

# Utah Latino Health & Disability Needs Assessment Report

October 2006

Compiled by the Center for Persons with Disabilities at Utah State University

On behalf of the  
Utah Department of Health: Division of Community and Family Health Services



Utah Department of  
Health: Center for  
Multicultural Health  
(Office of Minority Health)

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The findings and opinions included in this report represent those of the authors and do not necessarily represent the U.S. Centers for Disease Control and Prevention.

The Utah Latino<sup>1</sup> Health and Disability Needs Assessment Report is the product of a collaborative research initiative between the Utah State University Center for Persons with Disabilities and the Utah Department of Health Division of Community and Family Health Services, under a cooperative agreement with the U.S. Centers for Disease Control and Prevention. The findings contained herein will serve as the basis for the Utah State Plan for Latino Health and Disability. The research design and methodologies were conceptualized by the Utah Latino Health Advisory Committee convened under this cooperative agreement by the Center for Persons with Disabilities. The LHAC membership roster, by individual affiliation, is included below.

#### Latino Health Advisory Committee (LHAC) Membership Roster

<b>Affiliation</b>
Three Native Spanish speakers with various physical disabilities
Native Spanish speaking parent of a child with autism
Hispanic Chapter: Family to Family Network Leader
Governor's Office of Ethnic Health Affairs: Hispanic Affairs
Comunidades Unidas (United Communities) in the Salt Lake valley
Utah Department of Health: Multicultural Health Advisory Committee
Physician specializing in health care to ethnic minority populations
Midvale City Community Outreach: Hispanic Affairs Director
Utah Department of Health: Bureau of Children with Special Health Care Needs
Mexican Consulate in Salt Lake City, Utah

The Utah State Plan for Latino Health and Disability, based on the findings in this document, will be submitted to the Utah Department of Health Ethnic Health Advisory Committee in the fall of 2006 for review and adoption. The plan will include statewide health initiatives consistent with the Utah Department of Health Center for Multicultural Health mission and vision, and will be designed to prevent secondary disabling conditions and promote good health among Utah Latinos with disabilities.

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<sup>1</sup> Utah government entities use the term "Hispanic" as an official ethnic designation. Latino appears to be the preferred term among those that the U.S. Census Bureau defines as being of Hispanic ethnicity. Therefore, we use the term, "Latino" wherever possible.

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## EXECUTIVE SUMMARY

The Utah Latino Health and Disability Needs Assessment Report is the product of a collaborative research initiative between the Utah State University Center for Persons with Disabilities and the Utah Department of Health Division of Community and Family Health Services, under a cooperative agreement with the U.S. Centers for Disease Control and Prevention.

Latinos in Utah represent the largest and fastest growing ethnic group (11% of the total population). While there is compelling data to indicate that the overall health status of Latinos is poorer than the overall Utah population, there is no data to specifically describe the health needs of Utah Latinos with disabilities.

This collaborative research project resulted in a summary of existing health surveillance data gathered from several UDOH sources, school data, and other health related databases. The main research effort of this project was the organization and implementation of 21 focus groups statewide with Latino individuals with disabilities and their family members. These were designed to evaluate the impact of disability and to investigate the health related issues that these individuals and their families face. In rank order (determined by the number of focus group sessions in which these topics arose), the issues faced by Latinos with disabilities and their families, and that appeared in at least half of the 21 focus group sessions are:

- Spoken English Proficiency of Person w/Disability
- Availability of Bilingual/Bicultural Health Care Providers
- Availability of Native Language Support Groups
- Cultural Incompatibility With Medical/Service Providers
- Legal Documentation and Access to Health Care Services
- Insurance Coverage Disparities/Availability of Coverage
- Lack of Written Material in Spanish
- Mental Health and Coping with Disability
- Discrimination Based on Disability or Race
- Technology Challenges (use of internet)
- Transportation to and from Health Care Facilities
- Family Focus Disability Education and Understanding of Disability

This information will be used to develop and implement the Utah Department of Health's Utah State Plan for Latino Health and Disability. Focus group participants and members of the statewide Latino Health Advisory Committee that advised this entire research process recommended that the plan include the following considerations:

- Bi-lingual/bi-cultural individuals should develop and provide health-related services
- Incorporate the use of existing community partnerships
- Health promotion activities should provide medical literacy in English and Spanish
- Culturally relevant support groups used to conduct health communication activities should be hosted by bilingual individuals

- Research methodology to improve surveillance of health issues related specifically to the target population needs to be developed and implemented.
- Integrate existing health promotion initiatives and training topics from the UDOH Center for Multicultural Health as the basis for health communication activities.

## SECTION ONE: CONTEXT

Utah is located in the western United States and is characterized by geographic diversity: high plateau, basin and range desert, and two distinctive mountain ranges (Wasatch and Uinta). Running north to south, down the center of the state is the Wasatch mountain range. At the western base of the Wasatch range is the Wasatch Front, a series of valleys that are home to most Utahns. The five most populous counties along the Front represent 6% of the total land area and are home to over 80% of the entire state population (2.43 million people.). The remainder of the population lives in rural or frontier areas where a significant portion of the land is either owned by the federal government and used for national parks or military installations, or owned and controlled by native nations. Utah covers an area of 84.9 thousand square miles (219,887 km<sup>2</sup>) with a statewide population density of 27.2 people per square mile, ranking forty-first among the fifty United States.

The annual growth rate in Utah from 2004 to 2005 was estimated at 48,877, or 2.0%, with an increase of 236,387, or 10.6%, since the year 2000. This includes a natural increase from births (Utah has the largest birth rate of any U.S. state) and an increase due to net migration. Just over 50% of Utah citizens are male and the median age of all Utah residents is 27.1 years, the lowest median age in the nation (over 40% of Utahns are under the age of 18). The largest ethnic group in Utah is Hispanic/Latino. The 2005 American Community Survey of the U.S. Census Bureau (ACS, 2005) indicated that nearly 11% of Utah's population lists itself as "Hispanic or Latino, of any race." See Figure One. According to official U.S. Census records over the past 15 years, the Latino population in Utah rose from 84,000 to nearly 264,000 individuals (UDOH, 2005), a three-fold increase. The Pew Hispanic Center (Pew, 2006) estimates that the undocumented Latino population in Utah is between 75,000 and 100,000 bringing the total number of Latinos in Utah to somewhere between 300,000 to 400,000. "Hispanic/Latino" is the fastest growing ethnic group in Utah with approximately 73% from Mexico (ACS, 2005).

