Institute continues with a class offered on an annual basis.

The state Medicaid agency has developed a data warehouse that affords access to Medicaid data by key data staff in the Department. However, the limitation of the data warehouse is that it does not currently include the managed care organization (MCO) data, which includes the majority of the Medicaid population in the state. Medicaid is working with the MCOs to obtain their data to be inclusive of all Medicaid participant data. Data staff has been able to link the Medicaid data with vital records data which provides us with invaluable information on outcomes of the Medicaid population versus the general population. The Data Resources Program in the MCH Bureau participates in several data integration efforts, as well as with the Department's survey unit to provide input on data needed on women of childbearing ages and children that are not available through other sources. The most recent linkage that has been accomplished is linking Hospital Discharge Data with Medicaid and Vital Records.

The Department has also made tremendous strides in the past five years with website development. Every program in the Title V agency has a website that provides the public and professionals with up to date information from program work. The Title V agency has also developed capacity in the area of online application systems, such as a WIC vendor online quarterly price survey that in the past was done with pencil and paper by the vendors and then entered into a database at the state. Now, vendors enter their prices into the online system, which dumps the data automatically into a database, reducing time and efforts.

In 2006, a new WIC information system was rolled out only to see significant problems for clinic operations including issuing vouchers. The system has been improved significantly and has been running satisfactory for the past 2 years. The Utah WIC Program has been involved in the three-state consortium to develop a new information system, VISION that may be a national model for WIC information systems. The multi-state initiative has had its own major challenges with programming bugs and functionality. VISION is now in the user acceptance testing stage in Utah after Colorado participated in testing two months ago.

The CSHCN Bureau staff participates in Medicaid's Utilization Review and EPSDT Expanded Services Prior Authorization Committee that meets weekly to determine coverage of non-covered services for Medicaid recipients. The CSHCN Medical Director, a pediatrician, has voting status on the committee. The Bureau's physical therapy supervisor is a consultant to the committee.

University of Utah School of Medicine Department of Pediatric physicians serve on numerous CSHCN advisory committees, including the BabyWatch/Early Intervention Program Interagency Coordinating Council, the Medical Home Advisory Council, the Newborn Hearing Screening Advisory Committee and the Genetics Advisory Committee.

The CSHCN Director is also involved in University of Utah and Primary Children's Medical Center (PCMC) based Health Services Research Committee. The CSHCN Family Advocate Coordinator serves on the Family Advisory Committee for PCMC.

The State Primary Care Office (PCO) collaborates with the Title V agency on the MCH Advisory Committee and its work. In addition, the PCO staff involves Title V staff in funding proposals to support rural and primary care in the state through its work with local health departments.

Overall system of care

The following is a description of health issues/system issues among maternal, infant, child, adolescent and children with special needs populations. Although Utah's fetal, infant and maternal death rates are relatively low, these deaths are tragic occurrences and some may be preventable. The Perinatal Mortality Review Program (PMR) was developed to review infant deaths due to perinatal conditions identified through vital records, and maternal deaths. The PMR is administered at the state level and enables statewide surveillance of these events. Health and vital records data are collected, summarized, and reviewed by perinatal health care specialists from different disciplines and settings to identify opportunities for prevention. Maternal deaths are identified through a matching of fetal death certificates and birth certificates with death certificates of all women of childbearing ages whose death occurred within one year of the pregnancy termination. Linking of certificates and expansion of the definition of maternal deaths to include those that occur within twelve months of a recorded pregnancy termination have resulted in an expected increase in maternal deaths due to improved case finding. Data for each case are collected and summarized by the Perinatal Mortality Review Coordinator who with other health care professionals, reviews the deaths to determine if they are directly related, indirectly related or not related to pregnancy. During the review process, recommendations made by the review team are recorded and used to plan interventions for the prevention of future deaths. Collaboration with professional organizations has enabled the Division to promote review findings to providers in order to address provider practice issues. Better consultation and referral networks within the state health care systems would promote better pregnancy outcomes.

Since 2004, the Maternal Child Health Bureau sponsors a Perinatal Taskforce comprised of community members, health care providers, health plan representatives, and Department staff. Staff has presented an overview of MCH issues for Utah mothers and infants, such as the declining percentages of women entering prenatal care early so that members can provide feedback on the priority needs for mothers and infants.

A number of existing systems currently collaborate to provide health care to uninsured children. These systems and efforts include the managed care system in the provision of services; the Department's CHIP, Medicaid, and the MCH programs in local health departments in providing outreach to get eligible children covered.

As a result of several years of data, UBDN identified certain birth defects to be more prevalent among different racial groups and higher in Utah than other states or countries. Utah has high prevalence rates of particular birth defects: oral facial clefts, gastroschisis and particular congenital heart malformations. Maternal age, both young and old, is a strong risk factor for some birth defects. The reasons for these high prevalence rates are

not clear but descriptive analyses are planned to assess epidemiologic characteristics for several birth defects. For example, through a CDC grant awarded to the University of Utah, the UBDN is currently investigating maternal characteristics and other exposures to determine their contribution in the etiology of gastroschisis. UBDN also identified some birth defects to be increasing in prevalence in Utah. For example, hypospadias and gastroschisis have significantly increased since 1999.

The UBDN evaluates the effectiveness of their folic acid prevention activities on NTD prevalence rates for Utah using the CDC's seven question folic acid module that is included in the Behavioral Risk Factor Surveillance Study's random household survey, which queries women in their childbearing years about folic acid awareness, knowledge and consumption. The UBDN utilizes these data to determine a more focused prevention activity plan for the state. Because funding for this activity was discontinued in 2003, the rate of NTDs has increased the past several years. An intervention such as providing multivitamins with folic acid with face to face education may have an impact on these rates. The first time motherhood grant provided funding to institute a multivitamin with folic acid awareness effort in local health departments and community health centers <http://www.poweryourlife.org>. Staff developed a DVD and printed materials to make the information easily available to mothers in WIC clinics (http://www.Health.utah.gov/wic/folic_acid.html).

Approximately 50% of resident women in their childbearing years do not consume a multivitamin with folic acid. Awareness of folic acid, an important B vitamin, and knowledge that folic acid prevents birth defects do not lead to multivitamin consumption. Women are more likely to consume a multivitamin with folic acid if they hear from their health care provider or clinic staff about the importance of taking a multivitamin. Because each year there is a new cohort of women entering their childbearing years, intensive statewide educational activities must be a continuous process.

Local delivery systems

Services for the three populations served through Title V are offered in a variety of settings: medical homes/private provider offices; public providers in local health departments, community health centers, a clinic for the homeless, several free health clinics, migrant health clinics; itinerant clinics offered through the CSHCN Bureau to rural communities without specialty providers; and specialty settings, such as the University of Utah Health Sciences Center, Primary Children's Medical Center, Shriners Hospital for Children, and the other Level III centers for perinatal care. These centers of excellence are able to provide centralized specialty and subspecialty services to high-risk pregnant women and children who have numerous disabling conditions, such as asthma, hemophilia, cystic fibrosis, diabetes, Down syndrome, cancer and orthopedic disorders. Although this centralization allows for better coordination of care because there are fewer providers, it also presents a problem of service delivery to high-risk pregnant women, high-risk infants, and special needs children in rural Utah.

Local health departments (LHDs) and community health centers (CHCs) provide the local systems of care throughout the state for the MCH population as well as adults. The 12 autonomous local health departments (LHDs) have their own unique governance and array of services. Most local health departments are multi-county districts covering large geographic areas. The Utah Department of Health contracts with each of the local health departments to provide various services and core public health functions on a local level, including maternal and child health block grant funds, immunization infrastructure, WIC administration, tobacco prevention, prevention block grant funds, and funds for local care coordination for CSHCN. Each local health department prioritizes its use of the Title V funds. The Department of Health is responsible for oversight of the state and federal funds that are distributed to the local health departments through contracts.

Most local health districts no longer provide primary care services for MCH populations. Services available through local health departments (LHD) vary depending on priorities as established by the health district. For example, prenatal services are no longer available through LHDs, although two districts provide clinic space and support staff for prenatal services provided by University of Utah Health Sciences Center providers or Family Practice Residency Program. Family planning services are available only through mid-level practitioners in several health district clinics. The shift away from direct services provided by local health departments reflects the changing public health system to focus more on health promotion and prevention services.

Despite a high number of physicians and mid-level providers working through a variety of private and public agencies, obtaining early, continuous prenatal care remains elusive for Utah women in certain categories. Unmarried teens living at home often do not qualify for Medicaid as their parents' earnings place them over the income standards. Unfortunately, many families caught in this situation either do not have insurance or their carrier does not cover a dependent's pregnancy and they lack adequate cash to cover the teen's pregnancy expenses. Women and their families working at low paying jobs may also find themselves just over income limits, unable to afford insurance, and without sufficient cash for prenatal care. For both of these groups, finding prenatal care in a timely fashion becomes a difficult task.

During FY2009, local health departments provided pregnancy related services to more than 9,400 women, of whom 20.4% were Hispanic, 1.1% were American Indian, 1% were Black, 1.3% were Asian and 74% were Pacific Islander. More than 30% of women seen in local health departments for pregnancy-related services reported no insurance and over 45% were on Medicaid. Of women seen for family planning services, almost 90% (89.8%) reported no insurance with only 1.8% on Medicaid.

Funding for family planning services for low-income women in Utah is problematic. Many women lose their Medicaid coverage approximately 60 days following delivery and are then without coverage to obtain effective contraception. Utah has experienced an influx of Spanish speaking immigrants many of whom are of undocumented status. From 2004 to 2008, the number of births to Hispanic women rose from 14.2% to 17.1% of all

live births. According to the 2008 Utah Healthcare Access Survey (UHAS), 38.1% of Hispanic women had no health insurance compared to 6.8% of non- Hispanic women.

The Alan Guttmacher Institute has estimated that there are approximately 147,000 women ages 13-44 years in Utah in need of low cost family planning services in Utah. Approximately 9,000 women who qualify for prenatal care each year lose their Prenatal Medicaid eligibility approximately sixty days after delivery, leaving them without a third party payer for family planning. Without access to long-term family planning, adequate spacing of pregnancies for optimal maternal and child health outcomes is very difficult for many of these women.

Although data on availability of mental health care services for women of reproductive ages have not yet been compiled, anecdotal reports indicate that this is a problematic area of access. Utah PRAMS data for 2008 indicated that postpartum depressive symptoms were reported by 12.3% of Utah respondents.

Local health departments provided services to almost over 10,000 children during 2009 of whom 30% were Hispanic; over 30% had no insurance and approximately 52% were on Medicaid or CHIP. Local health departments provided services to 1819 children with special health care needs.

The public health system in Utah is hampered in providing services to all in need due to funding shortages, staffing shortages, etc. Utah is faced with a growing population of families without insurance, especially those of undocumented citizenship status, placing a stress on a health care system with limited resources. Local health districts and community health centers in the state have been forced to place limits on the number of individuals served due to limited resources.

Seven of the twelve local health departments offer well child services to infants and children. Whenever necessary, referrals are made to providers/medical homes and/or clinics within the community for follow-up of identified health concerns. The local health departments strive to assist families in identifying primary health care providers for their children. The local health departments are encouraged to promote medical home for children they see in their clinics.

The Prenatal - 5 Nurse Home Visiting Program is available in nine of the twelve local health departments. Home visitation assists families in gaining access to information and services that support and strengthen their capacity to meet their own needs and those of their children. The Utah program, targeted toward at-risk pregnant women and children from birth to 5 years of age and their families, is directly managed at the local health department (LHD) level and staffed by local public health nurses. Home visits are conducted to assess child and family strengths and needs related to overall health and well being, and to provide anticipatory guidance, information, assistance, and/or referral to assist families in meeting identified needs. Local health departments continue their interest in P – 5 nurse home visiting as evidenced by the Nursing Directors' request to maintain the P – 5 funding separate from the other MCH block grant funds they receive

in the event that local support for this service doesn't continue. While these Prenatal – 5 home visiting program is not based on any one evidenced-based model, the local health departments value the funding so that they are able to better support families in need. One local health department has invested in the Nurse Family Partnership program and is currently serving about 100 families. As we learn more about the new federal home visiting funding as a result of the health care reform legislation, we will hopefully be able to support other local health departments interested in implementing an evidence-based home visiting program in their communities. The needs assessment for the federal home visiting funding will assist us in identification of communities in need as well as community readiness for a program.

Local health department participation in this MCH Block grant-supported program component, through contract, is voluntary. Contract funding to support the local services is limited and is clearly not sufficient to fully support the level of staffing needed to provide services to all in need. Several local health departments supplement MCH Block grant dollars with additional local or private dollars, which they have been successful in garnering through other funding sources. In areas with limited funding and severe nursing shortages, participation is usually reserved for at-risk pregnant women and young children determined by the public health nurse to have the greatest need for the services. One local health department has experienced severe nursing shortages and has been unable to provide services for a significant period of time.

Mental health services are available privately and through Medicaid Prepaid Mental Health Plans throughout Utah. However, services are not adequate for women of reproductive age, children, infants, children and youth with special health care needs, especially in rural Utah. Services for children who have undocumented citizenship or whose families do not speak English are also very limited, most markedly in rural Utah. In some rural areas of Utah, there may be mental health services, but adequate numbers of trained professionals are not available in specific specialty areas, such as autism and sexual abuse recovery. Collaborative efforts involving multiple agencies are underway to improve the mental health services for women and children in the state.

Mental health services for Medicaid recipients are delivered primarily through community mental health centers. The community mental health centers coordinate with other providers of children's services through case management and other mechanisms, e.g., regular meetings with other child-serving agencies. Because of strict health guidelines for children in foster care, community mental health providers work closely with the human services caseworkers and the Fostering Healthy Children nurses to insure mandated evaluation and treatment of children in foster homes.

The Utah Department of Health also has contracts with community health centers for maternal and child health services, mainly for immunization infrastructure. The Division does provide a small amount of funding from the MCH Block Grant to fund prenatal services for uninsured women in the Salt Lake Community Health Centers, Inc. system.

The 12 community health centers (CHC) and the Wasatch Homeless Clinic provide primary care to underinsured and uninsured MCH populations. Six of the community health centers are located in rural areas of the state. One CHC had been operated in conjunction with a local health department, but that relationship has been terminated due to differences of opinion about services. Three migrant farm worker clinics are co-located with Wasatch Front community health centers and a fourth clinic is located in Brigham City. Unfortunately, many of Utah's Hispanic workers, especially along the Wasatch Front, are not engaged in farm work and therefore do not qualify for these services.

The twelve community health center (CHC) agencies in Utah provided services to 113,125 individuals (4% of the state's total population) in 2009, an increase of more than 7,500 people from 2008. In addition to primary and preventive medical care, CHCs also provide dental care, mental health care, and other enabling services to assist patients with navigation of the health care system. They provide services to 24% of the population living under 100% of the FPL, 22% of the state's total uninsured population and 31% of the low-income, uninsured population in Utah. Of the individuals who receive services at one of the thirty CHC sites in Utah, 59% are uninsured, 23% are covered by public benefit programs (Medicaid, Medicare, CHIP), 73% live at or under 100% of the FPL, and 95% are under 200% of the FPL. Although CHCs have continued to grow to meet needs in communities, estimates indicate that as many as 200,000 additional Utahns would benefit from expansions of CHC service sites. Since 2004, the number of patients seen in community health centers has grown by 44%, while the State's population has only grown by 13%. CHCs serve a diverse cross section of Utah's communities, with 44% of the clinic patients reporting as being Hispanic or Latino (vs. 12% for the State), 10% American Indian/Native American (versus 1% in state), and 32% of clinic patients residing in rural Utah counties. In 2009, CHCs provided prenatal care to 4,317 women, performed 2,058 deliveries, and maintained a low birth weight rate of 5.6% (well below the 2008 Utah rate of 6.8%). Also, Utah's CHCs provided essential care to over 6,400 people experiencing homelessness, and provided 10,614 H1N1 vaccinations during the 2009 outbreak.

Community-based dental clinics are available in some parts of the state, which include: two community health center (CHC) dental clinics in Salt Lake County; five Family Dental Plan Clinics (Medicaid only) in Salt Lake City (2 sites), Ogden, Provo, and St. George; three local health department dental clinics in Vernal, Heber and Tooele; five donated dental services clinics in Salt Lake City, Ogden, Wendover, St. George and Logan; and three school and community-based clinics (preventive services only) in Salt Lake City and Ogden. Funding has been requested to establish dental clinics in community health centers in Price. CHC dental clinics have been established in Ogden, Layton, Provo, St. George, Bicknell, Montezuma Creek, Green River and Bear Lake. None of the community-based centers provides specialty care, such as treatment under general anesthesia or orthodontic treatment. Primary Children's Medical Center provides some services for children requiring extensive dental care, especially those cases requiring anesthesia. The Fostering Healthy Children program has negotiated with local dentists to donate their time at the "Christmas Box House," in Salt Lake City, where

children are first housed as they are removed from their homes due to abuse or neglect. Dentists volunteer their time, and provide initial dental examinations and treatment for children as they enter foster care. This has been especially important for these children, as they often suffer from severe dental disease due to poor nutrition and neglect.

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In Utah, 15% of Medicaid-covered children and adults receive dental services from six Family Dental Plan Clinics, which are Medicaid-only clinics managed by the Division of Medicaid and Health Financing, located in Salt Lake City, Ogden, Layton Provo, and St. George. Additionally, there is one local health department Medicaid-only dental clinic in Vernal. Seven community health center dental clinics are also available to serve adults and children who are covered with Medicaid or can pay on a sliding fee scale. Three of these clinics are located in Salt Lake County.

Although Medicaid adult dental benefits have been restored or eliminated several times over the past 10 years, full dental benefits are covered for pregnant women on Medicaid. Unfortunately, the changes in adult dental coverage create confusion about the dental benefits for pregnant women resulting in some women not being seen by a dentist during pregnancy. Access to a dentist willing to provide services for Medicaid participants is difficult for many in the state due to low provider reimbursement rates, which has led to provider unwillingness to serve the Medicaid population. Advocates continue their work to restore the benefits as an ongoing service.

In the 2009 Utah legislative session, adults with disabilities who qualify for Utah Medicaid lost all Medicaid dental service coverage and the legislature cut the reimbursement to dentists for services to children on Medicaid. This reduction in dental reimbursement was rejected by federal CMS and thus had to be reinstated in the 2010 session. The state was required to pay Medicaid dental providers up to the original pre-2009 rate. People with severe disabilities, whether or not Medicaid recipients, also find access to oral health care difficult, because often dentists are reluctant or are not trained to treat people with disabilities in the traditional office settings or are not able to provide care under anesthesia, if needed. Primary Children’s Medical Center’s Dental Clinic sees children to age 8 and the University of Utah Dental Clinic provides access for Medicaid recipients. Rural access to specialty dental services is very limited with few areas having a pediatric dentist at all.

CSHCN complements private sector services by continuing direct or enabling community based services where there are gaps in these services for children. This year, in collaboration with Champions for Healthy Communities, CSHCN began an ongoing community needs assessment process to determine the capacity for communities to serve

children with special needs and families. This process will allow the Bureau to tailor services and conserve funds as services become available in a community. Throughout Utah, a combination of State CSHCN programs, rural or local health department clinics, private providers and medical homes provides “safety net” services for Utah’s children and youth with special health care needs.

In Utah, local providers through contract with the BabyWatch / Early Intervention Program (BWEIP) serve children from birth to 3 years of age. BWEIP contracts with 15 private and public providers throughout Utah to provide direct and care coordination services for these children.

People with disabilities find it especially difficult to access oral health care for several reasons including: most individuals with disabilities are Medicaid recipients; many dentists are reluctant and/or not trained to treat people with disabilities in the traditional office setting; many dentists are not willing and/or do not have the appropriate anesthesia permit to see individuals with severe disabilities in a hospital or surgical care center; and, few tertiary care facilities in rural Utah where dental treatment can be conducted for people with severe disabilities.

The Bureau of Children with Special Health Care Needs in collaboration with the University of Utah, Division of Pediatrics continues to provide direct and enabling services to children with special needs who are unable to access services through other sources. Due to funding constraints, the Bureau’s direct and enabling services are focused on children in three groups: 1) young children birth to age 8 years with suspected developmental/genetic/hearing disorders; 2) children to age 18 needing developmental evaluation in rural Utah; and 3) newborn ICU graduates, birth to 6, whose birth weight is less than 1200 grams, who have had ECMO, or who have known disabling conditions. These direct services include multi-disciplinary developmental evaluation clinics in Salt Lake City and in 7 satellite sites; early intervention services in 12 rural and 7 urban centers (Baby Watch Early Intervention Program); and newborn follow-up multi-disciplinary developmental evaluation clinics for newborn ICU graduates in Salt Lake, Provo and Ogden through the Neonatal Follow-up Program). Information and care coordination are provided by CSHCN staff to improve access to SSI services and for Spanish speaking families. Care coordination is provided for children who are followed in CSHCN clinics or early intervention centers and to children served by dedicated case management programs such as the Fostering Healthy Children Program and the Technology Dependent Waiver. These direct and enabling services are described in more detail in the Overview section.

