



**Nevada Needs Assessment
for Children
with Special Needs**

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TABLE OF CONTENTS

Table of Tables	iv
Table of Figures	v
Acknowledgements	vi
Executive Summary	vii
Introduction	1
Overview of the Needs Assessment	3
Data Collection Methods	5
Primary Data Collection Descriptions	7
Secondary Data Collection Descriptions	8
Strengths and Limitations of Data Collection Methods	9
Descriptions of Children with Special Needs	11
Prevalence and Distribution	11
Type of Special Needs	13
Demographics	15
Socioeconomic Status	16
Children with Special Needs and Their Families’ Needs	20
Descriptions of Universal Needs	21
Financial Assistance Needs	21
Information Needs	22
Medical and Mental Health Needs	22
Special Education Needs	22
Social Support Needs	22
Other Needs	23
Universal Barriers to Meeting Needs	23
Financial Support	24
Information About Available Resources and Public Assistance Application Process	25
Medical and Mental Health Professionals	26
Service Coordination	28
Early Childhood Transition	29
Other Barriers	30
Service Delivery System	32
Gaps in Services	32
Duplication of Services	39
Challenges to Delivering Services	39
Strengths of Service Delivery System	40
Discussion	41



Summary of Selected States’ Service Delivery Models.....	44
Innovative Strategies to Address Challenges and Barriers	44
Sufficient Financial Support.....	44
Information Dissemination	45
Sufficient Number of Medical and Mental Health Providers and Services	45
Service Coordination.....	46
Early Childhood Transitions.....	46
Arizona	47
California.....	50
Florida.....	54
Idaho	57
Illinois	59
Iowa.....	61
Kentucky	64
Maine	66
Michigan.....	68
New Mexico	71
North Dakota.....	74
Oregon.....	76
Utah.....	78
Washington.....	80
Wisconsin	82
Wyoming.....	84
References.....	86
Appendix A: Real Choices Systems Change Grant Information	
Appendix B: State of Nevada Government Organization Chart	
Appendix C: Demographic Information About Nevada’s General Population	
Appendix D: Focus Group Materials	
Appendix E: Physician Survey Materials	
Appendix F: Key Stakeholder Interview Materials	
Appendix G: Secondary Data Sources	
Appendix H: Resource Inventory Summaries	



TABLE OF TABLES

Table 1. Data Collection Methods and Sources	6
Table 2. Children Enrolled in Special Education by Primary Disability	14
Table 3. Demographic Comparison: National and Nevada CSHCN	15
Table 4. Distribution of Nevada Children and Youth (0-19 Years) by Ethnicity .	16
Table 5. Children with Special Needs and Their Families' Universal Needs.....	21
Table 6. Other Needs	23
Table 7. Universal Barriers Families Face in Trying to Meet Needs.....	24
Table 8. Other Barriers for Selected Populations	31
Table 9. Federally-designated Medically Underserved Areas of Nevada	34
Table 10. States Reviewed for Summary.....	44



TABLE OF FIGURES

Figure 1. Regions of Nevada Identified for the Needs Assessment	4
Figure 2. Nevada Population by Region.....	4
Figure 3. Distribution of Special Education Children by Region.....	12
Figure 4. Percentage of Special Education Children to Total Child Population.....	13
Figure 5. National Survey Categories of Children with Special Needs	14
Figure 6. Comparison of Nevada and U.S. Household Median Income	17
Figure 7. Federal Poverty Level (FPL) Statistics for Nevada CSHCN.....	19
Figure 8. Percentage of Nevada Children Living in Poverty by Region.....	18
Figure 9. Levels of Need.....	20
Figure 10. Medical Providers per 10,000 General Population by Region (U.S. Census 2000 data).....	33
Figure 11. Mental Health Providers per 10,000 General Population by Region (U.S. Census 2000 data).....	35
Figure 12. Social Support Service Agencies per 10,000 General Population (U.S. Census 2000 data).....	36
Figure 13. Distribution of Services in Rural Regions	37
Figure 14. Distribution of Services in Southern and Western Regions	38
Figure 15. Children with Special Needs & Their Families’ Hierarchy of Needs	41
Figure 16. Relationship between Hierarchy of Needs and Barriers.....	42



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EXECUTIVE SUMMARY

LeCroy & Milligan Associates, Inc. conducted a needs assessment regarding children with special needs for the Nevada Bureau of Family Health Services. This mutli-method assessment was completed over a five-month period from August through December 2004. Completion of this needs assessment represents an opportunity for community input into the process of prioritizing needs and designing and implementing positive changes to the system of care for children with special needs in Nevada.

For the purposes of this project, children with special needs were defined as:

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

Children with special needs can have conditions that range from asthma to developmental delays such as autism or cerebral palsy, or chronic mental health or behavioral conditions such as ADHD, schizophrenia, or bipolar disorder.

According to the findings from U.S. Centers for Disease Control's National Survey of Children with Special Health Care Needs (National Survey) that were released in 2004, there were approximately 58,639 children with special needs living in Nevada in 2001. This represented about 11 percent of the Nevada total child population aged 0-17 (approximately 533,000). Most of the children with special needs lived in urban centers: 66% in the Las Vegas area and 22% in the Reno/Carson City area. However, as a percentage of the total child population by region, children with special needs were at least as prevalent in the rural regions as they were in the urban regions.

As reported in the National Survey, 44 percent of Nevada children with special needs required above routine of use medical, mental health, or other services. An additional 22 percent had conditions that resulted in functional limitations. In addition, approximately 5,000 Nevada children with special needs were in poverty or without health insurance.

Children's and families' needs and the barriers to meeting those needs were identified through data collection efforts conducted throughout the urban and rural

regions of Nevada¹. There were some needs and barriers identified that cut across regional and population boundaries. They are listed in the following table.

Children with Special Needs and Their Families' Universal Needs	Universal Barriers to Meeting Needs
<ul style="list-style-type: none"> ▪ Financial support for non-covered expenses ▪ Adequate healthcare insurance ▪ Medical and mental health pediatric specialists and timely diagnoses ▪ Coordination of services ▪ Professionals who are informed about special needs issues ▪ Information about available resources and procedures for obtaining services ▪ Education about children's conditions and training on how to advocate for their children ▪ Social/emotional support, particularly respite and counseling 	<ul style="list-style-type: none"> ▪ Virtually <u>all</u> families with children with special needs <u>have financial needs that are not being met</u>. ▪ Information about available resources and services is difficult to obtain. ▪ The public assistance (i.e., Medicaid) application process is complicated and time consuming. ▪ There are not enough medical and mental health professionals to meet the demand. ▪ Multiple submissions of applications and assessments are often required because services are not coordinated. ▪ Early childhood transitions into school are often difficult.

Other needs related to specific populations or regions that were commonly mentioned include:

- Counseling for parents and siblings for emotional support and development
- Transition services for young adults with special needs who want to live independently (e.g., housing, vocational training)
- Transportation to service providers--particularly from the rural regions where families have to travel several hours to urban centers to see medical specialists
- Translation services for non-English speakers
- Skilled nursing services for home, school, and child care settings

¹ For this needs assessment, Nevada was divided into 5 regions to examine differences between urban and rural areas. These regions were:

1. Central (rural):: Esmeralda, Hawthorne, Lincoln, Mineral, Nye counties; population^a 45,307
2. Eastern (rural): Elko, Eureka, White Pine counties; population^a 56,206
3. Northern (rural):: Churchill, Humboldt, Lander, Lyon, Pershing counties; population^a 91,149
4. Southern (urban):: Clark County; population^a 1,560,658
5. Western (urban):: Carson City, Douglas, Storey, Washoe counties; population^a 457,352

^a KIDS COUNT County Profiles 2004 (2002 data)



Barriers related to specific populations were also discussed. For example, there are no telecommunication capabilities on the remote reservations and foster parents often lose certain benefits when they adopt their foster children.