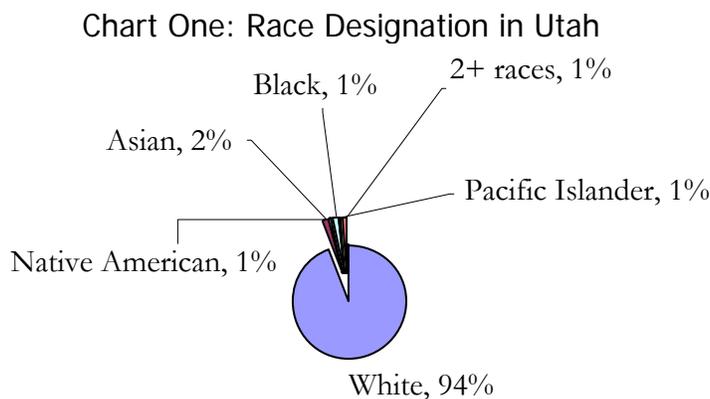


Chart Two: Ethnic Designation in Utah

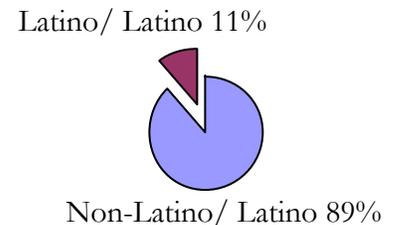


Figure One: Race and Ethnicity in Utah

## General Health Status in Utah

The health outlook for the predominant White population is very good. The state has a strong history of both recognizing and actively addressing statewide health concerns, and designing and implementing initiatives to address health promotion. The religious teachings of the predominant religion (over 70% of the state's population self-describe as being affiliated with the Church of Jesus Christ of Latter-day Saints, or Mormons) discourage the use of alcohol and tobacco, excessive use of meat, and using any substance that is addictive. Physical activity and the liberal use of fruits and vegetables in the diet are also encouraged.

Over a dozen UDOH health promotion programs exemplify Utah's commitment to providing health education/ communication information to its citizens. The results of these programs may account for the relatively lower (as compared to the U.S. population) rates of obesity (56% in Utah; 59% U.S. overall) and higher rate of adults who report engaging in the recommended amount of physical activity (56% in Utah; 46% U.S. overall), among others. Estimates in 2004 indicate that high risk behaviors such as 30-day tobacco use and alcohol use rates in Utahns over age 12 are lower than the national average (20.1% vs. 29.5% ; 29.2% vs. 50.4%, respectively) (SAMHSA, 2006a,b). A recent online publication by the Centers for Disease Control and Prevention indicates that Utahns experience lower than national rates for all risk factors (e.g., high blood pressure, high cholesterol, diabetes, obesity) related to cardiovascular disease (CDC, 2005). Data from the Office of Public Health Assessment (2005) in Utah indicates that the predominant White population is more likely than the overall population to: (a) have health insurance, (b) access early prenatal care, and (c) engage in regular physical activity; and is much less likely to contract infectious diseases.

The general health status of the Utah Latino population is less favorable. For example, over 15% of Utah Latino adults experienced an injury within the past 12 months that was severe enough to limit activities for at least one day and/or require medical attention (Bureau of Health Promotion, 2002). Additionally, Latinos represent a relatively high percentage of Utahns who report fair or poor health (24.4% Latino; 9.5% Non-Latino—Bureau of Health Promotion, 2002). This health data defines a group of individuals at high risk for poor health and secondary disabling conditions. As for Latino individuals with a disability, the national Healthy People 2010 document describes a dismal baseline. Healthy People 2010 goals 6-2 and 6-3 indicate that twice as many children and over 4 times as many Latino adults with disability report feelings of sadness, unhappiness or depression as their counterparts without disability (U.S. Department of Health and Human Services, 2000). Additional data describing health disparities for Latino Utahns with and without disabilities is included in Section Three: Research Findings.

## UDOH Efforts in Ethnic Health

A rapidly growing ethnic minority population, particularly the Latino population, has prompted the Utah Department of Health (UDOH) to proactively take steps to address health issues and disparities in a culturally-competent manner. First, in mid-2004 the UDOH hired a Multicultural Health Coordinator to ensure access to health programs for Utah's minorities. Second, the UDOH developed an Ethnic Health Advisory Committee and placed it in the Utah Department of Health, Division of Community and Family Health Services. This committee, staffed by the Multicultural Health Coordinator who is a native Spanish speaking physician, is committed to increasing access to health care and eliminating health disparities in Utah's diverse populations by engaging in strategic planning to implement and achieve the UDOH Healthy People 2010 goals and objectives. The Committee guides policy analysis relating to the public health status of Utah's diverse populations and advises on the impact of UDOH policies on these populations. Third, in November 2005, UDOH established the Center for Multicultural Health, Utah's Office of Minority Health funded by the

Centers for Disease Control and Prevention. During the past 12 months the Center has received a Utah state legislative mandate to ensure that health promotion activities developed for Utah citizens are developed and implemented in culturally competent ways. The main health issue areas for 2006 and 2007 are: access to health insurance, asthma, cancer, diabetes, HIV and AIDS, heart disease and strokes, immunizations, mother and child health, obesity, oral health, and tobacco use. Fourth, the Center has engaged in a number of activities to promote the health and well-being of Latinos, including those with disabilities. For example, the UDOH and private non-profit organization, Utah Issues, co-sponsors an annual health summit, “Eliminating Inequalities in Utah: Profiling Local Solutions to Create Better Healthcare for All.” Participants (public health agencies, providers and clients) examine various community-based models and explore innovative solutions to facilitating better health care for all Utahns. They also sponsor cultural competence training for local health department staff. Public and private sector organizations collaborate to reduce cultural and communication barriers to health care. The Utah Partners for Health consortium sponsored by the UDOH gathers community leaders on a regular basis to discuss concerns about the growing number of uninsured and working poor individuals, this includes Latinos who represent the group with the highest uninsured rates.