CSHCN provides direct services in their Salt Lake City office for three specific populations: follow-up of premature infants, developmentally delayed preschool age children, and developmentally or behaviorally disordered school age children and youth. The Bureau of Children with Special Health Care Needs in collaboration with the pediatric tertiary care centers continues to provide direct and enabling services to children with special needs who are unable to access services through other sources. These direct services include rural multi-disciplinary pediatric clinics; early intervention services in 12

rural and 7 urban centers; newborn follow-up multi-disciplinary clinics for newborn ICU graduates in Salt Lake, Provo and Ogden; and two behavioral and developmental clinics in Salt Lake City through the Bureau's Adaptive Behavior and Learning Environment (ABLE) and the Child Development Programs. The System Development Program works with the clinical programs to improve the provision of enabling services to all children with special needs in the areas of transition, cultural sensitivity and improved access to SSI services. Case management and other enabling services are provided to children who are followed in clinics or early intervention centers and to children served by dedicated case management programs such as the Fostering Healthy Children Program and the Technology Dependent Waiver.

Clinic and care coordination services provided by CSHCN programs include Hearing, Speech and Vision Services; Early Intervention; Child Development Clinic; Neonatal Follow-up Program; Adaptive Behavior and Learning Environment Clinic; Fostering Healthy Children; and the Technology Dependent Waiver Program. These direct and enabling services are described in more detail in the Overview section. The CSHCN Bureau itinerant clinics hold community coordination meetings with local medical home providers, public health or mental health workers, human service workers and families as well as family advocates to develop a multi-agency care plan for each child evaluated in the multi-disciplinary CSHCN clinics.

CSHCN complements private sector services by continuing direct or enabling community based services if there are gaps in these types of services for children. A combination of State CSHCN programs, rural or local health department clinics, private providers and medical homes provide services for Utah's children and youth with special health care needs. The CSHCN Bureau has been working with pediatric offices throughout Utah to enhance their capacity to provide medical homes for children with special needs and their families. Division staff members provide technical assistance, consultation (administrative and clinical), training and/or mentoring as needed to local health departments, contracted private providers, medical homes and community health centers that provide services to mothers and children.

Through the Utah Collaborative Medical Home Project, CSHCN, in collaboration with the University of Utah, is implementing a statewide system to support primary care physicians in providing medical homes for children with special health care needs. As part of this system, a website was developed to meet the needs of the practices to provide coordinated, comprehensive and family centered care. The MedHome Portal www.medhomeportal.org provides users with up-to-date information on chronic diagnosis, practice guidelines, care coordination, and statewide resources. The site also includes a module directed at families, a transition module with resources, and an education module directed at physicians, care coordinators and families. The website is a work in progress as the site is continually updated with information and new modules. Information is primarily directed toward primary care physicians however it is readily accessible to families of children and youth with special health care needs and other health care or educational providers.

Through a state/local partnership in nine rural areas, the CSHCN Bureau contracts with local health departments to provide on-site nursing case management and clerical support services, including scheduling of clinics, providing follow-up after specialty clinics are held, management of records and development and implementation of individual care plans (See Community Based Services map.) The Bureau also contracts with the private non-profit parent organization Liaisons for Individuals Needing Coordinated Services (LINCS) for parent consultants to attend clinics, provide family advocacy and assist in the promotion of family-centered care for children seen in the itinerant clinics. The nurse case manager is responsible to assist the patients' medical home and families by coordinating specialty and tertiary care. The Bureau of Children with Special Health Care Needs contracts with four local health districts to coordinate clinical services for the itinerant clinics in the rural areas of the state. State staff meets with local health officers and nursing directors on an as needed or requested basis.

One of the other sites initially involved in the Medical Home Program was the Northwest Community Health Center, a community health center clinic in Salt Lake City serving a primarily Hispanic population. CSHCN supports a full-time Coordinator and a part time Family Advocate for the Medical Home Project and now serves nine primary care medical home practices around the state through technical support, monthly phone conferences, email broadcast resource information, office trainings and family advocate support. A quarterly medical home newsletter, which is sent out to all pediatricians and family practitioners in the state, is topic oriented and includes local, state, and national resources pertaining to each topic. The Project has an advisory committee with representatives from the community including families, educators, mental health providers, clergy, ethnic groups, physician specialists, and school nurses.

State's Effort to Promote Comprehensive Systems of Services

Title V agency has developed strong collaborative relationships with a number of other state agencies, local agencies and private not-for-profit organizations in order to accomplish its work.

Participation with collaborative groups has provided staff with opportunities to become aware of and have input into some community-based services that they might not have opportunities for. Examples include: HIV task forces, participation at health fairs, and community teen-pregnancy prevention groups. Head Start-State Collaboration funding provided local early childhood councils with the opportunity to expand their efforts, involve additional partners, and seek local solutions for improving the system of services for the early childhood population. These efforts allow staff to provide technical assistance and support to community solutions to community problems.

The Pregnancy RiskLine collaborates on projects with state and county agencies and has a close relationship with health care professionals throughout Utah. Continuing education for physicians, mid-level practitioners, pharmacists, genetic counselors, nurses and other medical care providers is on-going from the Pregnancy RiskLine. Relationships with the University of Utah's Divisions of Medical Genetics, Perinatology

and School of Pharmacy result in 24 student rotations per year through the Pregnancy RiskLine.

Collaboration with community-based organizations, non-profit clinics and other providers of services including Utah's largest non-profit insurance and hospital provider, Intermountain Healthcare, result in referral of clients. In return Pregnancy RiskLine provides in-service and other trainings. Agencies such as adoption service providers, teen pregnancy services, family advocacy programs and projects supporting Utah's ethnic and Medicaid's low-income populations partner with the Pregnancy RiskLine to make certain services are equitably delivered and appropriate for these underserved populations. Pregnancy RiskLine leads activities to reduce fetal exposure to alcohol, tobacco and other drugs of abuse and educates mothers on the availability of substance abuse treatment programs. Agencies that collaborate with the Pregnancy RiskLine are the Utah Indian Health Advisory Board, Utah Substance Abuse Advisory Council, Drug Exposed Newborn Committee, Utah Fetal Alcohol Coalition, Utah Alliance for Drug Endangered Children, Utah Association of Counties, League of Cities and Towns and state Departments of Human Services, Alcoholic Beverage Control and Corrections. As a founding member of the Organization of Teratology Information Services, the Pregnancy RiskLine collaborates with other teratology education and research centers across the US and Canada to increase knowledge that is then provided to agencies, health care practitioners and the public throughout Utah.

The major method of coordination between the VIPP and LHDs is through contracts, which allow the program to monitor activities and coordinate with the LHDs. The LHD injury prevention coordinators and the VIPP meet together on a regular basis to discuss problems, successes, and plans for the future. The VIPP actively participates in these discussions and tries to coordinate the various needs and requests. The VIPP has been requiring LHDs to adopt standardized evaluations of the contracted programs. For example, a booster seat project was contracted with all the LHDs and a standardized observation was required so that data could be gathered on booster seat use in Utah.

The VIPP strongly encourages and provides latitude for LHDs to develop and implement intervention strategies that are applicable to local areas. In addition, the LHDs are encouraged to base intervention strategies on current research. Some adaptation to fit the needs of the local area may be necessary and is acceptable; nevertheless the interventions should have a foundation of science. The current Utah Injury Prevention Strategic Plan contains action items under each section that will provide the framework for intervention strategy priorities. A thorough literature review will be conducted to obtain appropriate evidence-based intervention strategies. An annual review of the VIPP's priorities and contract activities with the LHDs will be conducted to synchronize with the strategic plan.

Another example of state agency coordination is the Interagency Coordinating Council (ICC), an interagency group that provides advice to the BabyWatch/Early Intervention Program. The ICC membership represents Utah's statewide early childhood services community and is comprised of 25 members. By specifying types of members included

on the ICC, the state is able to bring together clinical staff, political appointees, parents of special needs children, and administrative representatives of various agencies or providers such as Mental Health, Human Services, Education, Department of Insurance, Head Start, Workforce Services, Division of Services for People with Disabilities, physicians and representatives from contract Early Intervention providers.

The ICC provides a broad vision of the service system based upon the participation and contributions of all relevant providers and consumers. The mission of the Utah Interagency Coordinating Council (ICC) for infants and toddlers with special needs is to assure that each infant and young child with special needs will have the opportunity to achieve optimal health and development within the context of the family. The ICC has several subcommittees, such as the Parent, Finance, Outcomes, and Transition.

Consultation provided to the Child Abuse Prevention Task Force provides an opportunity to share ideas for broad strategies for primary prevention of child abuse including home visiting and parenting education. Community-based injury prevention programs targeting children and youth have included booster seat promotion, child car seat promotion, occupant protection, bicycle safety, bicycle helmet promotion, pedestrian safety, water safety, drowning prevention, falls prevention, fire safety, firearm safety, school safety, and home safety. For the past five years, all LHDs are participating in the implementation of a statewide effort to survey and improve booster seat use among children age 4-8 years.

Title V staff work collaboratively with other state agencies, such as the Office of Education, Juvenile Justice, School for the Deaf and Blind, the Office of the Courts, Utah Highway Safety Office, to name a few. These efforts occur in conjunction with various activities to improve the health of mothers, children and children and youth with special needs. The Bureau of CSHCN also works with various state agencies that relate to the population served through its work, such as the Governor's Council on People with Disabilities, Special Education, state vocational rehabilitation, and the Social Security Administration.

Relationship of State and local public health agencies

Representatives of the local health officer association and the local nursing director association are invited to participate in various Division advisory committees or task forces in order to ensure their input and support. MCH programs have staff that work closely with local health department staff on MCH services and needs. The Bureau of Children with Special Health Care Needs contracts with several local health departments to coordinate clinical services for the itinerant clinics in the rural areas of the state. State staff meets with local health officers and nursing directors during their quarterly meetings on an as needed or requested basis.

The relationship between the local health departments (LHDs) and the MCH / CSHCN programs has been strong on some levels, although in the past couple of years, it has been strained. Dr. Sundwall, the Department's Executive Director, has made a commitment to working with local health departments. He has appointed a Department liaison for the

local health departments, a position that had been abolished a number of years ago. The local health departments have improved their financial stature by billing for services provided to the public when possible.

Staff from MCH Programs provide technical assistance, consultation (administrative and clinical), training and/or mentoring as needed to local health department nurses involved in conducting activities related to maternal and child health services, including prenatal, family planning, nurse home visiting, and school nursing. Program monitoring and data collection are also conducted at the state level to assist in program planning and evaluation. Contracts for MCH services, including immunizations, promote medical home for children. Title V staff has worked with local health department staff to increase awareness of the impact on families when they have to go to more than one place to get care rather than receiving what they need in the same site.

The major method of coordination between the VIPP and LHDs is through contracts, which allow the program to monitor activities and coordinate with the LHDs. The LHD injury prevention coordinators and the VIPP meet together on a regular basis to discuss problems, successes, and plans for the future. The VIPP actively participates in these discussions and tries to coordinate the various needs and requests. The VIPP has been requiring LHDs to adopt standardized evaluations of the contracted programs. For example, a booster seat project was contracted with all the LHDs and a standardized observation was required so that data could be gathered on booster seat use in Utah. Community-based injury prevention programs for youth with special health care needs have included safety restraint use in motor vehicles, bicycle safety, bicycle helmet promotion, pedestrian safety, school safety, fire safety, and home safety.

The Oral Health Program works with state and local partners to identify and address oral health needs of Utah's children to assist them in planning, developing, and implementing improved programs and/or effective systems of care and to improve access to and appropriate utilization of dental health services among Utah's children. Consultation and technical assistance services offered by Program staff in regard to needs assessment, statewide data and surveillance, promotion of oral health prevention measures, program planning and systems development are available to the local health departments as well as to public and private agencies and providers within the State.

The Bureau of Children with Special Health Care Needs contracts with four local health districts to coordinate clinical services for the itinerant clinics in the rural areas of the state. State staff meets with local health officers and nursing directors during their quarterly meetings on an as needed or requested basis.

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Relationship of State and federally qualified health centers

While the relationship with community health centers in the state is positive and collegial, it needs to be nurtured more since the community health centers are critical for primary care for a large population of individuals without insurance. Division staff has developed a stronger relationship with the State Primary Care Association, State Primary Care Organization and the community health centers by invitations to sit on Division advisory committees.

Two community health centers in Salt Lake County, one in Ogden, Layton, Provo, Green River, St. George, Bicknell, Montezuma Creek and Bear Lake include dental clinics. The Oral Health Program works with the Association of Utah Community Health (AUCH), Utah's Primary Care Association, to provide technical assistance to these clinics and encourage the addition of dental clinics in other community health centers.

One of the other sites initially involved in the Medical Home Program was the Northwest Community Health Center, a community health center clinic in Salt Lake City serving a primarily Hispanic population. CSHCN supports a full-time Collaborative Medical Home project Coordinator, Family Advocate Coordinator and now supports twenty six primary care medical home practices around the state through technical support, , email broadcast resource information, office trainings and family advocate support. A quarterly medical home newsletter, which is sent out to all pediatricians and family practitioners in the state, is topic oriented and includes local, state, and national resources pertaining to each topic.

CSHCN included the Navajo Reservation-based Montezuma Creek Community Health Center in the initial 2001 Utah Medical Home project. One of five practice sites the Family Practice provider and an identified team of nurse and family advocate participated in the three year Medial Home training project. Although the grant has ended, this practice team continues to be an active Medical Home site and they have added four members to their team, including a physician assistant, a medical assistant and an administrator. A second site initially involved in the Medical Home program was the Northwest Community Health Center, a center serving a primarily Hispanic population.

Relationship of State and primary care association

The Executive Director of the Association of Utah Community Health (AUCH), Utah's Primary Care Association, sits on various advisory committees and provides feedback on issues that arise. The Oral Health Program works with the Association of Utah Community Health (AUCH), Utah's Primary Care Association, to provide technical assistance to community health center dental clinics and encourage the addition of dental clinics in other community health centers.

Coordination efforts that address Medicaid /CHIP

The Title V programs in the department have a close working relationship with the Division of Medicaid and Health Financing (MHF), Utah's Medicaid agency. Programs in the MCH Bureau as well as those in the CSHCN Bureau regularly work with Medicaid to coordinate efforts for women of childbearing ages and children, including those with special health care needs.

The Maternal and Infant Health Program works closely with colleagues in Medicaid on a wide variety of projects including: consultative support for oversight of services through their Managed Care contracts, provision of Perinatal Case Management for a sub-group of Salt Lake County Medicaid enrolled pregnant women and collaboration in the administration of the Presumptive Eligibility Program. The Maternal and Infant Health Program staff works with the Division of Medicaid and Health Financing to certify smoking cessation interventions for pregnant Medicaid participants. Medicaid provides some funding for the PRAMS project for the portion of survey participants who are on Medicaid.

Both MCH and CSHCN will be collaborating with Medicaid and the University of Utah on a recently awarded CHIPRA grant to promote medical homes for children on Medicaid.

Oral Health Program staff has well-established working relationships with Utah's Medicaid staff, and regularly combines efforts with Medicaid staff to improve availability and accessibility of Medicaid dental providers throughout the State. Program staff participated in defining and establishing a basic scope of dental benefits for Utah's Children's Health Insurance Program (CHIP), and continues to serve in a consultative capacity to the Utah CHIP administrator on issues relative to accessing needed dental care for children on CHIP. The Dental Director also consults with the CHIP administrator, the CHIP Advisory Committee and PEHP regarding expanding the CHIP dental benefit package and the PEHP dental provider panel. The State Dental Director serves on the preauthorization committee for EPDST services to assist Medicaid in determining medically needy services.

The Oral Health Program has been working with Medicaid to promote dental care as a part of prenatal care. Studies have shown an association between periodontal disease and preterm/low birth weight babies.

Title V staff have participated in two grants awarded to Utah Medicaid by The Commonwealth Fund, Assuring Better Child Development (ABCD). ABCD-I supported developmental screenings and targeted case management by public health nurses in local health departments. ABCD-II has built upon the successful implementation of the Early Childhood Targeted Case Management Service developed by the ABCD-I grant. The ABCD-II grant, through UPIQ, has supported social-emotional developmental screening of infants and toddlers by pediatric practices. The third year (2006) of the ABCD- II project supported screening for maternal depression by pediatric practices. The ABCDII Project has been completed.

CSHCN Bureau works closely with Medicaid to insure information for, outreach to and access for potentially Medicaid eligible children and youth with special health care needs and their families. CSHCN houses an on-site Medicaid eligibility worker, who works closely with the Travis C. Waiver Program, CSHCN clinical programs and other Medicaid staff at two adjacent tertiary care facilities.

The CSHCN Medical Director and Therapy Service Coordinator participate in the Medicaid Prior Authorization /EPSDT Expanded Services Committee. Through their participation, they have expanded the knowledge base of the Medicaid prior authorization committee to improve the coverage of services to children who are enrolled in Medicaid, resulting in improved coverage of specialty services for children. The Medical Director has been given voting status on the committee. She has also promoted a number of positive policy and membership changes on the Prior Authorization committee, which will streamline the process of approval for children requiring authorization for medical procedures, which are “medically necessary” but not covered by the Medicaid state plan.

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CHIP in Utah is a stand-alone program administered by the state Medicaid agency. The Title V staff from various programs interface with CHIP staff about eligibility, services, and challenges. For example, when Utah CHIP faced a significant budget limitation due to higher than expected demand for enrollment, oral health services were eliminated. The State Dental Director worked with the CHIP staff to quantify the impact of the decision to cut services to maintain the CHIP expenditures within the budget. The CSHCN Bureau continues to work with the CHIP staff to expand services and outreach to children with disabilities or those who are at risk. However, Utah’s CHIP program has limited coverage of certain services such as physical, occupational and speech therapies, mental health, and dental services, so that many of the more severely disabled children find better coverage through SSI and Medicaid. Additionally, as part of all the CSHCN Bureau clinics, resource specialists and/or a Medicaid/CHIP outreach worker provide parents with on-site consultation on accessing resources for coverage of care

Coordination of Title V with Other federal grant programs

The Division is the recipient of a number of federal grants, including WIC, Immunization Program, PRAMS, Early Childhood Systems grant, Preventive Block Grant, disease-specific prevention grants such as arthritis, cancer, as well as other federal grants, such as Early Hearing Detection and Intervention (EHDI), the Autism Spectrum Disorder/Developmental Disabilities MCH grant, the Utah Newborn Screening/Clinical Health Information Exchange MCH grant, HRSA Grant for Coordinated Dental Access System, to name a few.

Coordination of Title V with Providers of services to identify pregnant women and infants who are eligible for Title XIX and to assist them in applying for services

The Division of Community and Family Health Services maintains MOAs with 26 agencies (Qualified Providers) to provide screening for presumptive eligibility (PE) for prenatal Medicaid at 60 sites throughout the state, including 12 local health departments and other agencies such as community health centers, a farm worker health program, a homeless clinic, Indian Health Service provider, University of Utah clinics, several

hospitals and a family practice residency program. Provider enrollment in the program has increased over the last five years. The Division provides telephone presumptive eligibility screening for Salt Lake County residents through the Maternal and Infant Health Program's Baby Your Baby by Phone. The Baby Your Baby Hotline refers callers needing financial assistance for prenatal care to their closest Qualified Provider (QP) site. WIC clinics also refer pregnant women needing financial assistance for prenatal care to a Qualified Provider. Women denied PE are referred to either the Department of Workforce Services (DWS) or to one of Medicaid's Bureau of Eligibility Services (BES) outreach workers for a more in-depth screening for Medicaid. QP workers provide presumptively eligible women with Medicaid applications and contact information for their closest DWS or BES office.

The Division collaborates with the Bureau of Health Promotion on media campaigns to promote Baby Your Baby messages. The TV and radio messages in English and Spanish encourage women to call the Baby Your Baby Hotline for information on financial assistance for care. Print materials have been placed in college newspapers, local weekly newspapers along the Wasatch Front and on billboards along major travel routes. Media materials include the Baby Your Baby Hotline number and the Baby Your Baby website address where information on financial assistance for care is available. The implementation of UtahClicks), a web-based online application for programs, such as Presumptive Eligibility, has increased access to financial assistance for several programs. The UtahClicks system will accept applications for several programs, including PE, CSHCN programs, Early Intervention, and Head Start.

Coordination efforts that address social services

The Division of Family Health and Preparedness coordinates its efforts for the MCH/CSHCN populations with many other agencies in the state. The Division works closely with the Department of Human Services, which serves the maternal and child population statewide related to child welfare, mental health and substance abuse.