Inventories of resources were completed to identify and document medical, mental health, and community service providers at the regional level. The inventories include private- and public-sector organizations and form the basis for a public system of information about available resources. These inventories are organized into spreadsheets for easier automated searches and contain information that will assist families and professionals to locate and contact appropriate service providers. For each provider, at a minimum, the following information is presented: name, address, phone number, region located and region(s) served, and type of provider (e.g., pediatrician, pediatric specialist, psychologist, community service organization).

The inventories and the information collected from the needs assessments participants were used to identify gaps in services (i.e., unmet needs). In general, there are not enough medical, mental health, or social service providers to meet the demand in any regions of the state, but there are some gaps in services more severe than others, including:

- Pediatric specialists: the rural regions have very few to no pediatric specialists and the urban regions have too few to meet the demand; some specialties are not represented at all in the state; the number of geneticists is also far too low to meet the demand
- Mental health providers, especially psychiatrists
- Respite care for families with medically-fragile children that require specialized medical care
- Childcare for medically-fragile children that require specialized medical care
- Dentists that accept Medicaid
- Remote regions (especially reservations) have little to no services of any kind

Finally, selected states' service delivery models were assessed to identify innovative and effective strategies for removing or diminishing barriers to delivering services in these states. Because many of these barriers are similar to those being experienced in Nevada, the Bureau of Family Health Services intends to incorporate appropriate best practices from other states to help address barriers in Nevada.

Much of the information contained in this report was collected through qualitative methods including focus groups, key stakeholder interviews, and surveys. A multi-method approach was used to help ensure broad representation and to identify

converging patterns of information across all methods. All the designated regions of the state (see footnote on previous page) were represented in all methods of qualitative data collection.

Data from the U.S. Centers for Disease Control, U.S. Census Bureau, and the Nevada Department of Education were used for reporting on the prevalence, distribution, and demographics of children with special needs and their families. Telephone and Internet directories and current resource directories were used to develop the inventories. Previous reports and Internet resources were used to complete the summary of other states' innovative strategies for effectively reducing barriers to services. Information collected through the above-mentioned secondary data sources was supplemented with telephone calls to key individuals for clarification or confirmation purposes.

In summary, this needs assessment report represents a concerted effort to collect timely and comprehensive information about the issues facing children with special needs and their families. As such, it constitutes a valuable tool for planning, developing, and implementing new programs designed to bring enduring, positive systems of change to the service delivery system in Nevada.



INTRODUCTION

The Nevada Bureau of Family Health Services applied for and received a Real Choice Systems Change grant from the Centers for Medicare and Medicaid. This grant will be used to address the particular challenges facing children with special needs and their families. For more detailed information about the grant, please see Appendix A.

The Bureau, which is housed within the Nevada Division of Health (see Appendix B for organization chart), has adopted the federal Maternal and Child Health's definition of children with special needs as:

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

The Bureau's long-term goal is to develop effective and enduring improvements in community support for children with special needs and their families. These improvements will, in turn, increase accessibility to services in the state. Another key goal is to ensure that Nevada's children with special needs are provided services in the most integrated setting appropriate to help children transition into the social mainstream.

The Bureau decided that it was necessary to conduct a statewide needs assessment to "determine the nature and magnitude of challenges facing children with special health care needs and their families in Nevada." LeCroy & Milligan Associates, Inc. was contracted in July 2004 to complete the assessment. The needs assessment was conducted over a five-month period from August through December 2004. This report represents the culmination of findings from the assessment and is organized as follows:

- **Overview of the Needs Assessment:** Contains information about the design and data collection methods used to complete the assessment
- **Descriptions of Children with Special Needs and Their Families:** Provides information about the prevalence and distribution of children with special needs and about the demographics of these children and their families
- **Children with Special Needs and Their Families' Needs:** Contains information about universal and population/region-specific needs identified through the data collection. Also identifies barriers that families face in trying to get their needs met, the contributing factors and consequences of those barriers, and innovative strategies employed by other states to address similar barriers

- **Service Delivery System:** Provides information about the challenges faced by service providers in providing services to children and their families, gaps in services, and strengths of the system
- **Discussion:** Offers a method for organizing the information collected to facilitate prioritizing needs and decision-making
- **Summaries of Selected States' Service Delivery Models:** Includes a summary of the innovative strategies used by the 16 states reviewed, and individual summaries for each state



OVERVIEW OF THE NEEDS ASSESSMENT

Although needs assessments related to maternal and child health had been conducted in Nevada, none had been completed specific to children with special health care needs. To address this gap in knowledge, the Bureau decided to conduct a needs assessment that would address the following questions:

1. What is the demographic and socioeconomic status of children with special needs and their families?
2. What needs do children with special needs and their families have, and what resources are available to meet those needs?
3. What are the gaps in available resources, and what needs are not being met?
4. What service delivery models have been used effectively by other states to address gaps in services?

The Bureau was interested in knowing the answers to these questions at both the state and regional levels. Consequently, the regional divisions that had been used for previous needs assessments were adopted, which essentially divided the state into three rural and two urban regions (see Figure 1).

The difference in populations between Nevada's rural and urban regions cannot be overemphasized. The rural regions combined contain less than 10 percent of Nevada's total population. The two remaining regions, the southern and western, account for approximately 70 and 20 percent of the population, respectively (see Figure 2; also see Appendix C for more demographic information about Nevada's general population).

Figure 1. Regions of Nevada Identified for the Needs Assessment

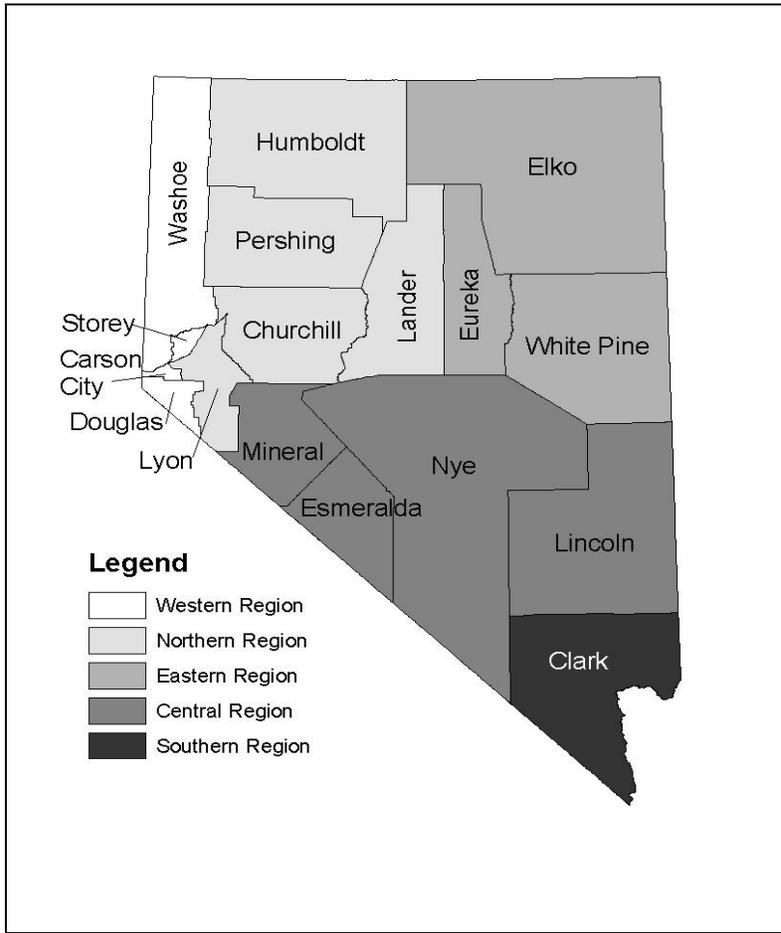
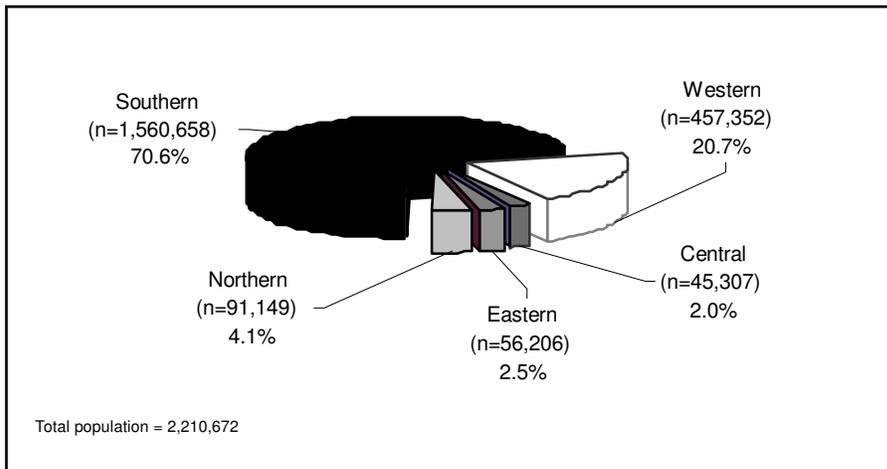