Finally, in 2004, UDOH partnered with the Center for Persons with Disabilities (CPD) at Utah State University to gather data to better understand the prevalence and issues related to disability in the Latino population. The next task for this collaborative project, *Proyecto Prevención*, is to develop and implement the Utah Latino State Plan for Disability and Health. The partners have worked together to gather relevant data from existing sources and from a series of community-based focus groups to develop and implement the plan. The overall goal of the plan is to improve the health and well-being of Latinos with disabilities and to prevent secondary health conditions related to disabilities (The Latino Coalition, 2006). The methods, results, and conclusions of this process are discussed in the next sections of the report.

## SECTION TWO: METHODS OF THE NEEDS ASSESSMENT PROCESS

Community-Based Participatory Research (CBPR) actively involves the community being studied in the research activities in order for it to directly benefit the people studied. In keeping with the guiding philosophy that community-based participatory research is the best way to develop, implement and interpret research (Minkler & Wallerstein, 2003), a Latino Health Advisory Council (LHAC) was formed. The role of this council is to advise project staff and provide feedback regarding focus group questions and procedures, and assist in the interpretation of data collected. The LHAC includes the immediate past-chair (and current member) and UDOH staff coordinator of the UDOH Ethnic Health Advisory Committee.

Over a period of 18 months, to begin the process of addressing the goal, the staff of *Proyecto Prevención* engaged in a variety of data collection activities that included:

1. Reviewing data sources
2. Implementing a statewide focus group initiative

Existing data was reviewed to determine prevalence of disability among Latinos living in Utah, and any describe other disability and health issues/needs relevant to Latinos living in Utah. To address prevalence of disability, several existing data sources were thoroughly reviewed. Information regarding general health issues, chronic illnesses, specific disabilities, and health needs was obtained from the use of focus groups since this data was not available from other sources.

### Reviewing Data Sources

In order to describe the prevalence of disability among the Utah Latino population, five different sources were reviewed:

1. Hispanic Health in Utah: A Survey Report (Bureau of Health Promotion, 2002)
2. Utah Health Status by Race and Ethnicity report (Office of Public Health Assessment, 2005)
3. Behavioral Risk Factor Surveillance System (BRFSS) data
4. Special education student enrollment data
5. Children with Special Health Care Needs (CSHCN) data

The first source, the 2002 Hispanic Health in Utah: A Survey Report focuses on Latino health and is based on a modified version of the Utah BRFSS questionnaire. The results are based on 939 telephone interviews with adult Latinos, 85% of which occurred with Latinos residing along the Wasatch front. The results were very useful in providing comparisons of Latino health status to the health status of the predominant White population (provided in the survey results section). Unfortunately data were not stratified for Latino individuals with disability were not reported. However, the results were reviewed to determine which items may have a correlation to disability.

The second source, Health Status by Race and Ethnicity, describes health disparities among sub-ethnic populations in Utah. The 69 health indicators derived from various public health databases ranging from 1997-2004 were the primary data source. The data indicators that demonstrated a significant difference or disparity between Latinos and the overall Utah population were reviewed. Indicators related to disability in the adult population were noted. Again, data specific to Latino individuals with disability was not reported.

The third source, the Behavioral Risk Factor Surveillance System (BRFSS) conducted by UDOH collects self-report data via telephone annually in each state. The Utah data is available online through Utah's Indicator Based Information System (IBIS). Race and ethnicity data were the primary focus variables as they related to summaries of health conditions and prevalence. The 2005 BRFSS sample size for Latinos was small (n=330).

The fourth source, special education data, was accessed through the website located at [www.ideadata.org](http://www.ideadata.org). This provided annual data about children with disabilities served under the Individuals with Disabilities Education Act (IDEA) through the Office of Special Education Programs (IDEA Data, 2005). The review consisted of comparisons of total numbers of the disability population served and percentages of students enrolled in special education, by race/ethnicity during the 2004 school year (the most recent available data).

The fifth source, CSHCN data, was accessed electronically from the Internet at <http://\cshcn.org>. Data was obtained by querying the 2001 (most recent data) prevalence and demographics datasets for all Utah children age 0-17 and for those categorized as children and youth with special health care needs. We further narrowed the query by race/ethnicity and by state (i.e., Utah). The results for each of these queries are based on derived data.

To date, there have been no other reliable sources for prevalence of disability. The LHAC asked CPD staff to review any other data sources that might provide insight as to the prevalence of disability. To date, reliable sources for this information have not been located.

### **Implementing a Statewide Focus Group Initiative**

The data sources in the previous section provided only limited information about factors that place Utah Latinos at high risk for health problems including data about the prevalence of chronic health conditions. Data about specific, long-term disability in this population, and its effects, is not available. Activity limitation information is available only as it relates to the prevalence of chronic health conditions, and this information is focused on temporary limitations (limitations for one day and/or requiring medical treatment). Prevalence of permanent disability (e.g., sensory, mobility, cognitive) among the Utah Latino adult population is not reported in data surveillance sources. Further, there is little or no data to describe the specific health promotion/ prevention needs, nor the types and/or effects of secondary conditions on Latino adults with disabilities in Utah. This is a great need since secondary conditions are more likely with this population due to language and culture barriers, limited access to health care including health insurance, and high rates of high-risk behavior.