Title V staff participate on a number of Department of Human Services (Utah's social services agency) advisory committees or initiatives. CSHCN Bureau staff participates on the Health Care Consortium for the Division of Child and Family Services (DCFS), Utah's child welfare agency, which meets monthly and advises DCFS on the health status issues for children in their system. The Council identifies barriers and works toward the development of solutions to improve access to and continuity of health care. Another related collaborative effort between the two agencies is the Fostering Healthy Children Program (FHCP). Through this program, CSHCN Bureau nursing staff co-locates with DCFS caseworkers and assists them in coordinating the children's health care. Since all foster children in Utah are covered through Medicaid, the FHCP staff collaborates closely with Medicaid to ensure that services are accessible for this population of children with special needs.

Within the Department of Human Services, the Division of Substance Abuse and Mental Health works with community mental health centers and substance abuse treatment providers. Division staff turnover has made engagement with Mental Health and

Substance Abuse difficult. We will continue to work with the Division and developing better ways to collaborate to promote mental health for children, adolescents and their families.

The Baby Watch/Early Intervention Program is collaborating with the Department of Human Services, Division of Child and Family Services (DCFS) to develop policy and procedures for the referral requirements under the Child Abuse Prevention Treatment Act (CAPTA). The new law requires the referral of children with substantiated cases of abuse and neglect to the Baby Watch program.

Coordination of Title V with Family Leadership and Support Programs

CSHCN employs the Utah Family Voices Director to provide consultation and support to CSHCN programs and families, as well as to infuse and enhance family centered values into all CSHCN Bureau programs and initiatives. The Family Voices Director works closely with the Utah Parent and Information Center in teaching and mentoring other families of children and youth with special health care needs. Also through the UPC, Utah Family Voices oversees the Family to Family Health Information program, funded through MCH. CSHCN works closely with the Legislative Coalition for People with Disabilities, which provides support and leadership training to consumers with disabilities, in working with the state and federal legislative system. Finally, CSHCN has worked with USU/CPD to support the Becoming Leaders for Tomorrow (BLT). The BLT project, funded by the Administration on Developmental Disabilities through Utah State University's Center for Persons with Disabilities, maintains an advisory committee of young adults. The young adults provide input to the CSHCN Bureau regarding transition services and materials. The young adults also speak at local, state, and national transition training events for providers, young adults, and families and have developed a Youth Leadership Toolkit.

Coordination efforts that address school health

School health in Utah is not well addressed in Utah. The Department has had a position for a school nurse consultant, but funding cuts eliminated that position. The Department has sponsored a number of meetings with the State Office of Education to discuss the need for a comprehensive school health initiative in the state. The group is gearing up to apply for CDC funding when a new funding announcement is released.

Utah's high ratio of students to school nurse makes the role of the school nurse very challenging. The issue of school health will require further discussion and development of strategies to improve the Department's involvement in school health. Unfortunately the State Office of Education does not have a staff member responsible of school health, making coordination with the State Office on this issue very difficult. The role and responsibility of the school nurse is not clear to many, including state legislators who pass bills that require school nurses to train everyone on glucagon administration, epi-pens, and so on. Most do not understand the restrictions of the nurse practice act in the state which limits what nurses can do, what can be delegated and to whom. It often presents a real challenge since these bills are passed without funding to support the required training. The 2007 Legislature appropriated \$1 million to local school districts

to enhance school nursing. Local districts applied to the State Office of Education for funds for the 2008 school year. Department of Health staff participated in the process and provided technical assistance to school districts for application of funding.

In Utah, children from birth to 3 years of age are served by local providers through contract with the BabyWatch/Early Intervention Program (BWEIP) located in the Bureau of CSHCN. Children 3-5 years of age receive early intervention services through the local school districts. Because of the strategic positioning of the Birth-3 BWEIP, CSHCN Bureau staff has a close working relationship with the state level staff and the contracted local service providers.

The CSHCN Medical Director hosts the Interagency Coordinating Council for the BabyWatch Early Intervention Program. The membership of this Council ensures a forum of collaboration among all the organizations and agencies and families of all preschool children in early intervention programs including MCH staff; State Office of Education; Services for Persons with Disabilities; School for the Deaf and Blind; Mental Health; Utah State University; State Office of Child Care, early intervention providers, parents; and a legislative representative.

Coordination efforts that address special education

CSHCN Bureau and the Office of Students at Risk (SARS), Utah's state level special education program, enjoy a strong working relationship and have collaborated on a number of projects. CSHCN Bureau and the Office of Students at Risk (SARS), the state special education program, enjoy a strong working relationship and have collaborated on a number of projects, such as Medical Home, the Utah ASD/DD Infrastructure grant and the continuing development of Learning Modules on the Medical Home Portal website, <http://www.medicalhomeportal.org/>, such as an ASD/DD module.

Coordination efforts that address early intervention

The BabyWatch Early Intervention Program (BWEIP) in the state Title V agency has fostered the facilitation of services and referrals between the programs, the provision of joint training and the coordination on contract development. BabyWatch Early Intervention Program (BWEIP) has also developed formal agreements between local Early Head Start and local Early Intervention programs for improved service delivery maximizing the resources of both agencies. Due to these agreements, BWEI programs may provide early intervention services to a qualified child in the Early Head Start setting. Baby Watch continues to link with University of Utah Medical Center to allow families to be contacted by early intervention professionals before their child leaves the newborn intensive care unit. When the family and the BWEIP staff make contact, services are offered and an Individualized Family Service Plan (IFSP) is developed in anticipation of the infant's arrival home.

The Baby Watch/Early Intervention Program has designed and implemented a state database called Baby & Toddler Online Tracking System (BTOTS). This system provides the capability to move specified data from the local Early Intervention provider locations to the state BWEI Program database. BTOTS provides the capability for the

local early intervention provider to perform their core, day-to-day activities and services as well as provide comprehensive data on the children and families they serve. The state BWEI Program can access the data from all providers in the state to produce reports on various aspects of the program. This function will significantly enhance federal requirements for data and compliance with IDEA regulations. The Baby Watch Program is designing a web-based version of BTOTS to enhance access in the field by local providers and by Baby Watch compliance personnel.

CSHCN Bureau staff has been active in providing technical assistance and consultation for a number of community development efforts. The BWEI program has a credentialing program for all early intervention staff. The credential requirements include in-service training in order to increase the skills of persons delivering services to children and families.

Coordination efforts that address developmental disabilities

CSHCN Bureau works with the Division of Services for People with Disabilities (DSPD) in a number of ways. Representatives from DSPD are on the BabyWatch / Early Intervention Program (BWEIP) Interagency Coordinating Council. The Division of Community and Family Health Services, CSHCN Bureau, is involved with the Coordinating Council for People with Disabilities, which includes participants from Medicaid, Vocational Rehabilitation, special education, and mental health to review current issues, coordinates interagency treatment funding for individuals.

Coordination efforts that address SSI and State Disabilities Determination Services Unit

In Utah, children who have SSI are generally eligible for Medicaid, although they must apply for the services. The SSI Specialist in CSHCN works with the Office of Disability Determination Services (DDS) that evaluates disability claims for SSI eligibility. The CSHCN SSI specialist receives DDS transmittals on children applying for SSI and contacts each applicant family either by mail or phone to advise them of their ability to apply for Medicaid and other resources. The specialist reviews the claims and provides outreach and referral for appropriate families to Medicaid, which requires a separate application. The specialist also provides information, referral and enabling services to families having difficulty accessing or utilizing services, such as Utah Legal Services, Disability Law Center or consultant staff in DDS. The SSI Specialist also participates on the Disability Determination Services Advisory Committee that has fostered cross training of CSHCN Bureau and DDS staff. It also provides the development of professional relationships among SSI, DDS and CSHCN Bureau staff so that conflicts over individual applications can be resolved.

Coordination efforts that address vocational rehabilitation

In Utah, the Office of Vocational Rehabilitation (VR) is housed in the State Office of Education. The CSHCN Bureau director is current chair of the State Rehabilitation Council (SRC), which is part of the State Office of Education, Special Education department. As an active member of the SRC, the bureau director has been directly involved in a 5 year needs assessment, program planning and evaluation efforts to improve rehabilitation service delivery for Utah consumers.

CSHCN physical and occupational therapy staff members are active in the Utah Center for Assistive Technology Center (UCAT), part of the Office of Vocational Rehabilitation, through coordinating direct care for individuals with disabilities, advisory boards, contractual assistive technology services and support of the UCAT assistive technology helpline and website, "Access Utah". This year, the MCH Traumatic Brain Injury grant was awarded to the Utah Violence and Injury Prevention Program, and moved from the Department of Human Services. This TBI project will promote awareness and resources for Utah adults and children with TBI and their families.

Coordination efforts that address state interagency transition programs

CSHCN Bureau continues to employ a transition to adulthood specialist and a full time, Spanish speaking SSI Specialist. CSHCN continues to provide transition to adulthood services for youth and young adults with disabilities, however direct transition services are being replaced with promotion, training and consultation to Medical Home providers about the issues surrounding transition for youth and young adults with disabilities.

CSHCN Bureau has established a Systems Development Program which houses the Bureau's transition to adulthood efforts. In addition to establishing the full time SSI Specialist/Program Manager, the CSHCN Bureau has contracted with a specialist to provide transition services, such as vocational/career, health and financial planning, to young adults (14 years of age and older). This specialist provides transition training and consultation to CSHCN Bureau staff, other agencies and health professionals and assists individuals and their families in developing and implementing individual transition plans.

Coordination efforts that address SSDI

The SSDI grant is housed in CSHCN. Funds from this project are combined with funds from UNS/CHIE to continue the development and refinement of the electronic health information exchange of Newborn Screening data with Medical Homes.

Coordination efforts that address Ryan White

The HIV/AIDS Program in the Department of Health, Division of Epidemiology and Laboratory Services administers the state's Ryan White Program. Utah does not have a Title IV grant due to its inability to compete because of its low rates of women, infants and children infected with HIV. Utah's Ryan White Program is required to spend approximately 10% of its funds, or \$303,000, on direct and support services to women, infants and children. This funding supports services such as health insurance continuation payment, purchase of High Risk Insurance Pool (HIP) coverage, drug assistance, childcare, transportation and case management services.

CSHCN Bureau has had few referrals of children to the Technology Dependent Waiver Program, although most of these children receive medical coverage through Medicaid and Ryan White funds.

Coordination efforts that address WIC

WIC is located in the Maternal and Child Health Bureau in the Division of Family Health and Preparedness. The coordination of WIC with other programs serving mothers and

children has been very strong. We have noted significant increase in coordination with Title V and involve WIC staff in breastfeeding and obesity prevention work. Collaboration between WIC and MCH programs has been strongly encouraged by the MCH Bureau, Division and Department leadership. WIC staff is included in MCH projects as appropriate, such as the MCH Data group, in development of reports related to nutrition, such as obesity, and so on. The Data Resources Program provides support to the WIC satisfaction survey development and data analysis.

The MCH Director continues to promote the importance of working together for health moms and children at the state and local level. Though required to make referrals, some local WIC directors do not see WIC as promoting the health of mothers and children, but just food vouchers and education. We continue to struggle with this concept at the local level. The Bureau will continue its efforts on a local level to integrate WIC more fully into the philosophy of the program goals of promoting healthy mothers and children beyond nutrition classes and food vouchers.

The Maternal and Infant Health Program collaborates with the WIC Program by providing consultation on such issues as pregnancy intendedness, appropriate weight gain in pregnancy, nutrition during pregnancy, and breast-feeding. The two programs have collaborated on development of education materials related to appropriate weight gain in pregnancy. When possible, PRAMS data are provided to WIC staff to help with their program planning. As a result of these collaborations, Title V programs have been able to enhance the overall continuity and consistency of services provided by all programs.

WIC nutritionists often serve as resources to other programs serving mothers and children, such as obesity prevention efforts. The collaboration with WIC is now strong which has resulted in better integration of WIC Program activities with each of the MCH programs and vice versa, working to accomplish the same goal of healthy mothers and children.

The Oral Health Program has been collaborating with the Utah Oral Health Coalition/Early Childhood Workgroup and WIC in developing educational material for pregnant women and children. A video and pamphlets have been developed for training and education on preventive measures to reduce the incidence of dental disease in the WIC population.

Coordination of Title V with Family Planning Programs

Title X dollars are granted to Planned Parenthood Association of Utah with which the Division has a strong working relationship. The Chief Executive Officer of PPAU has actively participated for a number of years on various advisory committees and task forces to address the needs of women of reproductive age in the state. In addition, Planned Parenthood was one of the community grantees of the federal abstinence-only funding to provide "*Growing Up Comes First*" which incorporated the requirements of the federal abstinence program through maturation classes for elementary youth. The program has standardized maturation classes for schools that utilize it in an environment that previously was an informal, unstructured event that usually involved a speaker

(usually a physician parent) talking to 5th-6th graders about "maturation". The "*Growing Up Comes First*" curriculum addresses issues beyond "maturation", including healthy decision-making, etc.

The Maternal and Infant Health Program provides consultation to 10 local health departments regarding their family planning programs. Education regarding family planning, including emergency contraception, and pre- and interconceptional care has been emphasized and referral to private providers discussed. Local health departments have been supported in their efforts to find funding to sustain their family planning services.

In 2004, the Division of Family Health and Preparedness' Maternal Child Health Bureau initiated the Perinatal Task Force to examine issues surrounding perinatal health in Utah, including family planning. A family planning sub-committee, with members from both the public and private provider sector, developed recommendations including support of Medicaid and Health Financing's 1115 waiver to extend Medicaid coverage for family planning services and re-focusing the Baby Your Baby campaign to promote healthy lifestyles prior to pregnancy and in-between pregnancies.

Four Constructs of a Service System for Children with Special Health Care Needs

This section is only a small representation of how the state addresses the four constructs of a service system for children with special health care needs. Sections of the needs assessment include many citations about the work of the state to foster a service system for these children. Please refer to these sections for a more complete picture of Utah's efforts in this arena.

State program collaboration with other State agencies and private organizations

CSHCN works in collaboration with partners at state, community and private levels of health care provision to develop and expand existing resources for all Utah children. CSHCN and the University Of Utah Department Of Pediatrics collaborate to provide multidisciplinary diagnostic developmental clinics to children and families in the Salt Lake City center and in rural Utah through CSHCN traveling clinics. Collaborative training efforts through the Utah Regional Leadership Education in Neurodevelopmental Disabilities (URLEND) and Utah Collaborative Medical Home project, including the Medical Home Portal website, support and expand the expertise of local private practitioners as they provide medical homes to CSHCN. Through the URLEND Program, collaborative partnerships are being developed to provide services, information, and educational support to families. Collaborative partnerships currently exist with CSHCN, the University of Utah School of Medicine, Utah State University Center for Persons with Disabilities, Primary Children's Medical Center, Shriners Orthopedic Hospital, and private providers. The Task Force on Mental Health of Infants and Toddlers works to improve the early identification, prevention and treatment of children with mental illness and behavioral disorders. It includes a diverse group of community early childhood practitioners, early intervention, state agencies, hospitals, pediatricians,

obstetricians and advocates to complete a needs assessment, incorporating existing options for infant and toddler mental health.

Administrative CSHCN staff has been active in the Oral Health Coalition, which continues to identify barriers and to develop and implement strategies to improve access to dental services. Finally, CSHCN continues to work with the state Medicaid community mental health centers to improve the ability of mental health providers to evaluate and treat CSHCN and to improve the communication among mental health providers and primary and tertiary care providers about CSHCN.

The CSHCN Bureau, in collaboration with numerous other public and private entities, is working toward the six MCHB core components of: 1) family/professional partnership at all levels of decision-making; 2) access to comprehensive health and related services through the medical home; 3) early and continuous screening, evaluation and diagnosis; 4) adequate public and/or private financing of needed services; 5) organization of community services so that families can use them easily; and 6) successful transition to all aspects of adult health care, work and independence. The Bureau has identified Utah's Collaborative Medical Home project as the cornerstone of building a successful system that addresses all the components. The Project is a collaborative effort with the University of Utah Department of Pediatrics, Utah State University, Medicaid and Utah Family Voices that provides outreach and support to medical homes statewide for children with special health care needs (CSHCN) in primary care settings. Originally funded by an MCHB grant, the project is guided by a broad-based advisory committee, composed of private pediatric and family practice physicians, families, allied health professionals and other state partners, such as education, vocational rehabilitation and Medicaid. At the heart of the six core components is family-professional partnerships at all levels of decision-making. Meaningful sustained family/professional partnerships are challenging to establish and maintain, especially when the family is not from the state's predominant culture.

CSHCN Bureau collaborates with other Department programs through committees and advisory boards such as the Traumatic Brain Injury Committee and the Child Fatality Review Committee. CSHCN Bureau provides consultation in the development of health care standards for programs that work with children with special health needs, such as the Violence and Injury Prevention Program, the Medicaid EPSDT Utilization Review Committee, and the Division of Child and Family Services Children's Health Care Consortium.

CSHCN Bureau participates in Senator Orrin Hatch's Advisory Committee on Disability Issues, a forum for national and state political issues affecting people with disabilities, provides direct input to Senator Hatch's office through conferences with his congressional aides. Through this committee the scope of involvement with other public and private agencies is significantly broadened to include the Disability Law Center, the ARC of Utah, School for the Deaf and Blind, Office of Rehabilitation, Governor's Council on People with Disabilities, University of Utah Medical Center Rehabilitation Services, Utah State University Disability Resource Center, and families

of people with disabilities.

CSHCN attends the Ethnic Health Advisory committee and the Indian Health Advisory committee, and works with them on specific health issues or program delivery. CSHCN has also with the Division's Office of Multicultural Health to identify barriers to care for children with special health care needs in ethnic minority families, as well as the DOH Workforce Diversity Taskforce to address issues of health care workforce diversity. CSHCN employs a social worker with specialized in outreach to Hispanic children with disabilities and their families, as well as many Spanish speaking clinicians and support staff.

CSHCN collaborates with other state agencies through numerous initiatives and grants. The Bureau of CSHCN was awarded a CDC grant for "Refinement of Utah's Early Hearing Detection and Intervention (EHDI) tracking and surveillance" activities. The 3 year grant was awarded July 1, 2008 and runs through June 30, 2011. The goals are to improve the timeliness and appropriateness of early hearing detection and intervention service to infants and their families by 1) refining and expanding Utah's existing surveillance and tracking for EHDI, and 2) integrating the EHDI surveillance and tracking system with other relevant public health information databases and service systems. CDC grant funds have been instrumental in the development of the Child Health Advanced Records Management (CHARM) data integration system.

The Utah Birth Defect Network is well integrated with perinatal providers, genetic counselors, and specialty pediatric providers throughout the state. The UBDN works closely with the University of Utah Health Sciences Center, Intermountain Healthcare, Primary Children's Medical Center, the Utah Chapter of the March of Dimes, and the Utah Perinatal Association.

The Utah ASD/DD System Development project staff and contractors have been a model of collaboration and coordination between federal, state, community and family partners. Partnerships include the Autism Council of Utah, the Utah Autism Initiative, Utah Parent Center, Utah Family Voices, Parent to Parent Health Information Center, the University of Utah Department of Pediatrics, Utah State University Center for Persons with Disabilities, families trained to assist other families, Medicaid, Early Intervention, Medical Home, private providers, among many others.

CSHCN Bureau works with Medicaid to administer the Travis C. Waiver, a home and community-based waiver currently serving 120 technology dependent children and their families. At this time, there are 45 children on the waiting list. CSHCN has established the capacity to provide contractual Administrative Case Management to children with special health care needs who are Medicaid eligible. CSHCN staff has also been involved in the development of a new Home and Community Based Waiver Program for children nearing the end of life. This waiver, if funded, will provide home-based services to 30 children in the first year. The CSHCN parent advocate coordinator participates on the UDOH Medicaid Advisory Committee.

CSHCN Bureau, Medicaid and Division of Child and Family Services (DCFS) in the Department of Human Services developed the Fostering Healthy Children Program (FHCP) to improve the health care of children in Utah's Foster Care system. FHCP is a collaborative effort between these two agencies, in which CSHCN Bureau nursing staff is co-located with DCFS caseworkers and assists them in coordinating the children's health care. Since all foster children in Utah are covered through Medicaid, the FHCP staff collaborates closely with Medicaid to ensure that services are accessible for this population of children with special needs.

The CSHCN Bureau Director serves as the Chairperson for the Health Care Consortium for the Division of Child and Family Services (DCFS), which meets bi-monthly and advises the DCFS Board on the health status issues for children in the child welfare system. The council identifies barriers and works toward the development of solutions to improve access and continuity of health care.

State support for communities

The Bureau continues to provide rural itinerant specialty clinics and supports the families and children served in these clinics with community case management teams through the local health departments in eight rural sites. Local nursing case management is also provided to children in foster care by nurses who partner with local Department of Human Services office staff in eight Utah sites.