Figure 2. Nevada Population by Region



Data source: KIDS COUNT County Profiles, 2004



Data Collection Methods

In order to answer the Bureau's questions, a multi-method and multi-site approach was implemented. Information was collected and samples were constructed to meet the Bureau's guidelines and to represent the regional areas identified in Figure 1. Data collection methods consisted of focus groups, interviews, and surveys (i.e., primary data) and reviews of existing data to extract pertinent information (i.e., secondary data).

Primary data were collected regarding families' needs, perceived challenges and barriers to meeting those needs, and the strengths and weaknesses of the overall care system as they had experienced them. This information was collected from parents and foster parents, advocates and service providers (including medical and mental health professionals) for children with special needs and their families, and representatives from various government agencies.

Secondary data were used to develop four resource inventories covering government agencies, advocates/community service organizations, and medical and mental health professionals who provide services to children with special needs and their families. These data were also used to gather demographic information and to develop the summary of other states' service delivery models. To clarify data questions, the needs assessment team conducted telephone interviews with appropriate representatives from the relevant agencies. The above information is summarized in Table 1.

Table 1. Data Collection Methods and Sources

Date Collection Method	Data Sources	Information Collected
Primary Data		
Focus Groups	Parents, advocates/community service providers, and government representatives	Perceptions of needs, challenges and barriers to meeting needs, resources used, and strengths-weaknesses of current system of care
Key stakeholder interviews	State and regional staff from the following areas: <ul style="list-style-type: none"> ▪ Education and early intervention services ▪ Medical and mental health ▪ Juvenile justice and child protective services ▪ Tribal health centers 	
Physician survey	Pediatricians, pediatric specialists, family practitioners, and internists (rural regions only)	
Secondary Data		
Review existing materials Phone interviews to clarify data	Existing resource directories, phone directories, Internet, advocates and providers written materials Nevada Dept. of Education Nevada Bureau of Early Intervention Services U.S. Centers for Disease Control & Prevention University of Nevada in Las Vegas U.S. Census Bureau U.S. Department of Education	Available resources Selected states' service delivery models and innovative strategies Demographic and socioeconomic status



Primary Data Collection Descriptions

Focus Groups

Focus groups were planned and implemented using guidelines from Krueger (2000), which include having similar types of people grouped together (i.e., parents), circle seating, open-ended and pre-determined questions, skilled moderator and note taker, and a systematic analysis process. The protocols and sampling design were based on requirements from the Bureau to cover both rural and urban regions. The purpose of the focus groups was to elicit information about participants' perceptions and experiences about children's and families' needs, resources used, challenges/barriers to meeting needs, and strengths and weaknesses of the overall service system.

Separate focus groups were held for parents and for advocates/providers. Locations were selected based on proximity to families with children with special needs and advocates/providers within each region. Parent groups were held in the evenings or during a time that was convenient for the specifically targeted group (e.g., Spanish-speaking parents). Provider groups were usually scheduled during mid- to late-afternoon. Participants were recruited through flyers and word-of-mouth by sharing the schedule with a variety of support groups such as the CSHCN Advisory Council, Nevada PEP, Family Voices, and schools. Parents were given an incentive of \$20 for their participation. Refreshments were provided for all focus group participants.

Each focus group took approximately 1.5 hours to complete. Information was collected through taking notes, collecting written responses to initial descriptive questions, and audio taping. Summary descriptions of the results were written after reviewing the notes from each session. Appendix D contains the locations of all focus groups and the number of participants attending, the focus group protocol questions, and summaries of responses to the questions.

Physician Survey

A two-page physician survey was developed to gather information on issues specific to medical providers such as the medical home model, Medicaid reimbursement, and their accessibility (i.e., hours open, etc.) and to assess their perceptions of needs and challenges, and barriers to meeting needs. Physician names and addresses were obtained from the Nevada Bureau of Licensing. The list included all currently licensed pediatricians, pediatric specialists (e.g., neurology, allergy, etc.), and family practitioners. For counties that had limited numbers of physicians, internists were included.

A total of 830 physicians were mailed a survey, a cover letter that described the purpose and use of the survey responses, and a self-addressed, stamped return envelope. Twenty-six surveys could not be delivered (e.g., not at this address, forwarding address expired), leaving 804 that were delivered. Appendix E contains copies of the survey and cover letter and a summary of the results.

Physicians could respond to the survey in one of three ways: 1) mail a hard copy in an enclosed self-addressed, stamped envelope, 2) FAX the completed survey, or 3) complete the online survey. A total of 109 surveys were received of which 96 responded to the children with special needs questions, for an overall 12 percent response rate. It should be noted, however, that the response rate for pediatricians and pediatric specialists was approximately 19 and 28 percent, respectively.

Pediatricians completed just under half (48%) of the surveys that were received, family practitioners completed 27 percent, and pediatric specialists completed 22 percent. Most of the completed surveys came from the southern region (59%) and the western region (30%).

Stakeholder Interviews

In order to gain insight and perspective from some key people in the state who might not have attended the focus groups, a final data collection strategy was used. A total of 29 key stakeholder interviews were conducted. The main groups identified for these phone interviews were described in Table 1. Each interview lasted approximately 30 minutes and covered the general topics of needs, resources, challenges/barriers, and strengths/weaknesses of the system. Additional questions were tailored to the unique perspective offered by the individual stakeholders. See Appendix F for a complete list of questions and a summary of the responses.

Secondary Data Collection Descriptions

Descriptions of Children with Special Needs and Their Families

Several information sources were used to develop a reasonably complete picture of children with special needs and their families. This was necessary because no single set of data contained the full complement of information needed. For example, some data sets only provide information on youth ages 4-19 or 0-17, rather than ages 0-22, while others only include statewide data, rather than regional- or county-level data. The data sources used and descriptions of the types of information provided are in Appendix G.

Resource Inventories

Resource inventories for government agencies, advocacy/community-based organizations, and medical and mental health providers were constructed using resource guides, Internet and phone directory searches, and information from advocates and providers. The inventories include location and contact information, populations served, and services provided.

Providers were contacted to confirm their contact and their appropriateness for inclusion in the inventory. Information was entered into separate Excel[®] spreadsheets. Appendix H presents summaries of the information contained in the inventories. Excel[®] spreadsheets containing all the information collected were provided to the Bureau separately on compact disc.