More information is needed to develop culturally appropriate health promotion and prevention activities targeted specifically to the Latino population. Therefore, a focus group initiative was organized and implemented throughout Utah along the Wasatch Front and in rural areas. Focus group discussion prompts were designed to evaluate specific health needs especially as they relate to self care and secondary conditions of Latino adults and children with disabilities. This needs-focused information provides much of the basis for the development and implementation of the Utah State Plan for Latino Disability and Health. The LHAC was instrumental in determining the geographic areas to hold focus groups throughout the state, assisting with recruitment activities, and identifying a Latino Community Liaison (LCL). All procedures and survey questions were reviewed and approved by the Utah State University Institutional Review Board.

## Recruitment

Latino Community Liaison (LCL). The LHAC helped to identify a Latino Community Liaison in each of the target communities. The primary requirement of the LCL was to have an established relationship with the target population. LCLs included LHAC members, promotoras<sup>2</sup> in local health clinics, prominent Hispanic/Latino community members with an interest in disability, agency case workers and service providers. The LCLs used their existing networks and contacts to disseminate information to the families/individuals about the focus groups. LCLs were not paid for their recruitment activities, however, several participated in the focus groups as some were individuals with disabilities or participated with their family members with disabilities.

Invitation Letter. Once individuals and families were identified by the LCLs as potential focus group participants, the next step was to invite them to participate. CPD staff, in collaboration with the LHAC, developed a letter in Spanish that was written at a basic literacy level for the ease of families and individuals to read and understand. The letter was duplicated and given to the LCLs for their distribution to potential participants in the Latino disability community. The LCL disseminated the letter by mail or in person. For those who were Spanish speaking, but could not read the letter, the information was read to them by the LCL. Upon receipt of the letter, potential participants were asked to contact Juan Carlos Vazquez, *Proyecto Prevención* Director, for specific information on how to be part of the focus groups. They were provided with a toll-free telephone number and an email address directly to Mr. Vazquez. Most, over 75%, used these communication methods to respond to Mr. Vasquez. Several who did not have access to telephones or email responded through the LCL as was the case for almost every invitee from the rural communities of Delta, Beaver, Beryl and Moab. In the majority of cases, Mr. Vazquez was able to establish an initial contact by telephone and a cultural connection was established. The contact from the LCLs and with Mr. Vazquez was conducted in Spanish which facilitated cultural connections with participants. Another important factor was that legal status information was not required for participation.

Telephone Follow Up. After an individual accepted the offer to participate, a follow-up telephone call was made several days prior to the focus group event. It was an effective way to continue the connection with individuals before the focus groups were conducted. For those who did not have access to telephones, the LCLs made personal visits to each invitee to remind them of the meeting and to confirm their participation.

Location of Focus Groups. Groups were held in informal settings to encourage participation including community meeting centers and church facilities. These locations were always accessible and conveniently located for the participants. The LCLs assisted in identifying the sites.

## Procedures

Focus group questions and procedures were developed in collaboration with the LHAC. The concept of participatory action research or PAR has been very intuitive for the individuals on LHAC as their suggestions were incorporated in the design, implementation, and evaluation of research activities. In addition to questions and procedures, LHAC members helped determine the locations, times, and potential participants for each focus group (Krueger & Casey, 2000). All of the focus

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<sup>2</sup> Promotoras are, “community members who serve as liaisons between their community and health, human and social service organizations. They work with organizations and institutions, formally and informally, as employees or volunteers to bring information to their communities. As liaisons they often play the roles of advocate, educator, mentor, outreach worker, role model, translator and more.” (Savinar, 2004).

groups were conducted in Spanish, with a native Spanish speaker serving as note-taker. A light snack-type meal was provided in each meeting as well as a \$25.00 gift certificate to a local grocery store for each individual or family as an incentive for participation.

Prior to the beginning of each focus group, participants were reminded of the purpose of the focus groups and the informed consent form was explained. Participants were asked to sign an informed consent and were also told that each session would be audio recorded and a note taker would record important points from the discussion. Participants were asked to introduce themselves at the beginning of the meeting, but to not use their full names or the names of other participants during the recorded discussion. Only one individual declined to sign the consent and chose to voluntarily leave the focus group setting.

The focus group sessions were scheduled for 90 minutes. However, less than 5 concluded at the appointed time. The focus group conversations tended to extend for at least 120 minutes. Individuals and families who participated in these activities indicated that the opportunity to visit with one another, to share their experiences and resources was a highly beneficial experience. Many families exchanged information and established new relationships.

Twenty-one (21) focus groups were conducted throughout Utah in 13 of Utah's 29 counties (see Table 1) with an average of 11 individuals per group. Over half of the participants were adults with disabilities. Table 2 lists the various countries that each of the 231 focus group participants designated as "country of origin."

Table One. Focus Group Demographic Summary

<b>Demographic Characteristic</b>	<b>Number</b>
Number of Focus Groups	21
Average participation per focus group	11
Total number of participants	231
Females	153
Males	78
Adults with disabilities	116
Parents of children with disabilities	112
Special Education Teachers/Service providers	2
Minority Ethnic Coordinator (Gunnison Correctional Facility)	1
Number of countries represented	16

Table Two: Continent and Countries of Origin

<b>Continent/World Region</b>	<b>Country (number represented from the country)</b>
North America	USA (10), Mexico (175)
Central America	Guatemala (8), El Salvador (2), Nicaragua (3), Costa Rica (1)
South America	Ecuador (7), Venezuela (2), Argentina (3), Uruguay (2), Peru (5), Chile (10)
Caribbean	Puerto Rico (1)
Europe	Spain (1)
Africa	Egypt (1)

### **Focus Group Data Analysis Procedures**

Each focus group session was audio recorded and a native Spanish-speaking note taker was present at 17 of the sessions. The 21 focus groups were conducted in their entirety in Spanish. Notes were taken in Spanish and translated to English for later review.

The original notes (in Spanish) from each focus group session were analyzed and evaluated post-hoc by the focus group leader and the note taker. The notes were reviewed as they listened to the full recorded audio of each session. The focus group leader and note taker conducted the note and audio recording review independently. Using a constant-comparative analysis method (Guba & Lincoln, 1989), individual issues/topics for each session were identified. The issues appear to fit satisfactorily into the Institute of Medicine (Institute of Medicine, 1993) conceptual framework for classifying health care barriers (i.e., structural, financial, personal/cultural). As this framework is an established conceptual structure, it was used to categorize the issues.