The Utah CSHCN Bureau continues to participate in "UtahClicks," a web-based resource application system for families. CSHCN clinical programs and the Baby Watch Early Intervention Program both offer electronic applications to families statewide.

CSHCN Bureau staff has been active in providing technical assistance and consultation for a number of community development efforts. The BabyWatch/Early Intervention Program has initiated a training program for early childhood staff through state universities and remote campuses. The state program also provides training and certification of providers throughout Utah in an effort to increase the quality of early childhood education providers. Fostering Healthy Children Program (FHCP) nurses provide education and training to foster parents and biological parents on health care needs of children in custody. FHCP nurses provide education and consultation to health care staff in the Salt Lake County Shelter, the Christmas Box House, Boys and Girls Group Homes. They also provide health care training to Human Service caseworkers in local offices statewide. FHCP participates in Child and Family team meetings on medically fragile children who are in Utah's Foster Care system.

The Utah Medical Home Collaborative staff provides training and technical support to physician offices in providing medical homes for children. The Medical Home Collaborative works with the University of Utah, Department of Pediatrics to support the Medical Home Portal website. Numerous community specialists have voluntarily developed condition specific modules for the website, which supports physicians, families, educators and paraprofessional in accessing resources and diagnostic

information. Medical Home Collaborative staff publishes a quarterly newsletter and presents at educator and family conferences. The Family Voices Coordinator provides training and support in the medical home offices. With the support of the ASD/DD System Development grant (MCH) new modules, training and parent support have been added to the Medical Home Collaborative effort for children, families and providers.

CSHCN, Utah Family Voices (UFV) and the Utah Parent Information and Training Center (UPC) collaborate on the Family-to-Family Center, to enhance community family-to-family activities and support development of a family database. Two Family Health Partners have been hired and trained to assist in family-to-family health information and education. Family Health Partners provide consultation and involvement in development of materials for various family-to-family projects such as the Utah Collaborative Medical Home project, the URLEND project and medical residency training. A toll free information and referral line has been established and staffed by trained parents. The Family to Family grant, in collaboration with the Utah Collaborative Medical Home Project, will establish a statewide Family Advisory Committee which will include key community representatives such as families of children and youth with special health care needs, a young adult with special needs, key CSHCN Bureau staff, private providers and a representative from Medicaid.

Hearing, Speech and Vision Services (HSVS) Program continues to provide training, in-service and consultation statewide to Early Head Starts, Head Starts, Early Intervention and local health departments on hearing screening protocol, monitoring risk factors and follow up. Additionally, HSVS provides technical assistance, training and support on newborn hearing screening policy and protocol to hospital newborn nurseries statewide. The two rural-based HSVS audiologists have portable auditory brainstem response diagnostic equipment that is used in the rural areas of the state. This provision allows for accurate and timely assessment of newborns that do not pass hospital newborn hearing screening, and dramatically reduces financial and travel difficulties for families in remote areas.

The Specialty Services Program addresses issues of transition, cultural effectiveness and access to Social Security and Medicaid for children and youth with special health care needs. CSHCN is collaborating with the Medicaid Infrastructure Grant/Workability to provide community-based, transition to adulthood training for Medical Homes in rural Utah.

Coordination of health components of community-based systems

CSHCN has promoted the systematic integration of community-based services for CYSHCN and their families throughout Utah through either leadership or participation in a number of state, local, public/private projects. These projects include the Medical Home Collaborative project; Autism Surveillance; the Utah Autism Spectrum Disorder/Developmental Delay infrastructure grant; Birth Defects Surveillance; itinerant multidisciplinary and specialty clinics throughout the rural areas of the state; collaboration with the Utah Regional Leadership Education in Neurodevelopmental Disabilities Grant (URLEND); Early Hearing Detection and Intervention Grants and the

Decreasing Loss to Follow-Up grant; SSI outreach, information, and referral and transition to adulthood for youth with special needs.

UDOH/CSHCN has developed a number of statewide, interagency, health care information systems which improve information access by local providers. These systems include: Newborn Laboratory Information System/Newborn Screening, the Utah Statewide Immunization Information System, Newborn Hearing Screening (EHDI), Vital Statistics, Birth Defects, WIC, the BabyWatch Online Tracking System (BTOTS) and is actively developing others. UDOH is also developing or expanding electronic information exchange capabilities, such as the Utah Newborn Screening and Clinical Health Information Exchange grant and the Child Health Advanced Record Management (CHARM) Initiative.

This year, CSHCN will collaborate with Utah Medicaid and the University of Utah, Department of Pediatrics, in their newly received Medicaid CHIP grant. The Department of Pediatrics will be developing an electronic management tool for Medical Homes serving children with special health care needs and their families.

CSHCN Bureau works with Primary Children's Medical Center (PCMC) charitable contributions to enhance the coverage of medical care for children with special needs. CSHCN and PCMC continue to collaborate on coverage of surgeries and treatments for children who have no other health care coverage options, such as adequate insurance, CHIP or Medicaid. The CSHCN Bureau provides in-kind support to collaborative specialty clinics with University of Utah Health Sciences Center, Shriners Hospital for Children and PCMC. CSHCN Bureau staff supports the Utah Center for Assistive Technology in providing evaluations and adaptation of equipment for children.

Coordination of health services with other services at community level

CSHCN complements private sector services by continuing direct or enabling community based services if there are gaps in these types of services for children. This year, in collaboration with Champions for Healthy Communities, CSHCN began an ongoing community needs assessment process, to determine the capacity for communities to serve children with special needs and families. This process will allow the Bureau to tailor services and conserve funds, when a service becomes available in a community. Throughout Utah, a combination of State CSHCN programs, rural or local health department clinics, private providers and medical homes provide "safety net" services for Utah's children and youth with special health care needs.

The CSHCN Medical Director hosts the Interagency Coordinating Council for the BabyWatch/Early Intervention Program. Membership of this council ensures a forum for collaboration among all the organizations and agencies and families of preschool children in early intervention programs.

The CSHCN Fostering Healthy Children program manager works closely with Regional Directors in the Division of Child and Family Services to ensure the availability of medical, dental and mental health services for children in Utah Foster Care. The FHCP manager also participates with numerous statewide service agencies to coordinate care

for foster children and their families, including Safe and Healthy Families, Group Homes, Mental Health Centers, the Foster Care Foundation, the Drug Endangered Child Committee and public/private service providers. Utah has provided consultation to a number of other states in how to provide the best health care monitoring for children in foster care, including the most recently, the Washington D.C. Human Services. The FHCP manager has participated in efforts to promote best practice health guidelines for children in foster care, through the Annie E. Casey Foundation and the Federal General Accounting Office.

Section 5: Selection of State Priority Needs

List of Potential Priorities

The results of the Stakeholder Survey, CSHCN Parent Survey, and Key Informant Interviews along with key data, such as national and state measures were reviewed to determine the state's priorities for FY2011 - 2016. The initial list of possible priority issues for the FY2011 – 2016 MCH Block Grant included a listing of the top ten priorities identified for the three populations as well as the health care access needs. We used the following coding category for each issue: (1) it is already being measured by a National Performance Measure; (2) it falls outside the area of responsibility of the MCH or CSHCN Director; (3) a system has already been put in place to address the need; or (4) the issue is too broadly focused.

Health Concerns Identified by Stakeholder Survey

Maternal and Infant Health Issues	
Infant abuse and neglect	3
Depression / mental health issues	3
Domestic violence/partner abuse	3
Lack of Insurance before, during, after pregnancy	2
Late or no prenatal care	1
Parenting knowledge	4
Alcohol, drugs, and tobacco	SPM
Poor nutrition during infancy	4
Small Babies / Prematurity	SPM
Poor nutrition during pregnancy	3
Lack of multivitamin use before pregnancy	SPM
Children's Health Issues	
Abuse and neglect	3
Lack of physical activity	SPM
Overweight/Obesity	2
Poor nutrition	2
Violence (bullying)	3
Depression/mental health problems	SPM
Lack of dental care	SPM
Lack of sexual health education	3
Drug, alcohol or tobacco use	1
Lack of after school supervision	4
Adolescent Health Issues	
Drug and alcohol use	3
Depression/mental health problems	SPM
Teen pregnancy	1
Suicide	1
Sexually transmitted diseases	3
Lack of physical activity	SPM
Eating disorders	4
Overweight/Obesity	3
Injuries due to motor vehicle	HSI
Access to contraceptives	2

Violence (bullying)	3
Children with Special Health Care Needs Issues	
Behavior problems	4
Depression/mental health problems	SPM
High out of pocket health care costs	4
Abuse and neglect	3
High insurance deductible	4
Lack of coordination of health issues	1
Lack of respite care	2
Lack of specialized child care	2
Lack of knowledge of community	4
Inadequate oral/dental health care	SPM
Youth with Special Health Care Needs	
Depression/mental health problems	SPM
Young adults transitioning to adult ins.	1
Behavior problems	4
High out of pocket health care costs	2
Lack of transition for CYSHCN	1
Lack of vocational job training	2
Youth/Young adults not being equal	4
Abuse and neglect	3
High insurance deductible	4
Drug, alcohol or tobacco use	SPM
Health Care Access Issues	
Restrictions on health insurance	4
High out of pocket expenses for health	4
Lack of health care insurance	2
Obtaining financial help for health care	4
Mental health services for adolescents	SPM
High insurance deductible	4
Mental health services for the young	2
Maternal mental health services	2
Access to drug abuse or rehab	3
Dental insurance	2

Health Concerns Identified by CSHCN Parent Survey

- Improve awareness, access and knowledge of mental health services
- Provide and promote early screening and identification/diagnosis of developmental delay, ASD/DD and other chronic and disabling conditions
- Promote the development of infrastructure to promote statewide electronic health record
- Adequate and affordable insurance coverage
- Promote a coordinated system of community and state support and service systems

- Promote family involvement and leadership
- Promote the development and improvement of transition to adulthood
- Improved oral health/dental home and family awareness and education about children and youth with special needs
- Continue to promote and provide increased rural access

Health Concerns Identified by Key Informant Interviews

We also conducted Key Informant Interviews of ten individuals with experience and interaction with the Title V agency. The individuals interviewed included local public health departments; a large private health care plan that also serves children on Medicaid; Utah chapter of American Academy of Pediatrics; Planned Parenthood of Utah; Voices for Utah Children, March of Dimes, University of Utah Department of Family and Preventive Medicine; American College of Obstetricians and Gynecologists; and the Legislative Coalition for Persons with Disabilities.

Issues identified as top priorities included:

- **Obesity** was the most prevalent issue across all MCH populations.
- **Lack of adequate insurance** coverage with high out of pocket costs and high insurance deductibles contribute to problems with access to health care.
- **Preconception care and family planning** were identified as priorities given the problem with women having closely spaced pregnancies.
- Not having access to health factors into **prenatal and post-delivery care**. Lack of Medicaid coverage for post-delivery care beyond 90 days is a problem.
- For adolescents, **inadequate information** was noted as an overall concern. Teens are not given adequate information to handle issues surrounding sexual activity, to make good decisions, protect themselves during sex, refuse a partner, ask a partner to use protection, etc.
- For children with special health care needs, it is particularly hard to access **mental health services, respite care, and social services** via DSPD.
- **Transition to adult health providers** is a very strong need for youth with special health care needs.
- Public health offices face **infrastructure and geo-political challenges**.

- **Coordination among key players**, such as the public health departments and the community health centers needs improvement.

Methodologies for Ranking/Selecting Priorities

In selecting the state priorities, the leadership team considered the top issues from the surveys, issues and trends that we have followed over the previous five years, and the status of national and state measures, to determine priorities using the following questions to guide us:

1. Of the issues identified by the surveys, which were the top ten?
2. Of those, were they representative of the issues that we had identified through our own work?
3. Of the issues identified, which were already are reflected in the National Performance Measures?
4. Of the issues, which were ones that we had the ability to impact?
5. Of these, which ones made a significant impact on specific populations, the size of the population, and seriousness of the problem?
6. Of the issues, which were priorities for mothers and infants, children and youth, and children and youth with special health care needs?

In the initial phase, the leadership team reviewed the top issues as identified from different surveys. The data team conducted special analyses to identify health priorities by types of stakeholders (parents, advocacy organizations, child care providers, health care professionals, local health departments, state organizations, academic institutions) and presented those in summary reports for the leadership team to review.

The Utah Perinatal Task Force was also convened to obtain input. The Perinatal Task Force is comprised of UDOH staff, community stakeholders, clinicians, and staff from academic institutions. UDOH staff presented trend data on key health status and healthcare access indicators for pregnant women, mothers and infants. Task Force members were then requested to identify priorities they were concerned about. Once a list was developed, members were given 4 votes to select their top priorities. Program staff used the list with vote counts, along with the survey results, to develop their top 10 priority lists. The CSHCN Bureau staff also shared the needs assessment survey information for input at their advisory meetings.

After discussion on selection of statewide priorities, the leadership team assigned the key program managers and directors to meet with their respective program staff to narrow the list and to recommend 9-10 top priorities for each of the three populations. These priorities were developed using input from program staff and stakeholders. The product from these meetings was a first priority list comprised of 26 health issues.

At this point, staff from each of the three populations met together to narrow this list to 13 issues (second priority list) through discussion and review of impact, numbers affected, measurability and availability of data, and ability to influence. The list was

finally reduced to 10 priorities. The Priority Selection Matrix on page 211 shows the process of final selection of state priorities.

Priorities Compared with Prior Needs Assessment

The leadership team developed ten priorities into state Performance Measures. We retained two of the previous state Performance Measures and developed eight new Performance Measures to reflect the new state priorities. New performance measures are indicated with (N) and previous Performance Measures are indicated with (P) in front of them:

State Performance Measures for Maternal and Child Health

(N) SPM 1: Increase percent of women of reproductive age (18-44 years) who report that they take a multivitamin pill or supplement containing at least 400mcg of folic acid daily.

(N) SPM 2: Reduce the percentage of primary Cesarean Section deliveries among low-risk women giving birth for the first time.

(N) SPM 3: Reduce the percentage of live births born before 37 completed weeks gestation.

State Performance Measures for Children and Youth

(N) SPM 4: Increase the percentage of Medicaid eligible children (1-5) receiving any dental service.

(N) SPM 5: Increase the percentage of primary care providers/medical homes that conduct routine age-specific developmental screenings in their practice.

(N) SPM 6: Decrease percentage of students who smoked cigarettes; smoked cigars, cigarillos, or little cigars; or used chewing tobacco, snuff, or dip on at least 1 day during the 30 days.

(P) SPM 7: Decrease the percent of adolescents who feel so sad or hopeless almost everyday for two weeks or more in a row that they stopped doing some usual activities during the last 12 months.

(N) SPM 8: Percentage of students who were physically active doing any kind of physical activity that increased their heart rate and made them breathe hard some of the time for a total of at least 60 minutes per day on 5 or more of the past 7 days.

State Performance Measures for Children and Youth with Special Health Care Needs

(P) SPM 9: Increase percent of children with special health care needs in the rural areas of the state receiving direct clinical services through the state CSHCN program.

(N) SPM 10: Increase the percentage of children (birth – 17) eligible for Medicaid DM who are eligible for SSI.

Priority Selection Matrix

First Priority List	Second Priority List	Final Selection
Program Priorities for Pregnant Women, Mothers & Infants		
1. Preterm births	1. Preterm births	1. Preterm births
2. Primary cesarean sections in low risk women	2. Primary cesarean sections	2. Primary C-sections
3. Short interpregnancy spacing	3. Short interpregnancy spacing	
4. Maternal mortality		
5. Multivitamin /Folic acid	4. Folic acid	3. Folic acid
6. Postpartum depression		
7. Elective inductions		
8. Weight gain during pregnancy		
9. Fetal mortality		
10. Prepregnancy overweight/obesity		
Program Priorities for Children		
1. Abuse and neglect		
2. Mental health	1. Mental health	1. Mental health
3. Obesity and physical activity	2. Obesity and physical activity	2. Physical activity
4. Oral health	3. Oral health	3. Oral health
5. Sex Ed/Teen pregnancy & STD	4. Teen pregnancy	
6. Drug, alcohol and tobacco use	5. Drug, alcohol and tobacco use	4. Tobacco use
7. Child development screening		
Program Priorities for CSHCN		
1. Improve access to mental health services		
2. Promote early screening and identification of developmental delay	1. Promote early screening and identification of developmental delay	1. Promote early screening
3. Promote statewide electronic health record		
4. Adequate and affordable insurance coverage	3. Insurance coverage & financial barriers	2. Insurance coverage
5. Promote coordinated system of community and state support and service systems		
6. Promote family involvement and leadership		
7. Promote the development and improvement of transition to adulthood		
8. Improved oral health/dental home		
9. Continue to promote and provide increased rural access to pediatric specialty services	4. Rural pediatric specialty services	3. Rural pediatric specialty services
	2. Access to coordinated care (medical home)	

In comparison, the previous FY2006 priorities included the following issues:

1. Depression and mental health
We changed this measure to address depression in youth due to availability of information and population affected. We wanted to target early childhood mental health, but do not have any data on this to report.

2. Obesity
We dropped this priority and replaced it with physical activity for youth. We selected physical activity as more of a measure youth engagement in physical activity, which reflects an intervention to prevent or reduce obesity.
3. Intendedness of pregnancy (includes short interpregnancy spacing)
Priority was dropped due to health care reform legislation that will provide women of childbearing ages with family planning services. Though it was dropped as a top priority, we will continue to monitor this measure and are anxious to see the impact on unintended pregnancy with better access to services.
4. Women of childbearing ages who do not have insurance
This measure was dropped due to health care reform legislation which should address this issue for women.
5. Rural health
6. Oral health – we changed this measure to look at early childhood dental services. The earlier a child receives a dental visit, the better the oral health will be later.

In addition we had the following listed as priorities but did not develop a State Performance Measure for any of these issues:

Ethnic/cultural issues

Ethnic and cultural issues – we never were able to develop a measurable PM for this area. With the Center for Multicultural Health’s work with programs, we think that we are well on our way to incorporating cultural awareness in our work.

Genomics

Genomics has been an up and coming issue, but since we had no way of measuring these efforts, it was dropped it as a state priority. It actually is beyond our capacity to address and federal funding supporting the genomics work has ended.

Access to health care for women of childbearing ages and children

Health care for women and children was dropped due to the health care reform legislation that will address many of the concerns we had about insurance and access to care. We realize that health care reform is not the perfect solution, but it is a start for improved access to care.

Medical home

Because Medical home is being addressed through our current work, we decided we want to address other issues that are not addressed well. Services

provided in a medical home in Utah include: health care services, care coordination, care plan development and implementation, family advocacy, and family involvement in decision making. Care coordination involves assessing needs, developing a plan of care, implementing the plan and evaluation of how the plan is working for the child and family needs. Care coordination within a practice facilitates access to services, continuity of care and support for families, improve health, developmental, educational, vocation, psychosocial and functional outcomes, and maximize efficient and effective use of resources. The critical components of the working care plan include: a prioritized list of needs, concerns and desired outcomes; medical, educational and social information pertinent to the identified need, concern or desired outcome; a plan/intervention for each need, concern or desired outcome: the person(s) responsible for each intervention; and the due date for the intervention to be completed and/or re-evaluated. Families must be the center of the care coordination process in order to accomplish a successful care plan. Medical home services include family support and advocacy. Family advocates may assist the family in ensuring that a child's needs are covered, assisting parents with their child's individualized education plan, or contacting a family to reach out to them.

FY2006 Final State Performance Measures

SPM1	The percent of women of reproductive age (18-44) who are uninsured.
SPM2	The proportion of pregnancies that result in a live birth that are intended.
SPM3	The percent of women with normal prepregnancy weight who deliver a live born infant.
SPM4	The percent of pregnant women with appropriate weight gain who deliver live born infants.
SPM5	The proportion of women who deliver a live born infant reporting moderate to severe postpartum depression who seek help from a doctor or other health care worker.
SPM6	The percent of children who are at risk of overweight and overweight
SPM7	The percent of youth during the last 12 months who feel so sad or hopeless almost every day for two weeks or more in a row that they stopped doing usual activities.
SPM8	The percent of children six through nine years of age enrolled in Medicaid receiving a dental visit in the past year.
SPM9	The percent of children with special health care needs in the rural areas of the state receiving direct clinical services through the state CSHCN program.

Priority Needs and Capacity

For all State Performance Measures, we do have the capacity to address each of the ten priorities. Since the priorities include all three populations, we have staff to address each area. Though we have vacancies, we plan to fill them which will enable us to better address the priorities, especially in the child health area.

Direct and enabling services

Four of the ten new State Performance Measures relate to direct and enabling services for children, including those with special health care needs. They include developmental screening for young children, Medicaid eligible children receiving a dental service, services to children with special health care needs in rural communities, and Medicaid DM eligible children enrolling in SSI if eligible.