Summary of States' Service Delivery Models

To determine which strategies being employed by other states are both innovative and effective in addressing the special health care needs of children, multiple sources of data were used, including:

- interviews with administrators, directors, and other staff serving children with special needs
- previous reports analyzing states' systems of care for children with special needs
- Title V narratives
- government and agency websites targeting children with special needs

Strengths and Limitations of Data Collection Methods

The major strength of multi-site/multi-source methods comes from the ability to look for converging or diverging patterns of responses across the methods and locations (i.e., regions). All regions were represented in all methods of data collection. This allowed for crosschecking results within each region.

The focus groups included a good range of parents and providers in terms of types of children with special health care needs that were represented (see summaries in Appendix D). Special populations, such as Hispanic parents and foster parents were also represented. The participants provided many insights into their experiences, perspectives, and needs, as well as suggestions for improvement in the "system."

The main limitations of this process came from the difficulty in recruiting participants. Some parents and providers had received recent similar requests for participation in focus groups and surveys that were part of other state program

evaluation efforts and were either confused or tired of participating. Some parents declined to participate because they believed there was no point in taking the time to share their perspective as they had “given up” and had low expectations for change in the state. These and other “hidden” or hard-to-reach- populations were not a large part of this needs assessment.

Another limitation was that some parents in the focus groups expressed concern that they “don’t know what questions to ask.” Therefore, some services or strategies, which are effective in other states, may not have been mentioned in focus groups. For example, if parents were not aware of family-based services, they may not know to expect it or ask for it.

The lists of providers that were used as contact lists, for example the licensed physicians list kept by the state, were often out-of-date. This resulted in returned surveys and emails and “disconnected number” phone messages.

The efforts that were made to recruit participants meant that those who did participate were “volunteers” and, therefore, did not represent random samples of the entire state population of parents and providers. However, as the needs assessment was not designed to determine exact quantifiable levels of need across all these groups, the results remain useful for decision making at a general level.

The questions asked during focus groups and interviews were general in nature. That is, they asked for broad perspectives on the needs, resources, challenges/barriers, and strengths and weaknesses of the systems that serve children with special needs and their families. As a result, they are meant to support broad, system-level planning and decision making. Should others wish to know more about the unique needs of different groups of children with special needs, we refer them to local and national advocacy groups and encourage them to invest in further investigation within Nevada and its local areas.

Another limitation concerns the information contained in the resource inventories. The needs assessment team relied on current phone books and Internet directories to collect this information, and phone calls were made directly to the majority of service providers to confirm contact information and services provided. However, this information can become outdated quickly and, therefore, it is likely that at least some information is not current. It should also be noted that the quality of these services were not formally assessed.

DESCRIPTIONS OF CHILDREN WITH SPECIAL NEEDS

This section includes information about the prevalence and distribution of children with special needs throughout the state and about the demographics of the children and their families.

Prevalence and Distribution

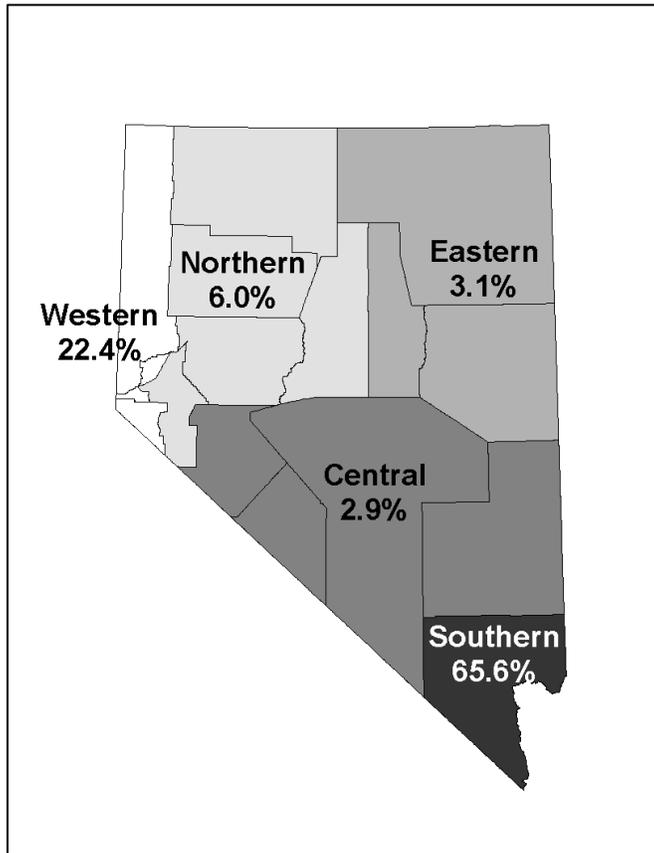
The U.S. Centers for Disease Control and Prevention (CDC) collected data for the National Survey² of CSHCN (children with special health care needs) on a statewide level. For the purposes of the National Survey, CDC defines CSHCN similarly to the federal definition used for this needs assessment (see the *Introduction* section for the definition). These data, collected in 2001, estimated the population of children with special needs in Nevada at 11 percent (58,639) of the total child population aged 0-17 years (approximately 533,000). In comparison, 13 percent of United State's children were estimated to have special needs. The number of children with special needs living in Nevada has no doubt grown since 2001 given the rapid growth in the general population.

The distribution of Nevada's children with special needs by region could not be estimated using the National Survey data because it is only reported at the state level. Therefore, data from the Nevada Department of Education on enrollment in special education were used. While these data are not inclusive of all children with special needs (see Table 2 for list of those included), they may be reasonably accurate as to the percentage distribution of children with special needs among the regions. According to these data, there were 45,201 children in K-12 special education programs in 2003. The distribution of special education children, and perhaps all children with special needs, closely follows the distribution of the general Nevada population (see Figure 3 and compare to Figure 2).

² More information on the National Survey can be found at <http://www.cdc.gov/nchs/about/major/slaits/cshcn.htm>



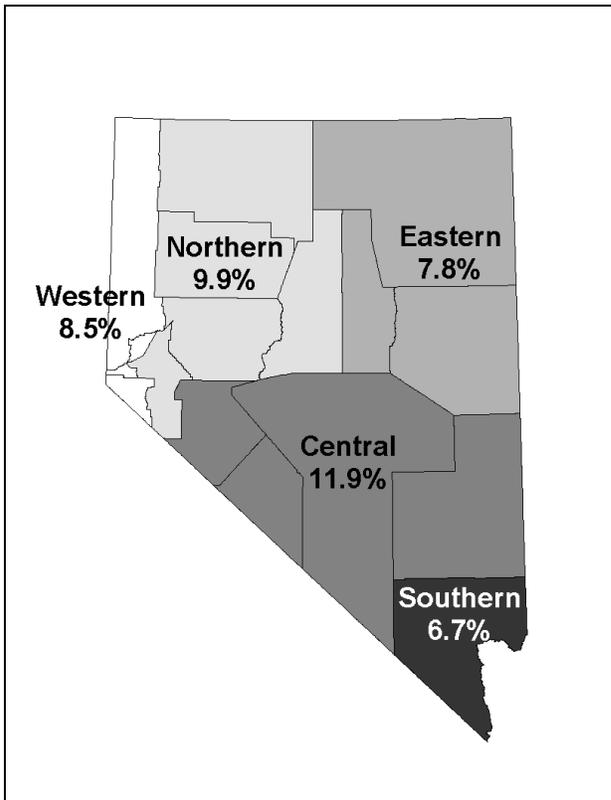
Figure 3. Distribution of Special Education Children by Region



Data source: Nevada Department of Education, 2004 (2003 data)

What is perhaps more relevant is the distribution of special education children as a percentage of the total child population within each region (see Figure 4). The two most rural regions, central and northern, have the highest ratios of children in special education to total child population in the state at 12 and 10 percent, respectively. The most populous region, southern, has the lowest level with just 7 percent of the total child population enrolled in special education. It should be noted that the various percentages among the regions may be due, in part, to differences in the ways school districts define eligibility (e.g., some school districts do not include ADHD) and to differences in the numbers of children with special needs who are integrated into regular classrooms.