Credibility of the focus group results is achieved through prolonged engagement and persistent observation with 231 participants statewide. The results are triangulated and confirmed by the supporting evidence in the quantitative data from the various existing databases. LHAC review of these results (English-version, with Spanish-version summaries for non-English speaking LHAC members), in their preliminary and final forms, provided an opportunity for peer debriefing which enabled researchers to “check the facts” with those who are most directly affected by the results—members of the Latino community. The fact that consistent issues emerged over 21 different sessions and in various parts of the state with the more than 200 participants being largely unknown to each other leads one to ascertain that the data resulting from this process is dependable (See Guba & Lincoln, 1989).

## SECTION THREE: RESEARCH FINDINGS

The majority of existing health-related databases do not provide specific prevalence data for subgroups such as “disability.” They provide data related to race and ethnicity, but further segmentation of the data can be done only through extrapolation. This is an unproved method, particularly for the Latino population in Utah which is largely “immigrant” and its characteristics are not fully understood. However, the limited available data can be used to tentatively describe health issues among Latinos. If the U.S. Census (Waldrop & Stern, 2003) disability prevalence rate for people over the age of 5 (approximately 14.9% of the total Utah population) is used, it is credible to posit that there may be just over 40,000 Latinos (age 5 and older) with some type of disability in Utah. This prevalence comparison method applied to Children with Special Health Care Needs (CSHCN) data does not hold (prevalence for Latinos is 7.4%; for Whites is 11%). However, when this method is applied to special education enrollment data, it appears to be valid (see “School Data” below). In general, the results below confirm that poor health indicators are generally higher for Utah Latinos than the general population thus adding credibility to the overall disability rate (just under 1 in 7) for Latinos in Utah.

### 2002 Hispanic Health in Utah: A Survey Report

Health status data for the Latino population stands in stark contrast to the predominant population. A 2002 report, Hispanic Health in Utah: A Survey Report, noted that nearly one-fourth of Latino adults report fair or poor health (primarily in rural and frontier communities), and nearly one in five Latino adults over age 65 have been diagnosed with diabetes. It states further, “Nationally and in Utah, Latino adults are more likely to have diabetes than those who are not Latino or Latino descent across every age category.” Obesity and overweight rates are much higher for Latino populations than for the predominant white population, 61% for Latinos, 52% for whites. The percent uninsured is much higher for the Latino population than for other race/ethnic groups. In Utah, 12.8 % of adults age 18-64 reported not having any health insurance. Among Utah Latino adults, 43.8 % reported that they did not have health insurance coverage. Latinos are overrepresented in AIDS treatment; 20% of all AIDS Drug Assistance Program clients in Utah are Latino, yet Latinos represent only 11% of the state’s population. Further, the report indicates that only 56% of Utah Latino adults had health insurance coverage in 2001, compared to 90.4% of all Utah adults.

### Health Status by Race and Ethnicity

The Health Status by Race and Ethnicity report published by UDOH (Office of Public Health Assessment, 2005) describes health disparities among subpopulations in Utah. Data comparing the predominant White adult population and Latino adults between 1997 and 2004 demonstrate large disparities. On 69 separate health measures the disparities between Whites and Latinos is larger than for any other minority group. The Latino population fared worse on 23 of the 69 health measures. For American Indian, African American, Pacific Islander and Asians, the number of health measure disparities was 19, 14, 6, and 4, respectively. High risk problems include access to care, lack of preventive care/health screening, and lifestyle (obesity and physical activity).

Access to health care is the most prominent disparity. Between 1993 and 2004 the number of Latinos indicating that they had health care coverage decreased by 12% from 88% to 76%. That means that nearly 1 in 4 (24%) Latinos don’t have health care coverage. Only 10% of Utah’s White population does not have health care coverage. Cost, however, does not appear to be a contributing

factor. During this same time period, the number of Latinos indicating that they couldn't get needed care due to cost remained fairly constant at about 18%.

Rates for several types of cancer screening (i.e., age 50+ colon cancer is 27.4% for Latinos, 37.2% for Utah overall; female Pap test is 72.7% for Latinos, 80.7% for Utah overall; and, male age 40+ PSA test is 42.1% for Latinos, 55.2% for Utah overall) and other health prevention methods such as adult flu shots (i.e., 31.3% for Latinos; 35.2% for Utah overall) were significantly disparate for Latinos. Obesity, poor nutrition/diet and lack of physical activity occurred at disparate rates for Latinos (i.e., 64% vs. 55.6% Utah overall; 16.4% eat 3+ vegetables daily vs. 22% Utah overall; and, 28% report no physical activity vs. 17.7% Utah overall, respectively). Indicators related to prenatal health (e.g., infant mortality, births to adolescents, neural tube defects) and infectious diseases were significantly, negatively disparate from the overall Utah population.

## **Disability and the Behavioral Risk Factor Surveillance Survey (BRFSS)**

The BRFSS does not ask questions about the disability issues on an annual basis. The last Utah BRFSS data that asked specific disability questions was in 2001. The survey asked if individuals were limited in their activities or used any type of special equipment. Thirteen and one half percent (13.5%) of the respondents said "Yes." Of this number, 10.7% said that they had a disability and needed no additional help and 2.8% said they needed additional assistance. Orthopedic (back or neck problems, broken bones, etc.) and arthritis accounted for 50% of those who said they had a disability. Nearly 24% didn't list the type of disability. The published data brief did not provide this data by race/ethnicity. Therefore, disability-related information pertaining to the Latino population was not available from the 2001 BRFSS. However, the 2005 BRFSS did ask questions related to overall health and well-being. The Latino sample for this question was small (N=330). Fair or poor was indicated by 25.07% (confidence bounds, 19.62%-31.44%) of Latinos. Only 11.89% of non-Latino respondents (N=4,777 on this item) indicated fair or poor health. There are not any published explanations for this large disparity between non-Latino and Latino Utahns. Some reasonable explanations include lack of access to direct care, inadequate preventative care, and poor lifestyles choices. There is not any official data for the Latino population of people with disabilities. since the disabled White population experience negative health conditions at the same of higher rates than the non-disabled White population, then it is logical suggest that Latino individuals with disabilities experiences disparities at higher levels than non-disabled Latino individuals.