Population Based

Six of the ten State Performance Measures are population based and include increase multivitamin use among women of childbearing age, reduce primary Cesarean Section births among low risk women, reduce preterm births, reduce in teen tobacco use, increase physical activity among youth, and reduce depression in youth.

Infrastructure Building

We have no State Performance Measure to address infrastructure building capacity, however, we believe that the infrastructure we currently have, with exception of the staff vacancies, is adequate to address the needs of mothers and children in the state.

MCH Population Groups

The priorities represent the three populations served by the Title V grant. We did not have an equitable distribution of numbers of priorities among all three population groups. However, we thought CSHCN population was well represented with the 6 specific National Performance Measures.

Priority Needs and State Performance Measures

Since each priority need is linked to a State Performance Measure, we will be able to easily measure and track progress on each.

- 1) Multivitamin (MV) use was selected because our NTD rates had dropped during a MV campaign and then increased after it ended. NTDs are probably preventable for 50% of women who get pregnant. NTDs cause significant disabilities we can prevent. We found that the majority of women in Utah did not take a MV prior to pregnancy.
- 2-3) Reduction in primary C Sections among low risk primiparas and reduction in late term births are related to increased morbidity and mortality that can be prevented in many cases with changes in obstetrical practices associated with these outcomes, such as elective induction of labor in a woman with an unripe cervix leading to an increase in C Sections and induction before 39 weeks of gestation resulting in a late preterm birth with all associated sequelae of respiratory disease, gestation age less than had been anticipated, etc. This measure in part responds to Key Informant issue regarding prenatal care, family planning, and close pregnancy spacing.

- 4) Developmental screening of young children is not routinely done for all children. They often are done after a problem is suspected which may delay a child's development due to late recognition. Our goal is to promote universal screening for young children either through a primary care provider, Head Start programs, early intervention program or other mechanism. The earlier we can identify a possible problem the earlier the child can be assisted in developing to his or her full potential.
- 5) Oral health is vital to overall general health. We know that children enrolled in Medicaid do not access dental services to the full extent covered. Given the low reimbursement rates for Medicaid dental services, parents have difficulty finding services for their child. Medicaid reimbursement rates were decreased in the 2009 Legislative Session, but were not allowed by CMS. It is difficult for dentists to know who can get services and the rates for services as the Legislature is constantly changing eligibility and rates. This measure in part responds to Key Informant issue regarding coverage and access.
- 6) We know that most smokers start in their teen years and that smoking is also associated with alcohol and other drug use among teens. If we can decrease initiation of tobacco use, we will have a healthier population and hopefully fewer youth who use alcohol or other drugs.
- 7) Obesity is a problem throughout the nation and Utah's population is increasingly becoming overweight and obese. Youth who engage in physical activity tend to be healthier and have healthier meals. Starting youth early to engage in and maintain physical activity will contribute to less overweight and obesity and healthier lives. This in part responds to Key Informant issue regarding obesity.
- 8) Mental health issues are not uncommon during childhood and especially in the adolescent years. The mental health service system is resource poor and the need for services largely unmet. Measuring the degree of adolescent depression will enable the system to recognize the shortage of providers and access to services. This in part responds to Key Informant issue regarding access to care, including mental health services.
- 9) Children and youth with special health care needs living in rural and frontier areas of the state have little access to specialty services. Vast areas have no pediatrician or other specialist to address the needs of these children. The CSHCN Bureau holds specialty clinics in rural sites throughout the state to provide services, such a neurology, cardiology, development pediatrics, orthopedic services among others. We plan to continue to provide these services, although we have had to cut back on the number of clinics due to state funding cuts. This in part responds to Key Informant issue regarding access to care, coverage, and geopolitical issues.
- 10) Many children who are eligible for Medicaid DM are also eligible for SSI disability benefits. However, we know that some families are not aware of possible benefits their children may be eligible. CSHCN staff will work to

increase the proportion of eligible CYSHCN who apply for benefits of both programs. This in part responds to Key Informant issue regarding coverage.

Section 6: Outcome Measures – Federal and State

During FY2009, 27 national and state performance measures, 19 were achieved and 8 were not. Of the 18 National Performance Measures, fifteen measures were accomplished and four of nine State Performance Measures were accomplished. The Measures that we did not accomplish included several that we had made progress on, but the indicator was slightly lower than the objective. The National Performance Measures that we did not achieve included: up-to-date immunizations for children, deaths of children due to motor vehicle accidents and youth suicides. The State Performance Measures that were not achieved included unintended pregnancies, weight prior to pregnancy and weight gain during pregnancy, seeking help for postpartum depression and services to children living in rural areas of the state.

The state will continue with the State Outcome Measure of maternal mortality as well as an additional Outcome Measure for fetal mortality. Maternal mortality is a very important outcome measure for Title V to monitor as some deaths are preventable. We recommend that MCHB add this measure to the next guidance for FY2013 – 2016. Maternal deaths occur more frequently than is measured by vital records reporting. We believe strongly that we can capture more maternal deaths related to pregnancy, identify causes for these deaths and develop strategies to prevent future deaths. Until we know the magnitude of the problem nationally, we will fail to address this tragic event for families. Fetal mortality, especially late term fetal deaths are by and large preventable. Our goal is to identify causes and associated factors of fetal death. We will work with vital records to improve data quality for reporting of causes of fetal deaths when possible.

Review of National Outcome Measures reveals that overall Utah is faring very well related to mortality for infants and children. Infant mortality fell to a rate of 4.7 per 1000 live births in 2008, the second lowest rate for the state in the past several years. The Black infant to white infant death ratio has significantly decreased to 1.6 (2006-2008) compared to 4.4 in 2005. Neonatal mortality is at 3.2 per 1000 live births, a drop from the 2006 rate of 3.5. Postneonatal mortality rate is 1.6 per 1000 live births, a relatively static rate for Utah. Concerning is that we have seen an increase in perinatal mortality rate over the past couple of years from 3.3 in 2005 to 5.1 in 2008. We will need to study this to determine the reasons for the increase. The child death rate was 20.1 in 2008 which was higher than the previous year at 17.9. We will need to examine this as well to determine the reason for the increase.

The State Outcome Measure of maternal mortality rate has increased over time from the 2005 rate of 7.8 to 18.0 in 2008. We believe that this significant increase is due to better case ascertainment. For the purposes of the MCH Block Grant, we in Title V report maternal mortality differently than Vital Records reports it to NCHS. We use the expanded definition of maternal mortality of deaths that occur within 12 months of the end of any pregnancy. We are able to ascertain more cases of maternal mortality related to pregnancy because we link death certificates of women of childbearing ages to birth and fetal death records to identify as many deaths as possible for our mortality review, thus providing us with more cases than are reported via death certificate data only. Each

case is reviewed by a panel of experts to determine the role, if any, of the pregnancy with the woman's death.

While Utah does fare relatively well compared with other states in perinatal, infant and child mortality, we continue to monitor individual death cases for identification of preventable factors to promote to reduce future deaths.

APPENDIX A
UTAH STAKEHOLDER SURVEY

Utah 2010 Title V MCH Block Grant Needs Assessment Survey



Page 1 - Heading

The Utah Department of Health is soliciting your views about the health needs and concerns of infants, children and women in Utah. Your input is crucial and will help us determine statewide prioritized health issues and develop plans to address them.

The survey consists of five sections:

Pregnant women, mothers and infants

Children and adolescents (ages 1 - 11 and 12 - 18)

Children and youth with special health care needs (ages 1 -11 and 12 - 22) (CYSHCN are those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally)

Health Care Access

Demographics

We encourage you to respond to any section which you feel you are able to contribute an opinion. You do not need to respond to a section that you are not familiar with.

We thank you for your valuable time!

Please click the "submit" button below to continue with the survey

Page 2 - Heading

Section 1: Health Needs Related to Mothers and Infants

Page 2 - Question 1

What are the important health needs of mothers and infants in Utah? Please read through the list of health issues below. Select the ones that you think are important in your community using the following scale:

1 = not at all important, 2 = somewhat important, 3 = moderately important, 4 = extremely important, 5 = don't know

Please click the "submit" button below to continue with the survey

	Not at all important	Somewhat important	Moderately important	Extremely important	Don't know
Alcohol and drug use during pregnancy	<input type="radio"/>				
Babies who are small at birth (less than 5 ½ pounds)	<input type="radio"/>				
Births to single mothers	<input type="radio"/>				
Birth defects	<input type="radio"/>				
C-section births among low-risk women	<input type="radio"/>				
Closely spaced pregnancies	<input type="radio"/>				
Dental care during pregnancy	<input type="radio"/>				
Depression or other mental health issues	<input type="radio"/>				
Developmental delays	<input type="radio"/>				
Diabetes – pregnancy related or types I/II	<input type="radio"/>				
Domestic violence/partner abuse	<input type="radio"/>				
Elective induction of labor prior to 39 weeks of pregnancy	<input type="radio"/>				
Excessive weight gain during pregnancy	<input type="radio"/>				
Exposure to secondhand smoke	<input type="radio"/>				

Infant abuse and neglect	<input type="radio"/>				
Lack of family planning services	<input type="radio"/>				
Lack of insurance after pregnancy	<input type="radio"/>				
Lack of insurance before pregnancy	<input type="radio"/>				
Lack of insurance during pregnancy	<input type="radio"/>				
Lack of multivitamin use before pregnancy (folic acid to prevent birth defects)	<input type="radio"/>				
Late or no prenatal care	<input type="radio"/>				
Low rate of breastfeeding initiation	<input type="radio"/>				
Low rate of ongoing breastfeeding	<input type="radio"/>				
Male/father involvement in reproductive health and parenting	<input type="radio"/>				
Overweight/Obesity	<input type="radio"/>				
Parenting knowledge	<input type="radio"/>				
Poor nutrition during pregnancy	<input type="radio"/>				
Poor nutrition during infancy	<input type="radio"/>				
Prematurity	<input type="radio"/>				
Smoking during pregnancy	<input type="radio"/>				
Sudden Infant Death Syndrome (SIDS)	<input type="radio"/>				
Unintended/ unplanned pregnancies	<input type="radio"/>				
Weight retention after pregnancy	<input type="radio"/>				

Page 3 - Question 2 - Open Ended - Comments Box

Please list below ANY OTHER health issues you consider being a significant problem for pregnant women, mothers and infants in Utah.

Page 3 - Question 3 - Open Ended - Comments Box

Overall, what would you consider to be the MOST important health needs for pregnant women, mothers and infants in Utah?

Page 4 - Heading

Section II: Health Needs Related to Children and Adolescents

Page 4 - Question 4

What are the important health needs of children in Utah? The following list refers to health needs related to children (1 - 11 years). Please read through the list of health issues below. Select the ones that you think are important in your community using the following scale:

1 = not at all important, 2 = somewhat important, 3 = moderately important, 4 = extremely important, 5 = don't know
Please click the "submit" button below to continue with the survey

	Not at all important	Somewhat important	Moderately important	Extremely important	Don't know
Abuse and neglect	<input type="radio"/>				
Acute & infectious diseases	<input type="radio"/>				
Anemia	<input type="radio"/>				
Asthma	<input type="radio"/>				
Chronic disease/conditions	<input type="radio"/>				

Depression or other mental health problems	<input type="radio"/>				
Drug, alcohol or tobacco use	<input type="radio"/>				
Eating disorders	<input type="radio"/>				
Inadequate health and safety in child care	<input type="radio"/>				
Inadequate immunizations	<input type="radio"/>				
Injuries due to motor vehicle crashes	<input type="radio"/>				
Lack of after school supervision	<input type="radio"/>				
Lack of child care or supervised care	<input type="radio"/>				
Lack of dental care	<input type="radio"/>				
Lack of physical activity	<input type="radio"/>				
Lack of sexual health education	<input type="radio"/>				
Lack of use of car seats and seatbelts	<input type="radio"/>				
Lead exposure	<input type="radio"/>				
Overweight/Obesity	<input type="radio"/>				
Poor nutrition	<input type="radio"/>				
Unintended injuries	<input type="radio"/>				
Violence (bullying)	<input type="radio"/>				

Page 5 - Question 5

What are the important health needs of adolescents in Utah? The list below refers to health needs related to adolescents (12 - 18 years of age). Please read through the list of health issues. Select the ones that you think are important in your community using the following scale:
 1 = not at all important, 2 = somewhat important, 3 = moderately important, 4 = extremely important, 5 = don't know
 Please click the "submit" button below to continue with the survey

	Not at all important	Somewhat important	Moderately important	Extremely important	Don't know
Abuse and neglect	<input type="radio"/>				
Access to contraceptives	<input type="radio"/>				
Acute & infectious diseases	<input type="radio"/>				
Anemia	<input type="radio"/>				
Asthma	<input type="radio"/>				
Chronic disease/conditions	<input type="radio"/>				
Depression or other mental health problems	<input type="radio"/>				
Drug and alcohol use	<input type="radio"/>				
Eating disorders	<input type="radio"/>				
Inadequate immunizations	<input type="radio"/>				
Injuries due to motor vehicle crashes	<input type="radio"/>				
Lack of after school supervision	<input type="radio"/>				
Lack of dental care	<input type="radio"/>				
Lack of physical activity	<input type="radio"/>				
Lack of sexual health education	<input type="radio"/>				
Lack of use of seatbelts	<input type="radio"/>				
Lead exposure	<input type="radio"/>				
Overweight/Obesity	<input type="radio"/>				
Poor nutrition	<input type="radio"/>				
Sexually transmitted diseases (STD)	<input type="radio"/>				
Suicide	<input type="radio"/>				
Teen pregnancy	<input type="radio"/>				
Unintended injuries	<input type="radio"/>				
Violence (bullying)	<input type="radio"/>				

Please list below ANY OTHER health issues you consider being a significant problem for children (ages 1 - 11) and/or adolescents (ages 12 - 18) in Utah?

Overall, what would you consider to be the MOST important health needs of children (ages 1 - 11) and/or adolescents (ages 12 - 18) in Utah?

Section III: Health Needs Related to Children and Youth with Special Health Care Needs (CYSHCN)

CYSHCN are those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.

What are the important health needs of children with special health care in Utah? The following health issues relate to children (between the ages of 1 - 11 years) with special health care needs. Please read through the list. Select the ones that you think are important in your community using the following scale:

1 = not at all important, 2 = somewhat important, 3 = moderately important, 4 = extremely important, 5 = don't know

Please click the "submit" button below to continue with the survey

	Not at all important	Somewhat important	Moderately important	Extremely important	Don't know
Abuse and neglect	<input type="radio"/>				
Behavior problems	<input type="radio"/>				
Depression and other mental health problems	<input type="radio"/>				
Drug, alcohol or tobacco use	<input type="radio"/>				
High insurance deductible	<input type="radio"/>				
High out of pocket health care costs	<input type="radio"/>				
Inadequate oral/dental health care	<input type="radio"/>				
Injuries due to motor vehicle crashes	<input type="radio"/>				
Lack of adaptive recreational and social activities	<input type="radio"/>				
Lack of after school supervision	<input type="radio"/>				
Lack of child care or supervised care	<input type="radio"/>				
Lack of coordination of health issues between health provider and school	<input type="radio"/>				
Lack of family support groups or network	<input type="radio"/>				
Lack of home health services	<input type="radio"/>				
Lack of knowledge of community resources	<input type="radio"/>				
Lack of a medical home	<input type="radio"/>				
Lack of physical activity	<input type="radio"/>				
Lack of respite care	<input type="radio"/>				
Lack of sexual health education	<input type="radio"/>				

Lack of specialized child care	<input type="radio"/>				
Overweight/Obesity	<input type="radio"/>				
Parents are not decision making partners with providers	<input type="radio"/>				
Suicide	<input type="radio"/>				
Unintended injuries	<input type="radio"/>				
Violence (bullying)	<input type="radio"/>				

Page 8 - Question 9

What are the important health needs of adolescents with special health care needs in Utah? The following health issues relate to young children and adolescents between the ages of 12 - 22 years with special health care needs. Please read through the list. Select the ones that you think are important in your community using the following scale:

1 = not at all important, 2 = somewhat important, 3 = moderately important, 4 = extremely important, 5 = don't know

Please click the "submit" button below to continue with the survey

	Not at all important	Somewhat important	Moderately important	Extremely important	Don't know
Abuse and neglect	<input type="radio"/>				
Behavior problems	<input type="radio"/>				
Depression and other mental health problems	<input type="radio"/>				
Drug, alcohol or tobacco use	<input type="radio"/>				
High insurance deductible	<input type="radio"/>				
High out of pocket health care costs	<input type="radio"/>				
Inadequate oral/dental health care	<input type="radio"/>				
Injuries due to motor vehicle crashes	<input type="radio"/>				
Lack of adaptive recreational/social activities	<input type="radio"/>				
Lack of after school supervision	<input type="radio"/>				
Lack of specialized child care or supervised care	<input type="radio"/>				
Lack of coordination of health issues between health provider and school	<input type="radio"/>				
Lack of family support groups or network	<input type="radio"/>				
Lack of home health services	<input type="radio"/>				
Lack of knowledge of community resources	<input type="radio"/>				
Lack of a medical home	<input type="radio"/>				
Lack of physical activity	<input type="radio"/>				
Lack of respite care	<input type="radio"/>				
Lack of support for CYSHCN transition to adult health care	<input type="radio"/>				
Lack of sexual health education	<input type="radio"/>				
Lack of vocational job training	<input type="radio"/>				
Overweight/Obesity	<input type="radio"/>				
Parents are not decision making partners with providers	<input type="radio"/>				
Suicide	<input type="radio"/>				
Unintended injuries	<input type="radio"/>				
Violence (bullying)	<input type="radio"/>				
Young adults transitioning to adult care – lack of insurance	<input type="radio"/>				
Youth/young adults not being equal decision making partners in transition to adult health care	<input type="radio"/>				

Please list below ANY OTHER health needs you consider being a significant problem for children (ages 1 - 11) and youth (ages 12 - 22) with special health care needs?

Overall, what would you consider to be the MOST important health needs for children (ages 1 - 11) and youth (ages 12 - 22) with special health care needs?

Section IV: Health Care Access Issues

Access to care is sometimes considered a major issue related to health. Thinking about your community, how much of a problem is this in your community?

Please rank these topics using the following scale:

1 = not a problem, 2 = somewhat of a problem, 3 = moderate problem, 4 = severe problem, 5 = don't know

	Not a problem	Somewhat of a problem	Moderate problem	Severe problem	Don't know
Access to care that is sensitive to individuals of different cultures	<input type="radio"/>				
Access to contraceptives	<input type="radio"/>				
Access to dental care	<input type="radio"/>				
Access to drug abuse or rehabilitation treatment	<input type="radio"/>				
Access to health care for CYSHCN	<input type="radio"/>				
Access to preconception health care	<input type="radio"/>				
Access to specialty provider	<input type="radio"/>				
Child care availability	<input type="radio"/>				
Coordinated care for CYSHCN	<input type="radio"/>				
Dental insurance	<input type="radio"/>				
Difficulty in finding a regular dental care provider	<input type="radio"/>				
Difficulty in finding a regular health care provider	<input type="radio"/>				
Early Intervention services	<input type="radio"/>				
Not having a regular health care provider	<input type="radio"/>				
Health care during pregnancy	<input type="radio"/>				
Health care for adolescents	<input type="radio"/>				
Health care for children	<input type="radio"/>				
High insurance deductible	<input type="radio"/>				
High out of pocket expenses for health care	<input type="radio"/>				
Home care services	<input type="radio"/>				
Lack of information about community resources	<input type="radio"/>				
Lack of health care insurance	<input type="radio"/>				
Lack of providers with experience in care of CYSHCN	<input type="radio"/>				
Maternal mental health services	<input type="radio"/>				

Mental health services for adolescents	<input type="radio"/>				
Mental health services for young children	<input type="radio"/>				
Obtaining financial help for health care	<input type="radio"/>				
Restrictions on health insurance for certain services	<input type="radio"/>				
Specialized services such as physical and speech therapy	<input type="radio"/>				
Transportation issues and proximity to services	<input type="radio"/>				

Page 11 - Heading

Section V: Demographics (This section asks general questions about you)

Page 11 - Question 13 - Choice - One Answer (Bullets)

Please indicate which category best represents you (please select one):

- Advocacy organization
- Business
- Child care/Day care provider
- Community based organizations (CBO)
- Community health centers/clinic
- Hospital
- Local health department
- Parent of child/youth with special health care needs
- Parent of child/youth with no special health care needs
- Primary care provider
- School
- Specialized health care provider
- State health department
- Student
- University/college faculty
- Other, please specify

Page 12 - Question 14 - Choice - One Answer (Drop Down)

In which county do you live?

- Beaver
- Box Elder
- Cache
- Carbon
- Daggett
- Davis
- Duchesne
- Emery
- Garfield
- Grand
- Iron
- Juab
- Kane
- Millard
- Morgan

- Piute
- Rich
- Salt Lake
- San Juan
- Sanpete
- Sevier
- Summit
- Tooele
- Uintah
- Utah
- Wasatch
- Washington
- Wayne
- Weber

Page 12 - Question 15 - Open Ended - One or More Lines with Prompt

Please provide the zip code information about your home and work address:

- Home zip code
- Work zip code

Page 12 - Heading

We appreciate your input. If you have any questions regarding the survey, please contact Janine Whaley at 801-538-6869.