Figure 4. Percentage of Special Education Children to Total Child Population



Data source: Nevada Department of Education, 2004 (2003 data)

Type of Special Needs

No single database exists that provides comprehensive information on the types of conditions experienced by Nevada’s children with special needs. However, the Nevada Department of Education data provides information about children enrolled in special education by their primary disability category.

Table 2 provides the number and percentage of children for each category for the entire state of Nevada. Over half (55%) of these children are categorized as “Learning disabled.” The next largest category is “Speech impairment” (17%), followed by “Developmental delays” (6.5%). About 2 percent of children with special needs have multiple disabilities.

Table 2. Children Enrolled in Special Education by Primary Disability

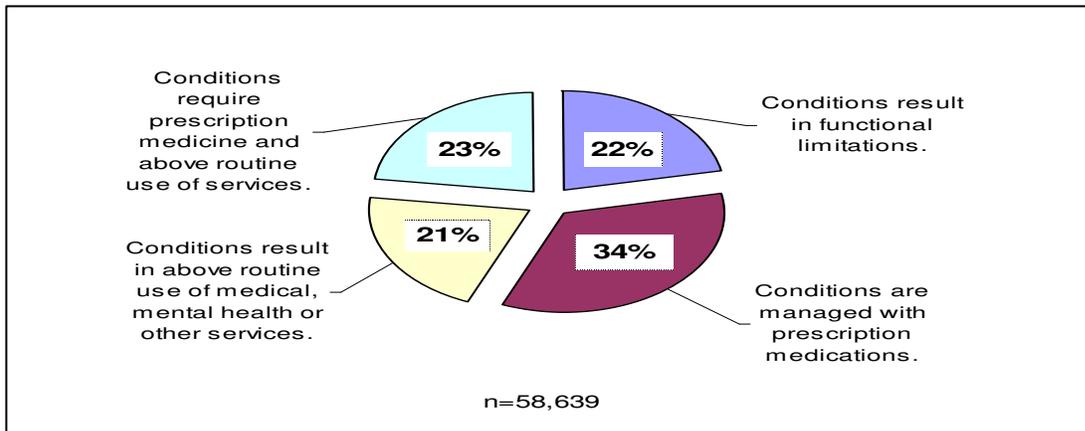
Disability Category	Number of Youth	Percent of Total Youth
Learning disabled	24,704	54.7%
Speech impairment	7,562	16.7%
Developmentally delayed	2,934	6.5%
Other health impairments	2,406	5.3%
Emotional disability	2,224	4.9%
Mental disability	2,031	4.5%
Autism	1,164	2.6%
Multiple disabilities	872	1.9%
Other disabilities ^a	1,304	2.9%
Total	45,201	100.0%

Data source: Nevada Department of Education, 2004 (2003 data)

^a Other disabilities includes: aural, orthopedic, brain injured, visual, and deaf/blind

The CDC’s National Survey data is more inclusive of children with special needs, but it is less specific about the types of special needs experienced by Nevada children. As shown in Figure 5, the largest category was that of conditions that are managed with prescription medications (34%). The remaining three categories were about evenly split (21%-23%).

Figure 5. National Survey Categories of Children with Special Needs



Data source: Centers for Disease Control and Prevention, National Center for Health Statistics, State and Local Area Integrated Telephone Survey, National Survey of Children with Special Health Care Needs, 2001

Demographics

Overall, the age and gender distribution of children with special needs in Nevada is similar to that of the United States (see Table 3). The majority of children with special needs aged 0-17 in Nevada were male (57%), which is higher than the percentage of males in Nevada overall (51%).

The ethnicity of children with special needs in Nevada is similar to that in the U.S. as a whole, with the exception of Hispanics. A statistically significant higher percentage of children with special needs in Nevada are Hispanic (18%) compared to the U.S. as a whole (11.5%).

Table 3. Demographic Comparison: National and Nevada CSHCN

Demographic Variable	Nevada Percent	National Percent
Age		
0-3 years old	10.2	10.6
4-7 years old*	23.9	19.9
8-11 years old	27.2	28.7
12-14 years old	27.4	28.5
15-17 years old	11.3	12.3
Gender		
Male	56.6	60.0
Female	43.4	40.0
Race/ Ethnicity		
White	64.6	68.4
Hispanic*	18.2	11.5
African-American*	10.0	14.2
Multi-racial	4.9	2.9
Other	2.2	2.6

Data source: Centers for Disease Control and Prevention, National Center for Health Statistics, State and Local Area Integrated Telephone Survey, National Survey of Children with Special Health Care Needs, 2001

* Statistically significant differences

The distribution of Nevada’s Hispanic children around the state may also have implications for meeting the needs of Hispanic families who have children with special needs. The southern region has the highest percentages of minority children (of all children within their region). This is followed by the western, eastern, and central regions (see Table 4).

Table 4. Distribution of Nevada Children and Youth (0-19 Years) by Ethnicity

Region	White	Hispanic	African American	Asian/Pacific Islander	Native American	Totals
Southern	48.2%	33.4%	11.3%	6.2%	0.9%	11,051
Western	66.5%	24.4%	2.4%	4.4%	2.3%	18,003
Eastern	68.9%	24.4%	0.8%	0.9%	5.1%	27,224
Northern	73.6%	19.0%	1.1%	1.7%	4.7%	443,161
Central	78.2%	13.5%	1.8%	1.5%	5.0%	118,478
State	53.9%	30.4%	8.7%	5.4%	1.5%	617,917

Data source: KIDS COUNT County Profiles, 2004 (2002 data)

Socioeconomic Status

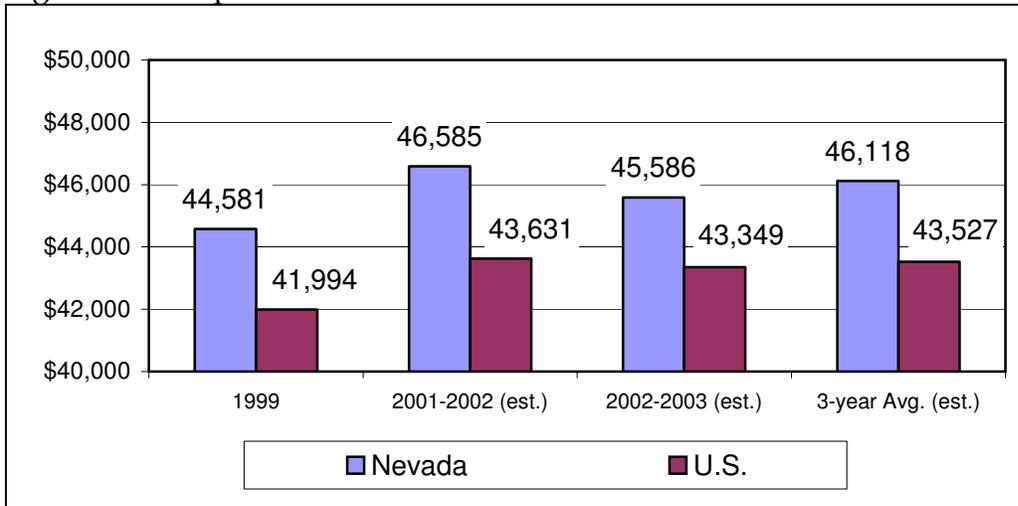
Socioeconomic status was examined through data regarding household income and poverty that were available through the U.S. Census and CDC’s National Survey on a statewide level. Data at the county level were also available from the U.S. Census Bureau 2000 data.