## **Children with Special Health Care Needs data**

The National Survey of Children with Special Health Care Needs) was used to determine prevalence of disability among the Utah Latino population of children age 0-17 years. According to the most recent data (2001), the prevalence of all Utah children with special health care needs is 11%. Latino children with special health care needs comprises 7.4% of all Latino children, which is below the state average and well below the averages for other race/ethnic groups (i.e., White, 11.5%; Black, 12.4%; multiracial, 14.4%).

## **Special education enrollment data**

The most recent special education child count data for children age 6-21 years (IDEA Data, 2004) indicate that 8.13% (42,806) of all White Utah children are served in special education; 8.68% (6,510) of all Latino children are served in special education and 8.7% of all Latino children are served in special education. Slightly over 12% (12.4 of all children age 6-21 served in special education are Latino. Prevalence rates for disabilities, across all categories, appear to be generally consistent with the prevalence rates for the predominant White population.

## Focus Group Findings

In a series of 21 focus groups, 228 Latino adults with disabilities and their family members and families of children with disabilities (3 additional participants were classified as service providers) identified a number of issues related to their health and well-being. Following the Drainoni, et al. (2006) structure for outlining health-related focus group responses, table 3 outlines the most significant participant-perceived health-related issues (in rank order according to the number of focus group sessions in which the issue was presented by participants) affecting the Latino population with disabilities. This structure is based on the Institute of Medicine (1993) conceptual framework for health care barriers. The health issues, while not specifically categorized as disability-related, should be considered as such due to the fact that focus group participants were selected based on their experience with disability, either as an individual with a disability or a family member of a person with a disability. Following the table is a brief description of these issues.

Table Three: Rank Ordered Health-related Issues for Utah Latinos with Disabilities, as per Institute of Medicine Health Care Barrier Framework.

Framework Area	Health-related Issue	Number of Sessions Presented
Personal/ Cultural	Spoken English Proficiency of Person with Disability/ Caregiver	21
	Availability of Bilingual/Bicultural Health Care Providers	21
	Cultural Incompatibility with Health Care Providers	16
	Availability of Native Language Support Groups	16
	Mental Health and Coping with Disability	13
	Discrimination based on Disability or Race	12
	Family Focused Disability Education	11
Structural	Legal Documentation and Access to Health Care Services	15
	Lack of Written Material in “readable” Spanish	14
	Transportation to/from Health Care Facilities	11
Financial	Insurance Coverage Disparities/ Availability of Coverage	15

### **Personal/Cultural Barriers**

#### *Spoken English Proficiency of Person with Disability/ Caregiver*

The most prevalent concern regarding access to health care for the Latino community was the language barriers. Focus group participants expressed concern that their limited proficiency in spoken English seriously impeded communication with health care providers. Health care providers often have limited (or no) access to bilingual staff. Many times children are required to translate for their parents and both the health care providers and their Spanish-speaking patients had difficulties transmitting information.

#### *Availability of Bilingual/ Bicultural Health Care Providers and Cultural Incompatibility*

There are many cultural differences between health care systems in the U.S. and Spanish-speaking countries. In the U.S., a health care provider visit is typically short (less than 15 minutes) and focused on identifying the presenting symptoms and recommending an appropriate treatment

regimen. Participants indicated that in their countries, a health care provider visit is characterized by a discussion of physical and emotional symptoms. They stated that physicians generally take more time to understand a health problem prior to making a diagnosis. The visits usually require 30 minutes at a minimum. Related to this issue is the understanding of disability and health as it varies across cultures.

Being bi-lingual is important but insufficient. Being bi-cultural is essential. Participants indicated that receiving services from someone who is both bi-lingual and bi-cultural is of highest concern for Latino individuals and families with disabilities. In order to appropriately provide effective trusted services, focus group participants indicated that a bi-lingual, bi-cultural setting needs to be achieved. Several described the use of “promotoras” in a health clinic in the Salt Lake City area. They indicated that having access to promotoras who both speak and understand the native language and culture enables them to be more open and forthright with health care professionals.

#### *Availability of Native Language Support Groups*

Most of the focus groups were longer in duration than planned due to the comfort level of individuals with disabilities and during these meetings. Many expressed how useful it was for them to attend a meeting in their own language with people facing similar challenges. It was typical to hear focus group participants asking, “...when the next meeting would take place?” They expressed significant interest in continuing the meetings in order to receive information, “leave the regular routine behind”, and connect and exchange information with families that have similar disabilities.

#### *Mental Health and Coping with Disability*

A large number of families explained that it is “overwhelming” to have to face with the reality of a disability, either their own or that of a family member, in addition have to face with issues such as language, legal status, being away from families that stayed in their countries of origin, lack of employment, associated with legal status. In other words, these particular groups of individuals have to deal not only with a disability but also with the issues of acculturation. As a consequence, they have developed a high level of stress, anxiety, and depression that affects their mental health. Therefore, many families have suggested continuing with monthly meeting such as the focus groups in order to find a way to cope with the reality of their situation. “It gives us something to look forward to” a family member expressed.

#### *Discrimination based on Disability or Race*

Many families felt that it is necessary for people in general to understand more about people with disabilities. Many examples were shared of how difficult it is for an individual with a disability to “fit” into society. Comments, attitudes, and behavior are not very positive toward people with disabilities, and “if you add that we are Latinos, it is a double challenge,” a parent commented. Several indicated that they felt that being placed on waiting lists for services was, “perhaps to do with our ethnicity.”