Thank you for helping us determine important health issues for women and children in Utah!

Thank You Page

Thank you for completing the survey. Please visit this link to get more information on Maternal and Child Health.
<<http://health.utah.gov/mch/>>

Survey Closed Page

The survey is now closed. Thank you for your participation. If you are interested to obtain the results of the survey, please contact Maternal and Child Health Bureau at 801-538-6869. Thank you!

APPENDIX B
UTAH CSHCN PARENT SURVEY

CSHCN Parent Needs Assessment Survey

CSHCN Parent Needs Assessment Survey



Page 1 - Heading

The Utah Department of Health is in the process of completing a statewide needs assessment. We are interested in learning about your child with a health or developmental issue. Your information will be very valuable in planning for services for children and youth with special needs over the next five years.

Children and youth (ages 0 - 22) with special health care needs are defined by the Federal Government as: "those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally".

The survey is designed to be completed one per child or youth with special health care needs. Feel free to complete another survey if you have more than one child or youth with special health needs.
Thank you for your participation!

Please click the submit button below to continue with the survey.

Page 1 - Question 1 - Choice - One Answer (Drop Down)

How old is your child? (Please select the age from the drop down menu provided below)

- Less than 1 year
- 1
- 2
- 3
- 4
- 5
- 6
- 7
- 8
- 9
- 10
- 11
- 12
- 13
- 14
- 15
- 16
- 17
- 18
- 19
- 20
- 21
- 22

Overall, how would you rank the level of your child's disability or special condition?

- Mild
- Moderate
- Severe

What is your child's diagnosis and/or special health care need(s)?

Does your child have health insurance?

- Yes (please answer question 5 and question 6)
- No (please skip to question 7)

What type of health insurance(s) does your child have? (check all that apply):

- Medicaid
 - CHIP
 - Military
 - Private or Commercial
 - Dual coverage
 - Other, please specify
-

Does your child's health insurance offer benefits or cover services that meet his/her special health care needs?

- Never
- Sometimes
- Usually
- Always
- Don't know/not sure

If you child has no health insurance, what are the main reasons? (Check all that apply)

- Coverage available is too expensive for our family
 - Our health insurance does not include children or dependents
 - Our child has pre-existing condition(s) and must meet waiting period criteria before eligible
 - Our child has reached their maximum lifetime benefit
 - Our child does not qualify for Medicaid or CHIP
 - Our child is uninsurable
 - Other, please specify
-

What is your estimated MONTHLY out of pocket expense to provide for this child's health care? \$_____

Was your child without a health insurance plan at any time in the last 12 months?

- Yes
- No
- Don't Know/not sure

Does your child have a primary care provider who provides your child's ongoing medical and well child care?

- Yes
- No (please skip to question 13)
- Don't Know/not sure

Does your child's primary care provider and/or office staff help with any of the following?

	Yes	No	Not Needed	Don't know/not sure
Appeal process for denials from health insurance	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Arranging appointments to specialists when needed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Care coordination	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Connecting your family with services, agencies and other health care providers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Family support needs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Resource information	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
School issues such as IEPs or 504s	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Is your primary care provider responsive to your family needs and values?

Yes	No	Don't know/not sure
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please indicate the type of health care provider(s) seen by your child in the last 12 months?

	Yes	No	Needed but not available
Physician / Primary Care Provider	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dentist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Mental Health Provider	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Physical or Occupational Therapist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Speech Therapist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

If you selected "other" in the above question, please describe the type of health care provider(s) seen by your child in the last 12 months.

When you visit your child's health care providers, how long is the travel time one-way?

	Less than 1 hour drive	1 hour --- 2 hours drive	More than 2 hours drive	Not applicable
Physician/ Primary Care provider	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dentist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Mental Health Provider	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Physical or Occupational Therapist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Speech Therapist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please indicate the specific services currently needed for your child with special health care needs.

	Service needed and available	Service needed but not available	Service not needed
Communication aids or devices	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Durable medical equipment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Home health care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Mobility aids or devices	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Prescription medications	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

If you selected "other" in the above question, please describe that specific service(s) currently needed for your child with special health care needs.

Are the following community services available for your child and family?

	Yes	No	Don't know/not sure	Not applicable
After school programs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Care coordination	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Community agencies or groups that work to improve services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Parent support groups	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Recreational and social opportunities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Respite care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Transition to adult services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Are there "other" community services available for your child and family that are not listed above?

Do you have transportation options to access health services and community resources?

Yes

No

Don't know/not sure

What is working well for your child and family in your community?

What is the biggest challenge your family has for getting needed services for your child?

Is your child on the Community Supports Waiver (DSPD) or the Technology Dependent Waiver (Travis C.)?

- Yes
- No
- Don't know/not sure

Does your child receive care at one of the Utah State Children with Special Health Care Needs clinic(s)?

- Yes
- No
- Don't know/not sure

Have you or other family members changed or decreased hours at work OR quit your job due to your child's special needs?

- Yes
- No
- Additional Comment

If your family speaks another language, did you have access to written material in your language or access to an interpreter?

- Yes
- No
- Don't know/not sure
- Not applicable

What is your child's gender?

- Male
- Female

Is your child of Hispanic or Latino origin?

- Yes
- No
- Don't know/not sure

Which of the following best describes your child? (check all that apply)

- White
- Black/African American
- American Indian/Alaskan Native
- Asian
- Pacific Islander/Hawaiian
- Other, please specify

What was your total household income from all sources before taxes in 2008?

- Less than \$10,000
- \$10,000-\$19,999
- \$20,000-\$39,999
- \$40,000-\$49,999
- \$50,000-\$59,999
- \$60,000-\$74,999
- \$75,000-\$99,999
- Greater than \$100,000

Including yourself and your child with special health needs, how many people usually depend upon this income?

- 1
- 2
- 3

- 4
- 5
- 6
- 7
- 8
- 9
- 10
- More than 10

Page 13 - Question 32 - Choice - One Answer (Bullets)

How many children and youth with special health needs do you have living in your household?

- 1
 - 2
 - 3
 - 4
 - Other, please specify
-

Page 14 - Question 33 - Choice - One Answer (Bullets)

What is your current marital status?

- Married
- Divorced
- Separated
- Widowed
- Single

Page 14 - Question 34 - Open Ended - One Line

What is your home zip code?

Page 14 - Question 35 - Choice - One Answer (Bullets)

How are you related to your child with special health care needs?

- Father
 - Mother
 - Other, please specify
-

Page 14 - Heading

If you have any questions or concerns regarding the survey, please contact Stephanie Robinson at: stephanierobinson@utah.gov
Thank you for helping us determine important health issues for children and adolescents of special health care needs in Utah!

Thank You Page

Thank you for your participation! Please visit this link to know more about programs and services available for children and youth with special health care needs. <http://www.health.utah.gov/cshcn>

APPENDIX C
UTAH KEY INFORMANT INTERVIEW

Focused Interviews with State MCH Partners: Obtaining Guidance to Better Understand the Issues

Diane D. Behl

Center for Persons with Disabilities, Utah State University

Purpose

An in-depth interview process was designed to complement other data collected over the past six months as part of Utah's Title V Block Grant Five Year Needs Assessment. Interviews were conducted with key stakeholders in Utah who could offer a broad perspective based on their extensive experience in maternal and child health issues. In particular, these interviews served to better understand the "story behind the numbers" in response to a broad-based self report electronic survey completed by over 700 respondents.

Procedures

Interview participants were identified by the Utah MCH director, who personally emailed invitations to them requesting their involvement. This laid the ground work for the consultants to schedule the interviews. Two skilled interviewers from Utah State University who were well versed in MCH systems conducted the interviews, and two public health graduate students served as note takers. Interviews were conducted via telephone at times selected by the respondents between May 10 - May 18, 2010.

Ten interviews were completed with respondents from the following organizations: local public health departments; a large private health care plan that also serves children on Medicaid; Utah Chapter of American Academy of Pediatrics; Planned Parenthood of Utah; Voices for Utah Children, March of Dimes, University of Utah Department of Family and Preventive Medicine; American College of Obstetricians and Gynecologists; the Legislative Coalition for Persons with Disabilities. Within these organizations, respondents included a practicing physician, nurse, and nurse practitioner.

Participants received letters of information describing the purpose of the interview and procedures to ensure their confidentiality. Prior to the interview, respondents also were sent the findings from the Utah Stakeholder Survey to review prior to the interview. Each interview lasted approximately 30-40 minutes. The respondents were asked to comment on issues pertaining to the constituency most relevant to their work. For example, the Utah Chapter AAP representative commented regarding the general population of children; Planned Parenthood spoke particularly to the issues of adolescents, etc. It is important to note that the responses reflect the perspectives of the individuals interviewed and do not represent the individual's organizational affiliation.

The results below reflect the responses of all the participants, with personally identifiable information omitted. The note takers submitted typed summaries to the consultants, who then verified the notes and synthesized the information. The summary below is organized by the primary interview questions.

How accurate are the "top ten" priorities resulting from the survey, and what are the factors that impact these priorities?

In general, the respondents all verified that the findings from the survey reflected the "top ten priorities" for maternal and child health populations. Some respondents would have slightly altered the order within a list, viewing some priorities as greater than the order presented. These views of their perceived priorities are revealed in the following key points made by respondents:

- **Obesity** was the most prevalent issue raised by the respondents, with many emphasizing this as a much greater priority across all MCH populations - young children, adolescents, and women. This was seen as more prevalent than drugs, mental health issues, or sexually transmitted diseases. Emphasizing this point, one respondent stated that Utah's percent of reproductive-age women who are obese has doubled in the last decade. Factors contributing to the obesity epidemic identified by respondents include a lack of parenting skills and knowledge about good nutrition, and the familial, multi-generational aspects. While obesity is a serious health concern at any life stage, the consequences of obesity during pregnancy can be c-sections, pre-eclampsia, dysfunctional labor, and other risks to the mother and infant.
- **Lack of adequate insurance** coverage is a big problem for all. High out of pocket costs and high insurance deductibles are part of the problem. Women on Medicaid have trouble finding providers because reimbursement rate is very low, making access to good primary care a challenge. **Access to health care** for those with no insurance or those on Medicaid is a big problem. In addition to lack of dental coverage, access to dentists that will accept Medicaid is a big problem.
- **Preconception care and family planning** were identified as priorities, given the problem with women having babies too close together. One respondent emphasized that there is a lack of funding to support family planning, particularly pregnancy prevention. Parenting knowledge—lack of awareness, lack of multi-vitamin and folic acid prior to pregnancy, and lack of seriousness about pregnancy, premature birth, and birth weight are factors. There is a lack of knowledge among women regarding fertility, when a woman is most likely to get pregnant, and when it's possible to get pregnant.
- Not having access to health or life insurance factors into **prenatal and post-delivery care**, which are especially problematic for Spanish speaking families. Lack of Medicaid coverage for post-delivery care beyond 60 days is a problem. As a result, mothers may suffer with untreated postpartum depression or don't get the needed information about waiting a safe period before they get pregnant again.
- **For adolescents, inadequate information** was noted as an overall concern. Teens are not given adequate information to handle issues surrounding sexual activity, to make

good decisions, protect themselves during sex, refuse a partner, ask a partner to use protection, etc. Respondents were unsure if private physicians are allowing teens to talk privately with them and whether they are ensuring confidential conversations. There are also issues concerning costs.

- For children with special health care needs, it is particularly hard to **access mental health services, respite care, and social services** via DSPD. Respite is so important, as one respondent put it, because there are many tired families and they're not taking care of themselves. Additionally, there is a lack of coordination among health care providers. Two respondents stated that one over-arching factor that impacts the lack of services for CSHCN is a lack of political will to provide the public funding. A political and cultural norm among legislators that the role of government is the place of last resort leads to people relying primarily on family, church, school and lastly the government in very limited situations.
- **Transition to adult health providers** is a very strong need for youth with special health care needs. This is due to a lack of support by pediatricians to prepare families and youth as well as a lack of adult health care providers with the knowledge and willingness to serve those with special health needs.
- Public health offices face **infrastructure and geo-political challenges**. For example, one respondent said that by virtue of public health and mental health having different jurisdictions, it often is hard to coordinate the two entities. Additionally, public health districts have limitations on time and funding to address the needs of women and children.
- **Coordination among key players**, such as the public health departments and the community health centers needs improvement. There needs to be a better understanding of one another's scope of practice, forms of payment, services offered as well as better communication overall to better meet the needs of the community. Community health centers were identified as important providers to meet the needs of women and children, particularly those without adequate insurance.

What are some solutions to address these needs?

Respondents' recommendations on addressing these issues were multi-faceted, identifying the importance of public awareness, education, and intervention across all ages. In general, dramatically increasing public awareness via large media campaigns was emphasized as a key solution to begin to address these issues.

- **An aggressive campaign against childhood obesity is needed.** First, education of mothers about proper feeding of infants is needed. One respondent explained that culture enters into this - Latino mothers especially don't understand the problems of overfeeding their baby. There needs to be more resources developed that are appropriate **for those with low literacy levels**. Additionally, doctors need to talk with mothers during pregnancy about good infant nutrition and the dangers of having overweight babies.

However, this a big problem that must be addressed by the broader MCH system; it can't be expected to only happen in the doctor's office.

- **Education about proper nutrition and exercise** needs to be emphasized with children, beginning at an early age. Physical education programs need to be reinstated in elementary schools and junior high in particular.
- Strengthen the provision of **preconception counseling** for women. Women must be made aware of the importance of optimizing their own health including body weight prior to getting pregnant. Healthy mothers are more likely to have healthy babies. Also, it is important to teach the importance of healing and breastfeeding. New mothers need to be prepared to spend weeks just healing, resting, and taking care of their newborn. Recognizing that the state's Preconception Campaign is ready and going this summer, one suggestion was to build on the UDOH's web-based Menstrual Cycle Quiz as well as develop something similar for alcohol, depression, drug abuse, domestic violence, etc.-- all of the top factors.
- Increased coordination among the Local Health Departments and other providers via **collaborating councils** would help communities provide better services to the high risk families. Respondents encouraged working more closely with other key partners, such as Medicaid home visiting programs, WIC, the schools, etc. to address these priority issues. Collaboration with the Spanish Health Coalition would identify strategies to best reach Latina women about the importance of preconception and prenatal care.
- **Increase the provision of home visiting services** for women and infants, expanding the service to women not receiving Medicaid and to women who have passed the Medicaid time limit. **Extend Medicaid eligibility and coverage** beyond the current 90-day post-delivery limit, ideally to two years post-delivery.
- Improving **access to high-quality mental health services** would help in addressing many of the "top ten issues", such as maternal depression, child abuse, etc.
- Several respondents identified the need to **get rid of the asset test** to qualify for Baby Your Baby. The test is costly and time consuming for workers to process. One respondent emphasized this point, saying that other states have discontinued looking at this test. It costs more to research applicants and enforce the asset test, than to have some people slip through to receive the extra care. A related suggestion was to increase the allowable asset amount, although that would still entail costly verification procedures.
- **Support a family planning waiver**, which would decrease the likelihood of an unplanned pregnancy. **Provide evidence to the state legislature** to increase their knowledge about the cost-effectiveness of early prenatal care and family planning, e.g., increased time between pregnancies decreases premature births and decreases stresses on the mother's health.
- **Increase the use of social media** as a part of public awareness campaign, such as Twitter, Facebook, and blogs to reach adolescent and minority populations - using the tools that will reach them more readily. Run public awareness campaign advertisements

in Salt Lake city-based newspapers, which then are available online and in statewide editions to all Utah residents.

- **Continued collaboration among state-level stakeholders** is important to address the priority needs of youth, particularly in regard to sensitive topics such as sex education, pregnancy prevention, and STDs. The establishment of a Children’s Cabinet, bring in state-level stakeholders together would foster a focus on the “whole child” as opposed to compartmentalizing child health and development. Continue the strong partnerships with groups such as the Parent-Teacher Association, the State Office of Education, and the local health departments. These constituencies are not only important in helping educate but they also serve as a referral source to connect youth with community resources.
- **Adolescents need to learn about health and healthy pregnancy** in school before they reach puberty. Relatively early and continued education about health issues and appropriate behavior are especially important and can be preventative measures for children with special needs.
- It is critical to **teach adolescents about the dangers of obesity**, particularly in regard to its impact on pregnancy. Second-generation Latina young women are especially in need of education, given that they are typically more at-risk for obesity than their first-generation parents who may still eat a culturally-traditional diet.
- Promotion of **standardized electronic medical records** will facilitate a team approach to care, helping providers work together.
- **Training for physicians** to better serve children and adults with special needs requires the provision of ongoing educational opportunities in the field.

What should the Utah Maternal and Child Health program consider in their five year plan?

Many respondents stated the Utah Department of Health and the Maternal and Child Health program is doing a lot of good, important work already, such as their preconception campaign. The following suggestions were offered to strengthen efforts to address these priorities:

- One respondent emphasized that MCH should **focus on the social issues that impact health**. For example, it is important to address maternal depression, which can impact the mother-child relationship and ultimately the child's mental health. In contrast, another respondent recommended that MCH take a stronger role in carrying the banner for improved health care coverage for needed services. Recognizing that MCH cannot lobby per se, they do have an important job in **educating policymakers**.
- Work closely with **community and faith-based organizations** to improve outreach to difficult-to-reach populations. Community and faith based organizations should be included in task forces to address these issues.

- Develop Utah Department of Health **guidelines to educate** both professionals and the general population **about the importance of full-term deliveries** to ensure healthy babies; ideally these guidelines would reduce the number of c-sections performed for convenience reasons rather than health concerns.
- **Local public health offices** said that they have noticed improving relationships among the state office and the local health offices. They appreciate the flexibility they are allowed to set their own priorities and spend their designated Title V Block grant funds accordingly. In fact, they would appreciate having more **time to write grant proposals** to meet community needs as well as more “pats on the back” for their efforts. Additionally, they would like MCH to work with the state Board of Education in **fostering public health department access into the schools.**
- The state should consider **supporting a waiver for children with physical disabilities**, similar to the Travis C. Waiver. Families of these children often have no support and also are in need of respite care. There was recognition that this requires political will from the legislature, but the Utah Health Department can play a role in supporting such an effort. Additionally, the state could help promote the dissemination of information about resources such as respite programs.
- The state should **be more vocal about the importance of family planning**, highlighting this as an important public health issue for mothers, babies, and the family. Help people in Utah understand that it is a good public health principle to *plan* for your pregnancies, and not just "let it happen." In addition, many people seem to be unaware that there can be much, much more to family planning than simply picking a preferred due month and taking folic acid. More needs to be done to promote preconception care and draw attention to the risk factors associated with premature births. The state should consider hosting a statewide conference that would bring together the private sector, Intermountain and University of Utah health centers, Local Health Departments to discuss what can be done to reduce the risk of premature births.
- Provide **financial support for family- to- family networking** for support families of children with special needs. The funding for such structures has been inconsistent, and there needs to be more of an effort made for families to have a consistent support network. Using social media, such as interactive websites and Facebook could be a good way to do this.
- The state could better support transition to adult health care providers for youth with SHCN by sponsoring **education opportunities for families and providers on the transition process**, and they could help create referral list of adult care physicians willing to serve young adults with special needs.
- Continue to work on state efforts to **develop public health policy in support of the medical home**, working with Medicaid and researchers in demonstrating cost-effectiveness of the medical home. This respondent said that there is great collaboration going on, and it needs to continue.

- There is still the need to **maintain constant focus on the importance of immunizations**, which requires constant education with families. We have to *maintain* these campaigns or we'll lose ground.

Conclusions

The interview process was found to be a successful way to obtain the perspectives of key stakeholders. The ease in scheduling and conducting the interviews with the targeted respondents is likely attributed to a strong relationship that already exists with the Utah Maternal and Child Health program and other key stakeholders.

Numerous respondents volunteered their perspective that the Utah Department of Health and Maternal and Child Health does a remarkable job in the efforts to improve the health of women, children, and adolescents with very limited resources. As one respondent stated, the state is accessible and is willing to collaborate when it's something that will benefit the public. The UDOH was described as always trying to engage the broader community and its healthcare providers. "Not every state is so lucky," as one respondent put it.