Household Income

Nevada’s median household income has been 5 to 6 percent higher than the United States’ median income over the past few years (see Figure 6). However, according to the 2000 U.S. Census data, 12 to 14 percent of all Nevada children were living below the federal poverty level of \$17,603 for a family of four.



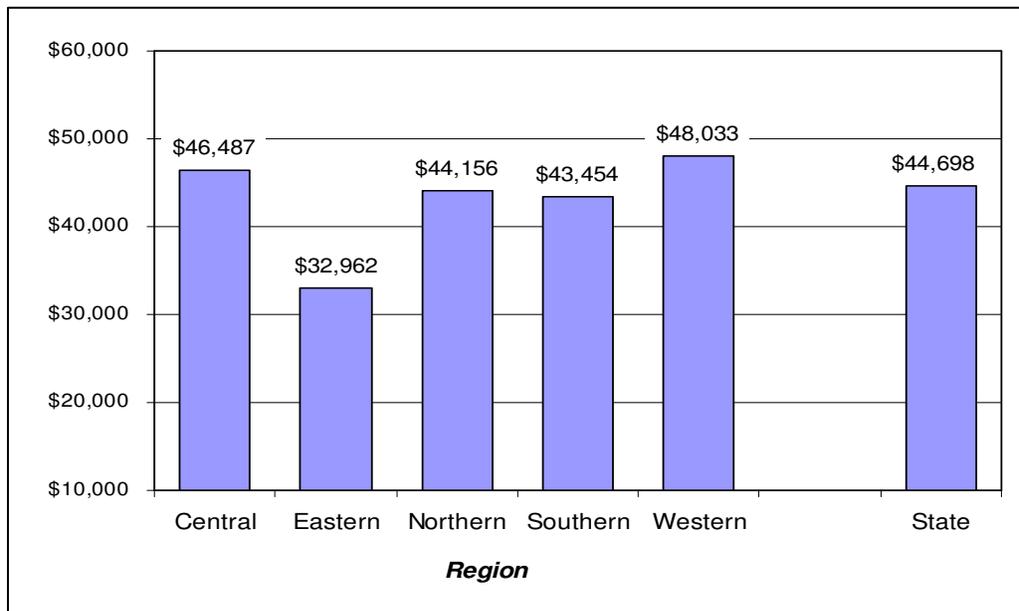
Figure 6. Comparison of Nevada and U.S. Household Median Income



Data source: U.S. Census, 2000 Quick Facts (1999 data); U.S. Census, Table 7 from *Income, Poverty, and Health Insurance Coverage in the United States: 2003*

The median household income ranged from \$32,962 in the eastern region to \$48,033 in the western region (see Figure 7).

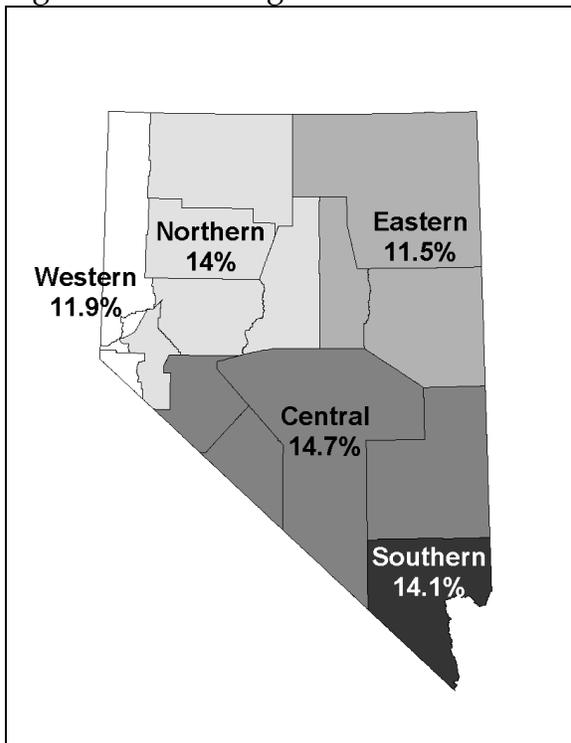
Figure 7. Average Median Household Income by Region



Source: U.S. Census, Small Area Income & Poverty Estimates, 2000 data

The distribution of the total child population living in poverty in Nevada varied slightly by region. As Figure 8 shows, the eastern and western regions had the lowest percentages at around 12 percent, while the remaining three averaged 14 percent.

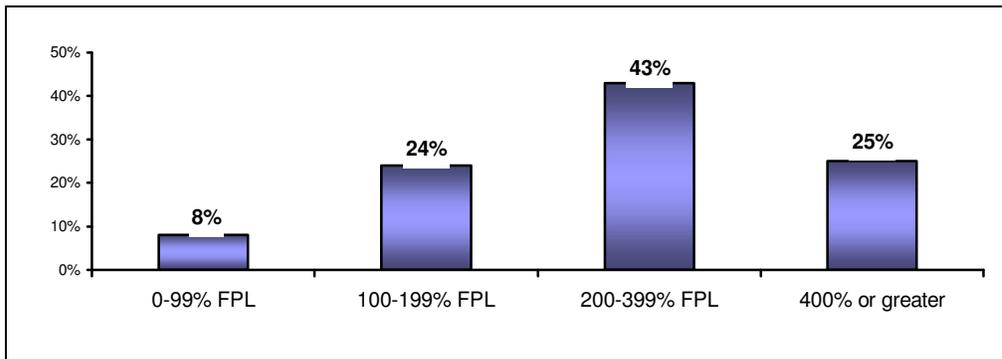
Figure 8. Percentage of Nevada Children Living in Poverty by Region



Data source: U.S. Census Bureau, Census 2000

According to the National Survey 2001 data, children with special needs were less likely to be in poverty than Nevada children in general. Eight percent of children with special needs were living below the federal poverty level, as compared to 12-14 percent for the general population identified through the U.S. Census. The largest percentage of children with special needs (43%) fell in 200-399 percent of the federal poverty level (see Figure 9). In 2001, the federal poverty level for a family of four was \$17,650.

Figure 9. Federal Poverty Level (FPL) Statistics for Nevada CSHCN



Data source: Centers for Disease Control and Prevention, National Center for Health Statistics, State and Local Area Integrated Telephone Survey, National Survey of Children with Special Health Care Needs, 2001

Health Insurance Coverage

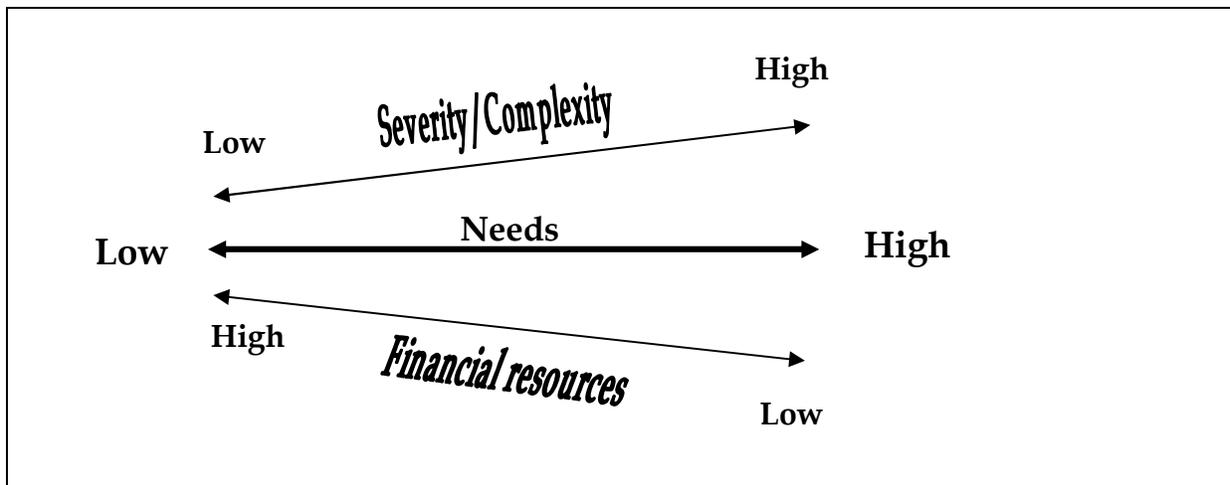
According to the National Survey, 92 percent of children with special needs in Nevada had health insurance in 2001, due in large part to Medicaid and Nevada Check Up (the State of Nevada's insurance for low income youth). However, 36 percent of the families surveyed felt their coverage was not adequate to meet their needs. The remaining 8 percent of children with special needs were uninsured, which is less than the 14 percent of all Nevada youth that were uninsured, but more than the national percentage (5%).