#### *Family Focused Disability Education*

The understanding of professional service providers that disability affects an entire family was not well communicated nor addressed in the life experiences of many focus group participants. Family members of children and adults with disabilities indicated that understanding of how to deal with disability is not provided in a way that respects disability-related Latino cultural moors. Disability is often discussed with families using medical jargon and in physiological and/or emotional terms. This type of explanation, apart from being provided in a foreign language (i.e., English), may be so incongruent with family/caregiver notions regarding the causes and effects of disability that the

information provided may be unheard or simply dismissed. Adults with disability almost universally indicated that their families needed education on how to reduce the “dependence” view of disability thus enabling a youth or adult child with a disability to be more independent; a U.S./American cultural expectation. The main concern is that training and outreach to families with a family member who has a disability must address the entire family needs, not just those of the individual who is considered disabled.

## **Structural Barriers**

### *Legal Documentation and Access to Health Care Services*

Legal documentation does not necessary equate to better services. Several focus group participants indicated that they had access to inadequate services, even though they were legally documented in the U.S. These inadequacies generally stem from other issues such as language barriers and lack of appropriate health insurance coverage.

### *Lack of Written Material in “readable” Spanish*

Many U.S. service providers appear to be making efforts to provide health communication materials in Spanish. Focus group participants appreciated this effort, but indicated that the translation is sometimes done in a way that does not convey the appropriate meaning, or the translation uses words and phrases that are not common in spoken Spanish. It was suggested that translations be conducted by several who can represent the regional differences in the Spanish language, and that the literacy levels of potential readers be accounted for. Participants indicated that there is a higher percentage of written language illiteracy among Latinos than for the English speaking population. The suggestion was to keep information simple and straightforward. One parent of a child with a disability suggested that, “it is better to get information in English than in poorly translated Spanish.” At least an individual can seek several independent translations of accurate source information.

### *Transportation*

The concern that transportation to and from health care facilities was raised in every rural focus group and in several groups not dependably or consistently served by public transportation. This issue is ubiquitous among all populations located in rural and remote areas of Utah. While the Latino population may have informal transportation networks, they are inadequate. For those whose legal status is questionable, they generally do not approach local government services designed to transport people to health care service providers.

## **Financial Barriers**

### *Insurance Coverage Disparities/ Availability of Coverage*

A number of families also talked about the limited services received due to their lack of insurance coverage. There are many procedures and equipment that are out of their reach due to either lack of insurance and/or their legal status. Several responses for this item came from individuals who had lived in other U.S. states. They migrated to Utah from larger states mentioning that they received more comprehensive services in California, Arizona, and New York. They indicated that health care providers were generally bi-lingual and bi-cultural and that funding was available to help them meet their health care needs. They further stated that health care services seemed to be more accessible.

## SECTION FOUR: CONCLUSIONS AND RECOMMENDATIONS

The research activities undertaken over the past 18 months provided a wealth of information regarding the health needs of Latinos with disabilities in Utah. However, considerably less data is available to describe the prevalence of disability in this population. The LHAC expressed concern regarding this paucity of data. Without a clear picture of the magnitude of the health issues it is difficult to obtain policy and legislative support for making improvements in service systems. For several reasons (e.g., immigration status, poverty, poor acculturation, and low participation in survey activities) gathering accurate prevalence data remains a huge barrier. However, data regarding specific needs is available and should be considered carefully as the State of Utah develops and implements a plan to address the health-related needs of Latino with disabilities and their families.

While the annual Utah Behavioral Risk Factor Surveillance System (BRFSS) and Utah's biannual Health Status Survey (UHSS) describe the health circumstances, by race, of adults who are healthy and those with chronic disease, these survey instruments lack specific questions regarding disability and the effects of disability in terms of secondary conditions. In the past five versions of the Utah BRFSS questionnaire, there has been only one question dealing with limitation of activity—

Using BRFSS questions as a foundation, the Hispanic Health in Utah survey report describes Utah Latino adults in terms of general health status, demographics and prevalence of chronic health conditions. Activity limitation information is presented only as it relates to the prevalence of chronic health conditions, and this information is focused on temporary limitations (limitations for one day and/or requiring medical treatment). Neither this report nor any of the current BRFSS or UHSS protocols include direct questions about activity limitations that are long-term. None of these data sources describe the ability of Utah Latinos with a disability to perform activities of daily living (ADL) or instrumental activities of daily living (IADL); i.e., the effects of disability. Finally, we do not know the prevalence of permanent disability (e.g., sensory, mobility, cognitive) among the Utah Latino adult population. Currently, there is little or no data to describe the specific health promotion/ prevention needs, nor the types and/or effects of secondary conditions on Latino adults with disabilities in Utah. This is a grave concern. Secondary conditions are more likely with this population due to language and culture barriers, limited access to health care including health insurance, and high rates of high-risk behavior.

The focus group results appear to indicate that personal and cultural issues are the largest issue for Latino individuals with disabilities and their families. Adding these concerns to those recently described by Drainoni et al. (2006) for a general cross-disability population suggests that this population is at high risk for secondary conditions related to disability. The magnitude of the problem is not well-defined in Utah, but UDOH certainly realizes that the problem exists and must be addressed.

The process of acculturation presents numerous challenges and life changes that could potentially benefit or adversely affect the health of immigrants as well as subsequent US-born generations. Many of these challenges were described during the focus groups (e.g., U.S. diet compared to traditional Mexican diet, availability of bicultural health care system). In addition, a 2006 commentary in the American Journal of Public Health (Abraido-Lanza, Armbrister, Florez, & Aguirre, 2006) supports the idea that many Latino families experience many changes due to the phenomenon of acculturation. For example, issues related to obesity may be best served by asking specific acculturation questions on nutrition (e.g., adherence to “traditional” diets consisting of low-fat foods such as beans, rice, and vegetables) or other culturally based behaviors (e.g., attitudes about exercise). This might help identify more specific components of acculturation that are associated with

particular health outcomes. Understanding the differences between one's primary culture and the new culture into which one moves, and then attempting to address those differences in a manner that is physically, emotionally and mentally healthy is a challenge.