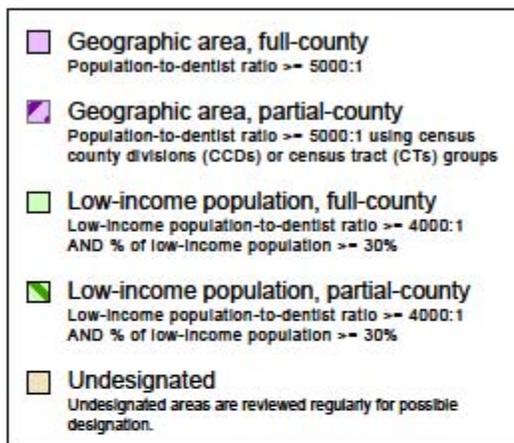
When taken together, the findings from these interviews reinforce the importance of the Maternal and Child Health program taking a "life course approach," beginning with educating and ensuring access to services for women - including young adolescent women - before they become pregnant. Providing preconception and postpartum care can support healthy maternal-child relationships and parenting skills, including importance of proper nutrition and exercise for their children. In turn, children need to receive education via MCH and other health providers as well as the school system. Finally, access to care via trained physicians to serve youth with special health care needs is essential to support the continued health as they enter adulthood.

The results from the interviews also reflect the importance of inter-agency collaboration needed to support a life course approach. Recommendations emphasized the importance of the Utah Maternal and Child Health program continuing its partnership with other state level stakeholders, such as Medicaid, the Office of Education, the Utah Chapter of the American Academy of Pediatrics. Additionally, the state can play a leadership role in fostering this inter-agency collaboration at the community level, strengthening the visibility and collaborative opportunities among the local health departments, faith-based groups, cultural or ethnicity-based groups, and the schools.

Finally, the use of social media to educate the public, particularly in reaching youth and young adults, is appearing to be more of a mainstream strategy to be used than a novelty. The Maternal and Child Health program is encouraged to use these valuable venues to achieve their goals and to reach their target populations.

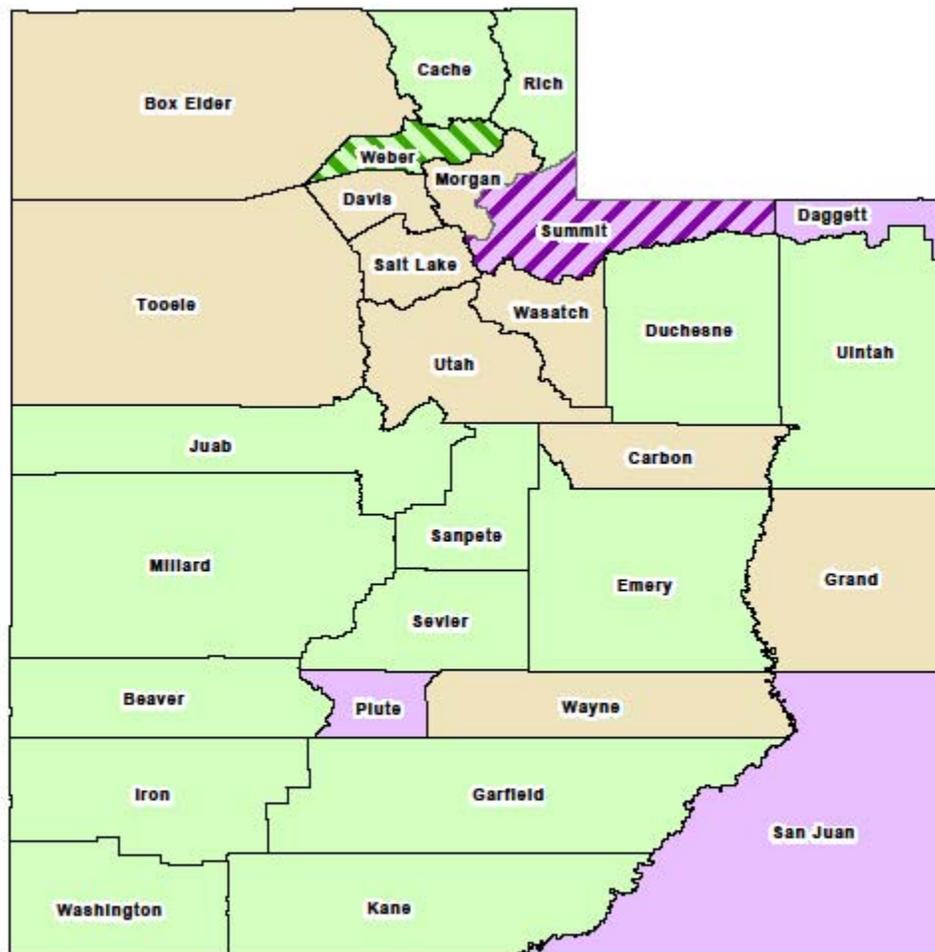
APPENDIX D
UTAH HEALTH PROFESSIONAL SHORTAGE AREA
MAPS

Utah Dental Care HPSAs¹ by County and Type of HPSA



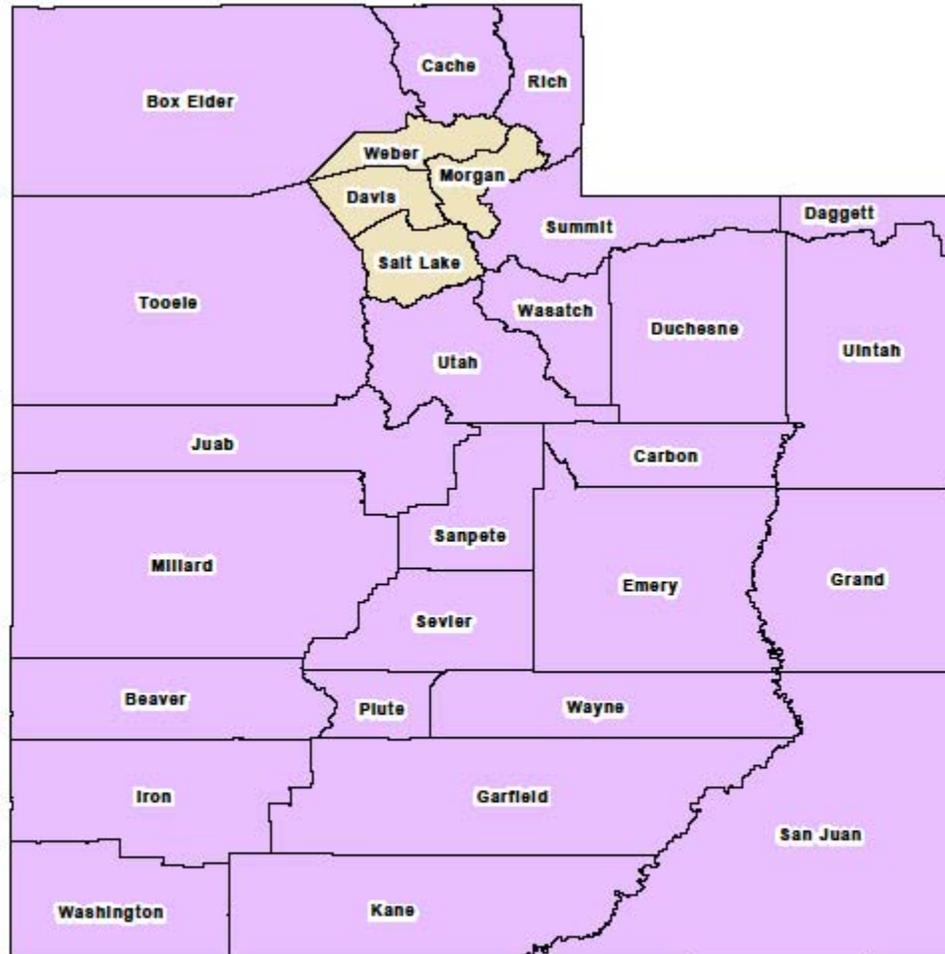
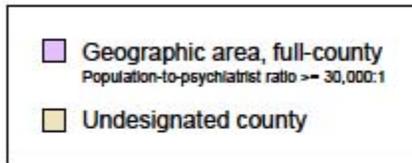
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¹ A HPSA is a Health Professional Shortage Area. A dental care HPSA is a measure of the shortage of dental providers serving the underserved population in a county, a group of census tracts, or a group of census county divisions. Shortage area designations are updated on a 3-year cycle.

Utah Mental Health Care HPSAs¹ by County and Type of HPSA

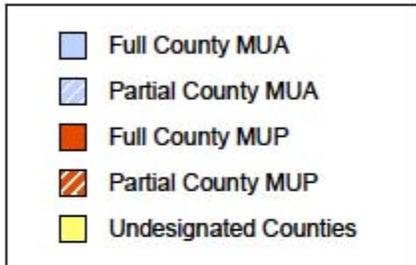


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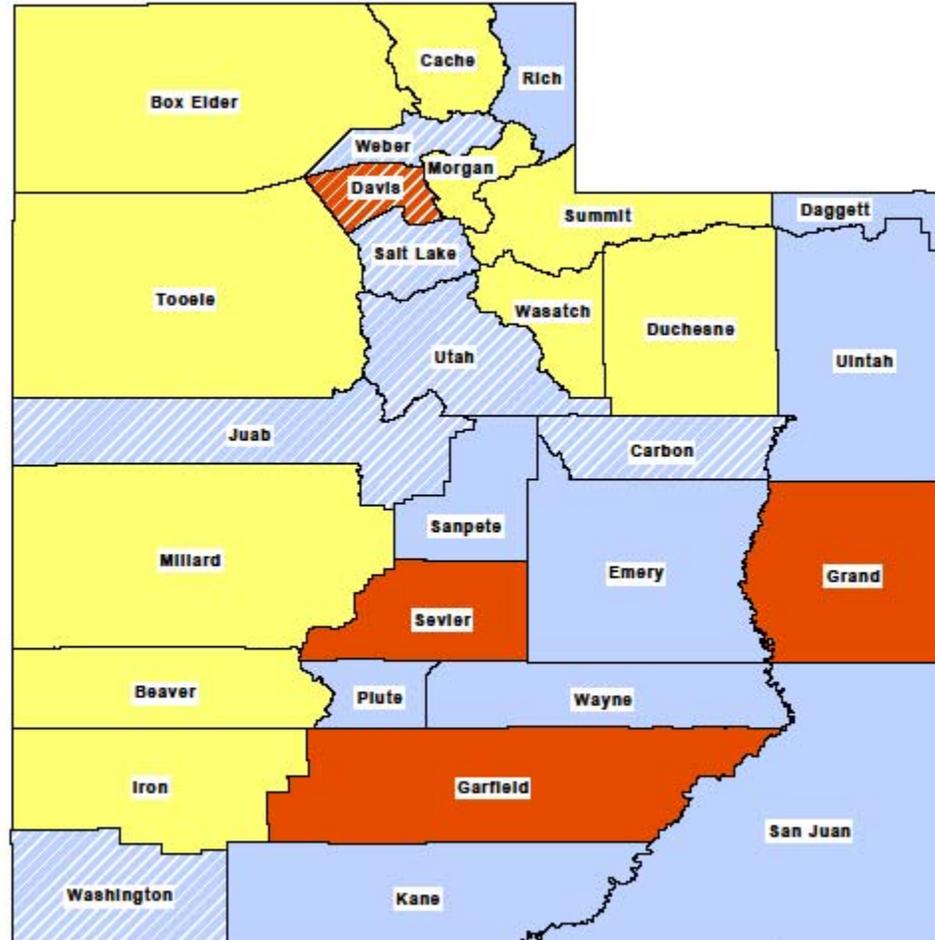
¹ A HPSA is a Health Professional Shortage Area. Utah's mental health HPSAs are based on the shortage of psychiatrists serving the medically underserved populations. A HPSA is updated every 3 years.

Utah Medically Underserved Areas and Medically Underserved Populations

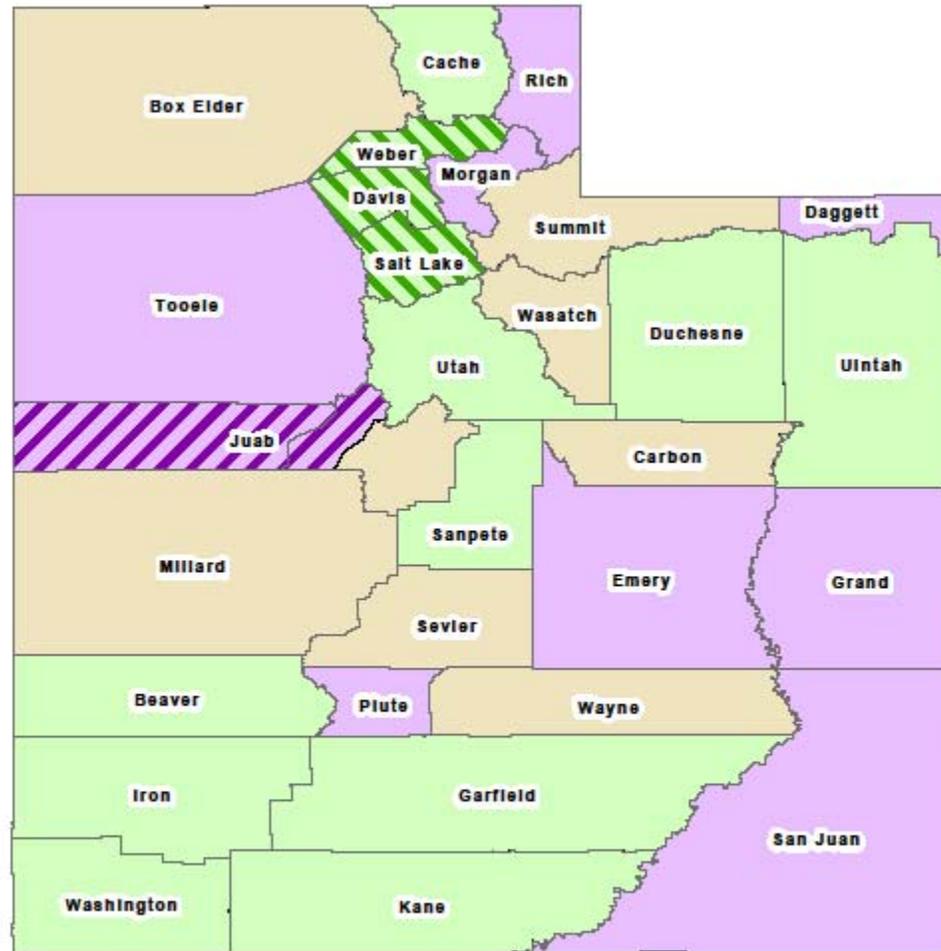
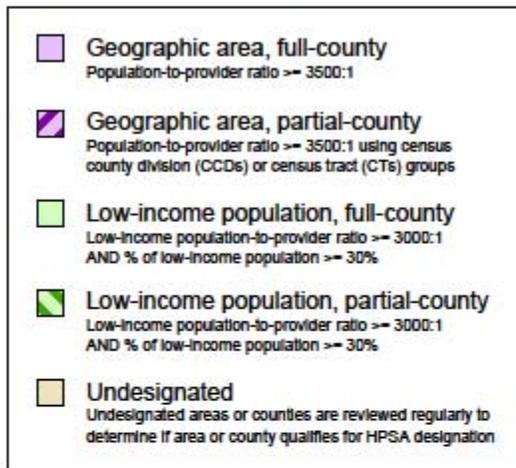


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Utah Primary Care HPSAs¹ by County and Type of HPSA

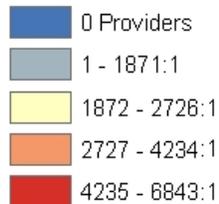
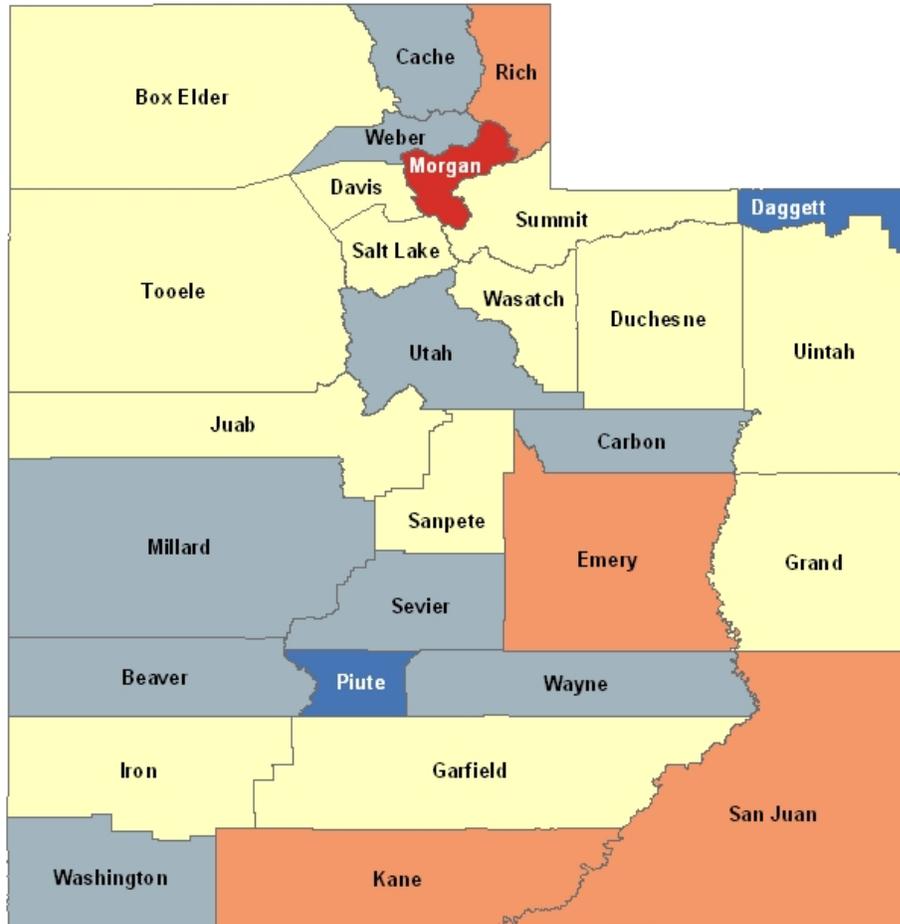


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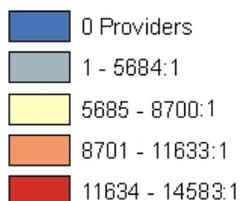
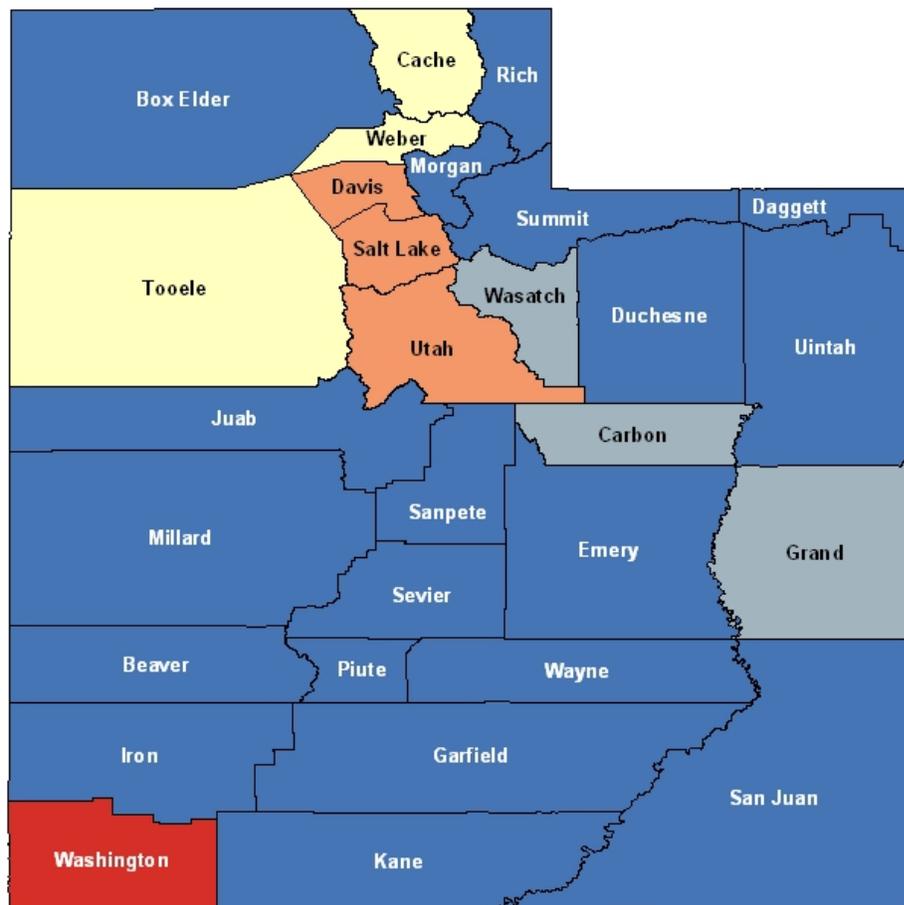
¹ A HPSA is a Health Professional Shortage Area. A primary care HPSA is a measure of the shortage of primary care providers serving the medically underserved in a county, a group of census tracts, or a group of county civil divisions. A HPSA is updated every 3 years.