While 8 percent of children with special needs living in poverty or without health insurance is not a large percentage, this amounts to nearly 5,000 of the estimated 58,639 children with special needs living in Nevada in 2001.

CHILDREN WITH SPECIAL NEEDS AND THEIR FAMILIES' NEEDS

Families fall on a continuum of need based on the severity or complexity (i.e., multiple diagnoses) of their children's disabilities and on their financial circumstances. As demonstrated in Figure 10 below, needs increase as the severity/complexity increases and the financial resources decrease.

Figure 10. Levels of Need



Families on the far right of this spectrum include those with children who have severe or complex needs and who cannot meet their basic needs such as food, clothing, and housing due to limited incomes, the parents' own physical or behavioral health issues (e.g., substance abuse), or some combination thereof. According to the providers who attended the focus groups, these families often do not pursue services for their children because they cannot assume the additional burden of time and effort it takes to apply for and receive services. This "hidden" population, which receives little to no services, is particularly challenging to reach and bring into the fold of public assistance. In contrast, families on the far left of this spectrum include those with ample financial resources and children with low severity of special needs.

Most families fall somewhere between these two extremes but still have varying levels of need depending on their particular circumstances. The information collected from the focus groups, interviews, and surveys indicate that all families with children with special needs share some of the same needs, regardless of their level of need or where they lived within the state. Henceforth, these needs are referred to as universal needs because they cut across all levels of need and geographic areas. These needs are identified in Table 5.

Table 5. Children with Special Needs and Their Families' Universal Needs

Children's	Families'	Both
<ul style="list-style-type: none"> ▪ Pediatric medical and mental health specialists ▪ Professionals who are informed about CSHCN issues ▪ Allied health professionals ▪ Socialization: recreation programs, more interaction with peers 	<ul style="list-style-type: none"> ▪ Information about available resources & procedures for obtaining services ▪ Financial support for non-covered expenses ▪ Social/emotional support, particularly respite and counseling ▪ Training on how to advocate for children 	<ul style="list-style-type: none"> ▪ Adequate healthcare insurance ▪ Timely diagnoses ▪ Coordination of services ▪ Education about children's conditions ▪ Respect and understanding

Descriptions of Universal Needs

The universal needs can be classified into the following categories: financial assistance needs, information needs, medical and mental health needs, education needs, and social support needs. These are discussed in order below.

Our children have the same basic needs for love and nurturing as all other children have.

--Focus group parent

Financial Assistance Needs

Families need financial support to cover medical and incidental expenses generated by their children with special needs. It is also needed to supplement lost income when one parent must stay at home to provide full-time care for their children. Families who fall on the far right of the spectrum need financial assistance to cover basic needs for the family in addition to assistance with medical and incidental expenses.

It was reported during focus groups and interviews that some families have basic care needs (e.g., housing, food, etc.) that are not being met. This is particularly true in the rural regions during the “bust” cycles of the mining industry when families lose income. In addition, parents sometimes have difficulty functioning on a day-to-day basis due to their own disabilities or mental health problems.



Information Needs

Many parents who participated in the focus groups talked about the need for information about the universe of services available to meet their needs. Another critical information need discussed was how to access services. In particular, parents need to know the eligibility requirements and application procedures for Nevada's public assistance programs.

Children with special needs and parents alike need to be well-informed (to the extent possible) about the nature of their particular disabilities or conditions. Information about prognosis, progression, symptoms, and best treatment practices is critical in helping to manage children with special needs at home.

Medical and Mental Health Needs

Parents and children with special needs require convenient and timely access to medical and mental health specialists who can diagnose and treat the children at the earliest age possible. According to several focus group participants, early diagnosis is often critical to decreasing the long-term impacts of the disabilities. Furthermore, families need access to pediatricians and pediatric specialists who are well versed in the medical and mental health conditions experienced by children with special needs.

Special Education Needs

Children with special needs often require special accommodations in schools that allow them to take full advantage of educational opportunities available to the entire school population. For example, some children with special needs require aides in the classrooms to help them with medical equipment, prescription medications, and other situations as they arise.

Social Support Needs

Parents talked about the support they need from professionals, family, and friends to deal with the many issues associated with raising children with special needs. They especially need respite, counseling, interaction with other parents who have similar issues, and respect and understanding. They stated that the general public does not have a good understanding of special needs issues and often are reluctant to socialize. They also mentioned that their children needed to be more involved in recreational activities with other children.

Other Needs

In addition to the universal needs discussed above, some participants identified needs that children and their families have that are often related to their levels of need, the regions where they live, or their ethnicity. These needs are summarized in Table 6.

Table 6. Other Needs

Population(s)	Description
Most families, but particularly those with more severe or complex special needs (e.g., medically fragile or developmentally delayed)	Counseling for siblings
	Grief counseling for parents
	Support groups for parents
	Dental care for children
Many families, but particularly those with more severe or complex special needs (e.g., medically fragile or developmentally delayed)	Transition services such as vocational training and group homes
All, but particularly rural families and Native Americans	Transportation and travel expenses reimbursements
Non-English speakers and writers	Translators and translations of written materials
Medically fragile children	Skilled nursing services for home, school, and child care settings
Medically fragile and children with other disabilities that limit mobility	Mobility and other medical equipment Home modification to accommodate wheelchairs and other special needs
Hearing impaired	Interpreters and equipment

It is important to note that some populations of children with special needs and their families were underrepresented in this needs assessment. This includes, for example, children with sensory impairments (hearing, speech) and families who had essentially “dropped out” of the system and who are underutilizing services or have stopped using services all together. For this reason, it is possible that some specific needs were not identified.

Universal Barriers to Meeting Needs

Certain barriers to meeting the needs of children with special needs and their families cross all populations, levels of need, and geographic regions. As will be shown, however, the degree of some barriers is higher in some regions and among

certain population than others. These universal barriers, which mostly center on accessibility to services, are summarized in Table 7.

Table 7. Universal Barriers Families Face in Trying to Meet Needs

- Financial support is not sufficient to meet most families' needs.
- Information about available resources and services is difficult to obtain.
- The public assistance (i.e., Medicaid) application process is complicated and time consuming.
- There are not enough medical and mental health professionals to meet the demand.
- Multiple submissions of applications and assessments are often required because services are not coordinated.
- Early childhood transitions into school are often difficult

Each of the barriers listed in Table 7 are discussed in detail below. The contributing factors to and consequences of each barrier that were identified through the primary and secondary data are included in the discussions. In addition, innovative strategies employed by other states to resolve each barrier are briefly described (full descriptions are provided in the *States' Service Delivery Models* section).