The vast majority of families expressed difficulties in adapting to a new environment. Many comments were made about dealing with the adverse weather conditions, in particular the cold weather in Utah. "The cold weather, the darkness and not being able to see sunlight for many weeks makes people depressed," expressed one of the participants. A significant number of individuals talked about the challenges of "getting used to" a new environment and experiencing depression, homesickness and anxiety.

As was observed in the Utah Hispanic Health Survey and the comments made by focus groups participants, there is a strong connection between the behavior adopted by Latino individuals and their health status. Abraido-Lanza and colleagues (Abraido-Lanza, et. al., 2006) suggest the following:

The integration of acculturation theory into public health research could advance the study of various Latino health issues. With respect to global health indicators, such as all-cause mortality and life expectancy, there is growing evidence of better health among Latinos than among non-Latino Whites. However, high levels of acculturation among Latinos are associated with increased rates of cancer, infant mortality, and other indicators of poor physical and mental health. These findings suggest that, in the process of acculturation, Latinos may be exposed to different risk factors or may adopt unhealthy behaviors that result in shifts in morbidity and mortality for various diseases (p.1343).

Health promotion and prevention activities for Latinos in Utah, particularly those targeted to Latinos with a disability, face formidable barriers (Bronheim & Sockalingham, 2003). Although local and state governments and community organizations work to address the broad health needs of Latino families, there has been only limited input from this target population. Health data describing the needs of this specific population is scarce and at present, strategies focused on the specific needs of Latinos with disabilities, particularly adults, in Utah are essentially nonexistent. Hence, the need for the information gathered in this report. This document will provide a solid foundation upon which to build and implement a plan for decreasing secondary disabling conditions and improving the health of Latinos with a disability in Utah (See U.S. Department of Health and Human Services, 2005).

## **Utah State Plan for Latino Health and Disability Recommendations**

The data summarized in this report will serve as the basis for the Utah State Plan for Latino Health and Disability. The following is a list of issues and recommendations to be considered in the development of the plan. They are presented in terms of topics and suggested methods for delivery. One additional item related to expanded surveillance research was strongly suggested by the LHAC. It is included below under "other".

### *Topics*

- Health promotion activities that provide medical literacy in English and Spanish are essential (NC Latino Health, 2003). These activities should teach skills and change behaviors to help families and individuals prevent primary and secondary conditions, and should respect native cultural practices. The use of promotoras is an established method for providing health promotion activities. Issues of acculturation (as described earlier) should be considered in plan development and implementation (See Bronheim & Sockalingham, 2003).

- A variety of topics that have to do with the “merging of two cultures” can be presented in order to close the gap between the Latino population with disabilities and service providers (i.e., acculturation) (NC Latino Health, 2003).
- The plan should consider integrating the existing health promotion initiatives and training topics from the UDOH Center for Multicultural Health as the basis for health communication activities (See NC Latino Health, 2003). Particular emphasis should be given to those training issues highlighted in focus groups as being of most importance (The Latino Coalition, 2006). Several of these topics are addressed in two existing curricula, Living Well with A Disability (Spanish version) published by the Rural Training Institute in Montana and Tomando Control de Su Salud (Taking Control of Your Health) published by the Stanford University Medical Center. See table 4.

Table Four: Training Issues of Importance to Latino Individuals with Disabilities and their Families

<b>Training Issues/Topics</b>
Work safety and on the job injury prevention
Automobile injury prevention: seat belt and child safety equipment
+ Preventive health care: regular medical and dental services
Nature of and perception of disability among Latino population
* + Self advocacy in the health care system
* + Nutrition for healthy lifestyle; Combating effects of U.S. acculturation on diet and nutrition
* + Mental health and stress management for adults and parents of children with disabilities
* Culturally relevant physical activity

+ Tomando Control de Su Salud

\* Living Well with A Disability

#### *Suggested Delivery Methods*

- Entities such as hospitals, clinics, and other service providers who implement the plan should utilize bi-lingual/bi-cultural individuals to develop and provide health-related services. These services range from general health communications and specific medical services. While it is important to translate into Spanish the health materials available for the general population, it may be more appropriate to develop curriculum materials and services specific to the cultural needs of the Latino population (NC Latino Health, 2003; The Latino Coalition, 2006).
- Providing services in health clinics is insufficient. The plan should incorporate the use of community partnerships such as those already established with the Mexican Consulate in Salt Lake City, Comunidades Unidas (United Communities), South Main Clinic in Salt Lake City. The concept of “Clinicas Mobiles” or Mobile Clinics in which services are provided to reach out to the Latino community in their own vicinities is a good model to follow. The plan should use established central locations in various towns throughout the state in which Latino families can receive information on how to access appropriate health services. This approach may accrue certain cost benefits to both the person with a disability and to the agencies/organizations that serve them (Ipsen, Ravesloot, Seekins, & Seninger, 2006). The Disability Support Center for Families in Salt Lake is a good example of a “trusted” location.
- Latino individuals tend to trust more others who share their cultural background. This includes health care providers and individuals/families in similar situations. A health promotion plan should include the use of support groups at hospitals and clinics hosted by

bilingual individuals in order to exchange better ways to establish better communication and exchange cultural points of view with service providers.

*Other*

- Research methodology to improve surveillance of health issues related specifically to the population of Latino individuals with disabilities needs to be developed and implemented (Andresen, Diehr, & Luke, 2004). This could be very costly and is likely beyond the ability of the state plan, but the plan could outline activities to be undertaken by the UDOH and its partners to improve health status survey activities in a manner that gathers information for the target population (See Krahn, Putnam, Drum & Powers, 2006).

## ACRONYMS

ADL	Activities of Daily Living
BRFSS	Behavioral Risk Factor Surveillance System
CPD	Center for Persons with Disabilities
CSHCN	Children with Special Health Care Needs
LCL	Latino Community Liaison
IBIS	Indicator Based Information System
IDEA	Individuals with Disabilities Education Act
LHAC	Latino Health Advisory Committee
UDOH	Utah Department of Health
UHSS	Utah Health Status Survey
USU	Utah State University

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