Population-to-Provider Ratios for General Practice Dentists in Utah



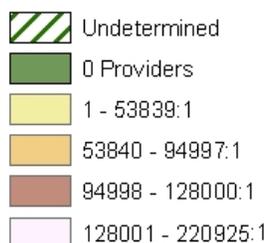
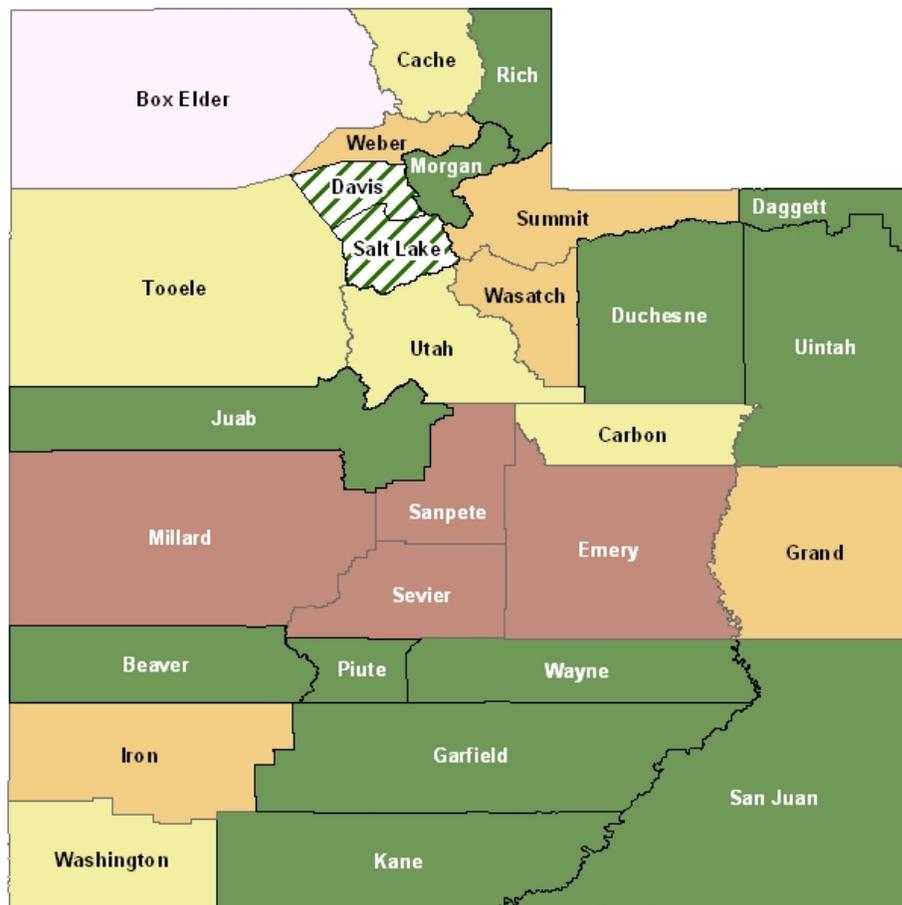
The number of providers is based on the total number of general practice dentists providing care for patients as counted in Health Professional Shortage Area surveys conducted between 2004 and 2010. Ratios are computed as follows: Resident-civilian Population / Total Weighted Dental FTEs. Total weighted dental FTEs are calculated using an assigned weight factor based on the dentist's age and the number of dental auxiliaries s/he has. Resident-civilian population is calculated by subtracting the number of institutionalized population from the total population. The population totals are from the 2004 Claritas data. The institutionalized population data are from the U.S. Census Bureau, Census 2000 data.

Population-to-Provider Ratios for Pediatric Dentists in Utah



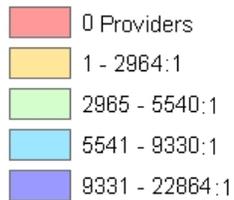
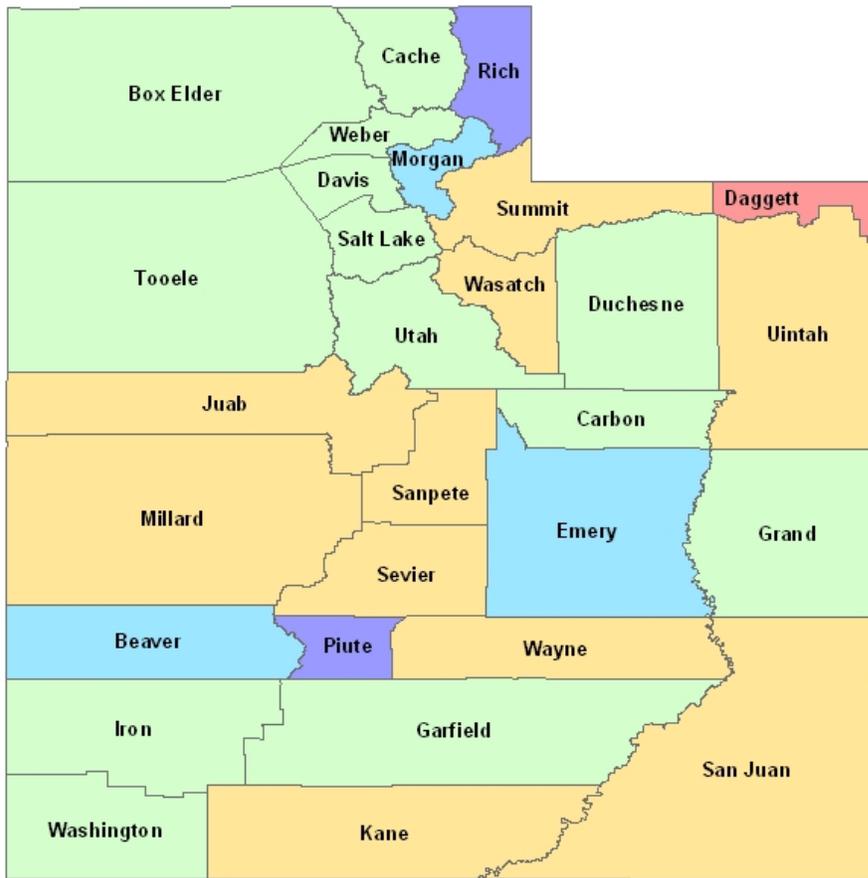
The number of providers is based on the total number of pediatric dentists providing care for patients as counted in Health Professional Shortage Area surveys conducted between 2004 and 2010. Ratios are computed as follows: Child Population / Total Weighted Pediatric Dental FTEs. Total weighted pediatric dental FTEs are calculated using an assigned weight factor based on the dentist's age and the number of dental auxiliaries s/he has. The child population is the number of children ranging from 0 to 17 years of age in 2004. The population data are from Claritas 2004 data.

Population-to-Provider Ratios for Psychiatric Physicians in Utah



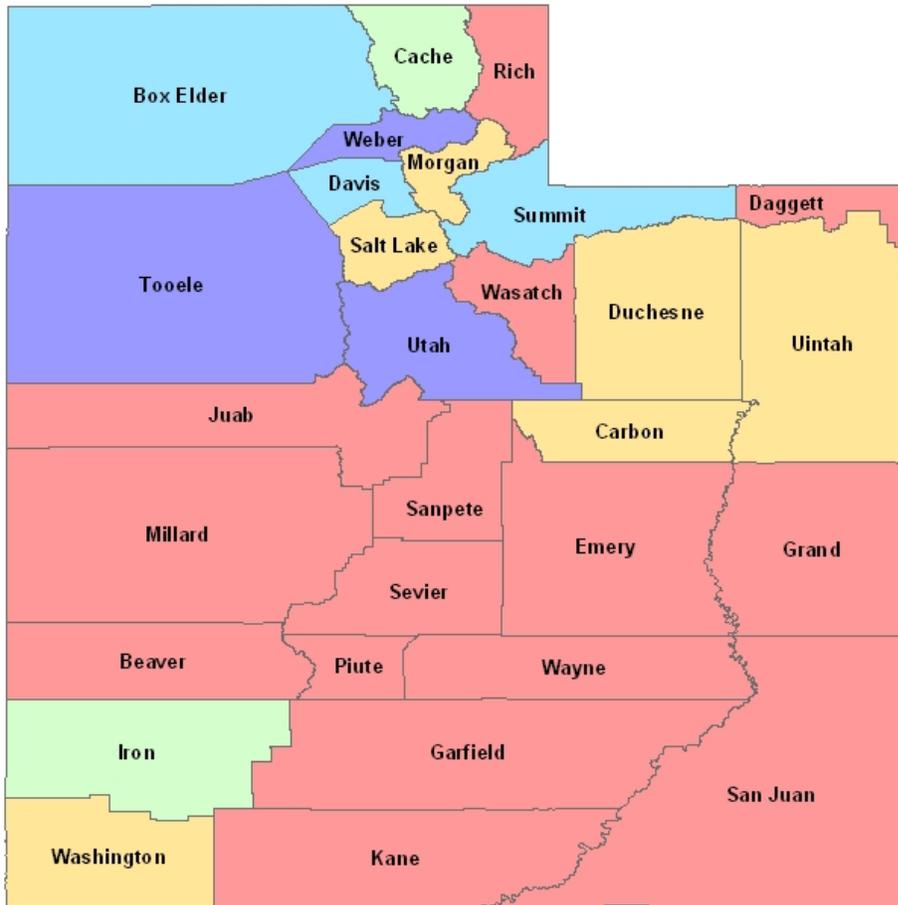
The number of physicians is based on the total number of psychiatric physicians as counted in Health Professional Shortage Area surveys conducted between 2004 and 2010. Ratios are computed as follows: Resident-civilian Population / Total Psychiatric FTEs. Resident-civilian population is calculated by subtracting the number of institutionalized population from the total population. The population totals are from the 2004 Claritas data. The institutionalized population data are from the U.S. Census Bureau, Census 2000 data.

Population-to-Provider Ratios for Family Practice Physicians in Utah



The number of physicians is based on the total number of physicians who are in family or general practice (FP) as counted in Health Professional Shortage Area surveys conducted between 2004 and 2010. Ratios are computed as follows: Resident-civilian Population / Total FP FTEs. Resident-civilian population is calculated by subtracting the number of institutionalized population from the total population. The population totals are from the 2004 Claritas data. The institutionalized population data are from the U.S. Census Bureau, Census 2000 data.

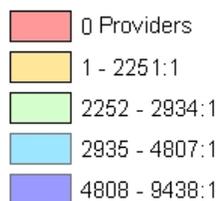
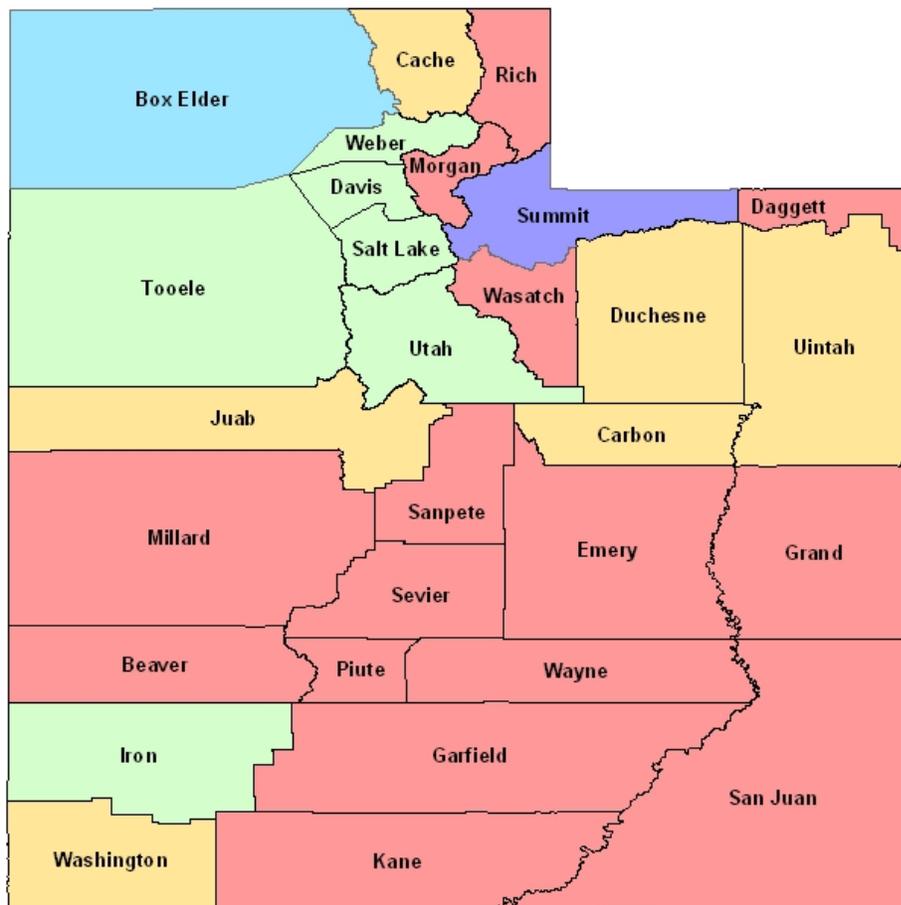
Population-to-Provider Ratios for Internal Medicine Physicians in Utah



- 0 Providers
- 1 - 9503:1
- 9504 - 12131:1
- 12132 - 18067:1
- 18068 - 23155:1

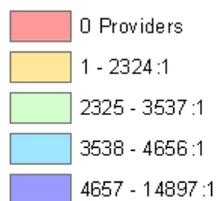
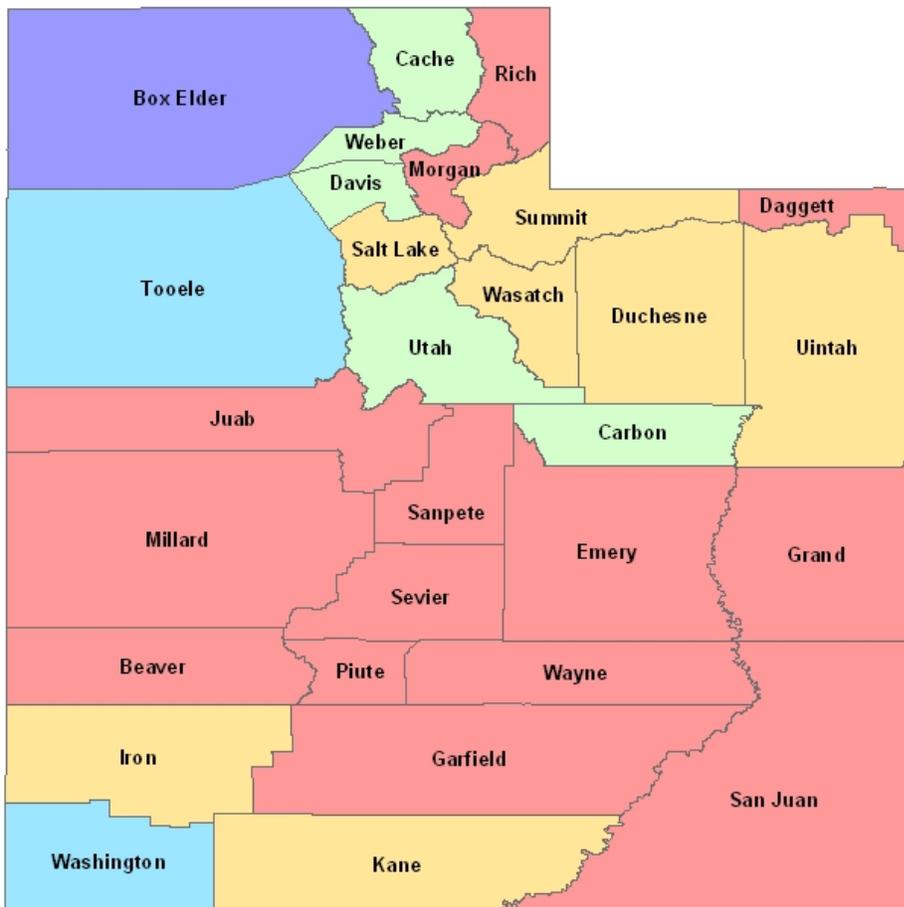
The number of physicians is based on the total number of internal medicine physicians (IM) who provide primary care for patients as counted in Health Professional Shortage Area surveys conducted between 2004 and 2010. Ratios are computed as follows: Resident-civilian Population / Total IM FTEs. Resident-civilian population is calculated by subtracting the number of institutionalized population from the total population. The population totals are from the 2004 Claritas data. The institutionalized population data are from the U.S. Census Bureau, Census 2000 data.

Population-to-Provider Ratios for OB-GYN Physicians in Utah



The number of physicians is based on the total number of OB-GYN physicians who provide primary care for patients as counted in Health Professional Shortage Area surveys conducted between 2004 and 2010. Ratios are computed as follows: Female Population / Total OB-GYN FTEs. The female population is the number of females ranging from 15 to 44 years of age in 2004. The population data are from 2004 Claritas data.

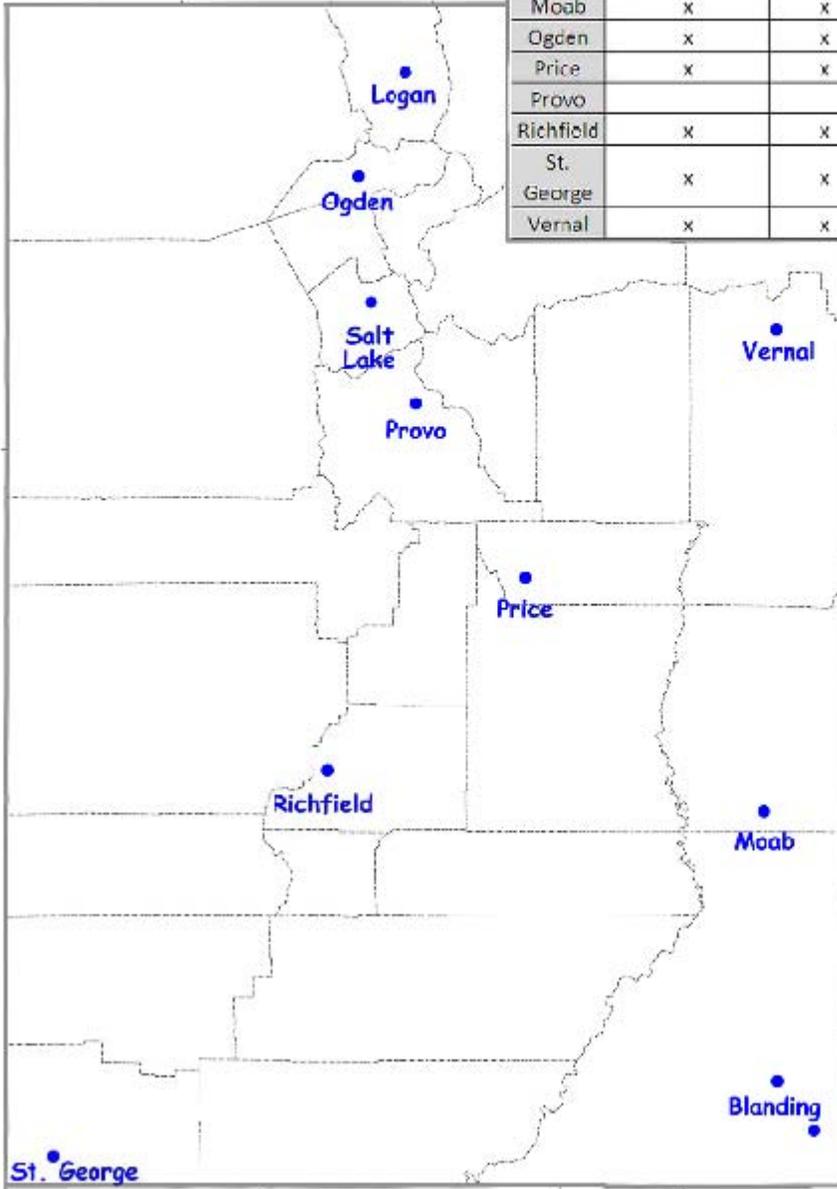
Population-to-Provider Ratios for Pediatric Physicians in Utah



The number of physicians is based on the total number of pediatric physicians who provide primary care for patients as counted in Health Professional Shortage Area surveys conducted between 2004 and 2010. Ratios are computed as follows: Child Population / Total Pediatric FTEs. The child population is the number of children ranging from 0 to 17 years of age in 2004. The population data are from the 2004 Claritas data.



CSHCN Clinics				
	Multidisciplinary Diagnostic	Neurology	Neonatal Follow-up Program	Orthopedics
SLC	x	x	x	x
Blanding	x	x		x
Logan		x		x
Moab	x	x		x
Ogden	x	x	x	x
Price	x	x		x
Provo			x	x
Richfield	x	x		x
St. George	x	x		x
Vernal	x	x		x



May 17, 2010