Financial Support

According to the needs assessment participants, virtually all families with children with special needs (with the possible exception of wealthy families) have financial needs that are not being met. From a financial perspective, families can essentially be classified into three groups:

1. Families who qualify for Medicaid.
2. Families who do not qualify for Medicaid, but who have private insurance.
3. Families who do not qualify for Medicaid and who do not have private insurance.

Each group faces a unique set of financial challenges. First, those who qualify for Medicaid must limit their income and assets in order to maintain their eligibility. In many cases, this means that only one parent can be gainfully employed, stretching the families' abilities to meet other family needs.

I can't work because caring for my child is a full-time job.
--Focus group parent

On the positive side, Medicaid covers more expenses than do most private health insurers (e.g., wheelchairs). Second, families who do not qualify for Medicaid but who have private insurance may have higher incomes than Medicaid recipients, but they face increased out-of-pocket expenses for services not covered by their insurance that would otherwise be covered by Medicaid. Finally, families who do not qualify for Medicaid and do not have private health insurance face the difficult decision to either limit the services their children receive or limit their incomes in order to qualify for Medicaid.

Contributing factors:

- Ineligibility for Medicaid (income too high)
- Families limited to one income
- Limited private health insurance coverage
- Loss of early intervention service after 3 (see *Early Childhood Transition* section for more details)

Consequences:

- Families have limited assets to meet other family needs or emergencies
- In some cases, bankruptcy or loss of homes
- Some parents stop pursuing services for their children

Information About Available Resources and Public Assistance Application Process

Many participants of the focus groups, particularly parents, expressed frustration with the lack of readily available information about resources, including public assistance programs. In particular, parents indicated that public and private sector programs are not well publicized and the application process for public assistance is complex and difficult to navigate lacking accurate, accessible information and guidance.

We shouldn't have to go through this.
--Focus group parent

A common occurrence at the focus groups was more experienced parents sharing information about resources with less experienced parents. This suggests the possibility of a more formalized parent-mentoring program connecting parents with varying levels of experience with the care system.

Contributing factors:

- Weak communication networks between and among private and public sector agencies
- Lack of central data collection point to develop and maintain comprehensive, current resource guide
- Professionals who are not well-informed about special needs issues and/or available resources

Consequences:

- Delays in receiving treatment and other important services
- High frustration levels among parents; dissatisfaction with the system
- Some parents stop pursuing services for their children

Medical and Mental Health Professionals

Shortages of medical and mental health providers, especially pediatricians, pediatric specialists, psychiatrists, and nurses are common throughout Nevada. A study conducted in 2001 by the National Academy of Pediatricians ranked Nevada 46th in the nation in the number of pediatricians, having a ratio of 30 pediatricians per 100,000 citizens compared to the recommended 50/100,000 (as cited in the Las Vegas Sun, 2001). Furthermore, pediatric specialists and geneticists are particularly rare which result in long wait times for appointments. Some parents at the focus groups indicated that they waited for several months for an appointment. In addition, because the pediatric specialists who are practicing in Nevada are concentrated in the urban regions, many families face long travel distances for their appointments.

We have to drive 3 ½ hours to Salt Lake City to see our child's specialist.
-- Focus group parent

Information collected through the focus groups, interviews, and physician surveys suggest that shortages of mental health providers are particularly acute, especially psychiatrists. Approximately 90 percent of the physicians who completed a survey indicated that there was a lack of mental health professionals in their geographic areas. Interviews with juvenile justice and mental health professionals concur with this assessment. This is particularly relevant for the juvenile justice population because research shows that the majority of children in this system suffer from mental or behavioral health disorders.

According to an interviewee in the nursing profession, Nevada also has the lowest nurse-to-patient ratio in the country – 520 per 100,000 population compared to the national average of approximately 800 per 100,000. This directly impacts children with special needs who have a need for skilled nursing in home, school, or daycare environments. While the shortages are not as acute as with other medical professionals, allied health professionals such as speech, occupational, and physical therapists are also in demand.

Shortages of all medical and mental health personnel are particularly acute in rural regions and on the reservations. For example, in Elko there are no pediatricians currently accepting new Medicaid patients. In addition, pediatric specialists are concentrated in the urban areas forcing rural families to travel long distances (i.e., to the Las Vegas or Reno urban areas or to California, Utah, or Idaho) for services (see the *Gaps in Services* section for more details). In at least one rural region the only way juvenile offenders who turn 18 can continue to receive mental health services in their region is to be incarcerated in the adult system.

Contributing factors:

- Rapid population growth that has outstripped the number of professionals
- Large rural geographic areas that are sparsely populated do not attract physicians
- Limited medical training facilities
- Physicians' frustration with Medicaid (slow payment); decreasing numbers accepting new Medicaid patients
- Medication restrictions on reimbursement for mental health providers (i.e., must be psychologist or psychiatrist)

Consequences:

- Delayed diagnoses due to long wait times
- Delayed treatment regimens
- Inappropriate use of emergency rooms for urgent or routine care
- Some parents stop pursuing services for their children
- Limited socialization for the families with children with special needs who need skilled nursing (i.e., parents must stay home to care for children)

Service Coordination

The needs assessment participants talked frequently about the difficulties that arise because services are not coordinated across the spectrum of service providers (e.g., school districts, mental or medical health providers, child care). The primary complaint was that parents are usually required to apply for services at each agency, which takes up time that would be better spent with their children.

We feel overwhelmed and are tired of fighting for services. We feel guilty that our children don't always get enough services or get them soon enough.

-- Focus group parents

Nevada is not alone in having a fragmented system of care for children with special needs. Across the county, “the system of care has developed in a patchwork fashion over time and consists of numerous disconnected programs with differing eligibility and funding criteria” (Farmer, J.E., 2003). This has led to families being overwhelmed by the policies, paperwork, and gaps in services (Farmer, 2003). The medical home model is recognized as a best practice for coordinating care for children with special needs. The American Academy of Pediatrics defines a medical home as:

“...an approach to providing health care services in a high-quality and cost-effective manner...The pediatric health care professionals and parents act as partners in a *medical home* to identify and access all the medical and non-medical services needed to help children and their families achieve their maximum potential.”

Family-centered care is a philosophy for providing care, and according to Patterson (2000), is a “core principle of best practices for children with special health care needs.” This approach is advocated by the Maternal and Child Health Bureau and parent advocacy organizations because it promotes partnerships between families and professionals that build on families’ strengths and increase integration into the community.

Neither of these models, however, is practiced to any great extent in Nevada. For example, according to the physicians who completed the survey, only 6 percent practice the medical home model and 24 percent use it to a limited extent. Nearly half (49%) were not familiar with the model.

According to the needs assessment participants, there have been some limited efforts in Nevada to better coordinate services. For example, one interviewee mentioned a program that improves integration for children with behavioral problems through collaborative efforts among schools, therapists, service coordinators, and family members that lead to effective methods for addressing the problems.

Contributing factors:

- Vast rural geographic areas that cover most of the state
- Lack of training about medical home model and best practices for service provision
- Weak communication networks between and among private and public sector agencies
- Lack of qualified professionals; high turnover rates in education and medical professions

Consequences:

- Delays in receiving treatment and other important services
- Duplication of efforts in applying for services
- High frustration levels among parents
- Some parents stop pursuing services for their children

Early Childhood Transition

Another area of concern that was consistently raised by the needs assessment participants is early childhood transitions into school. This was especially true for families who had received early intervention services (EIS), which cover children birth to 3 years of age who are assessed at 50 percent of normal development in one domain or 25 percent for two domains.

The federal Individuals with Disabilities Education Act mandates early intervention and school services for children with special needs up to 22 years of age. In Nevada, the Bureau of Early Intervention Services (BEIS) and the school districts, which are county level, are responsible for providing the required services. However, the services that each group is required to provide vary. School districts need only provide those services required to ensure that each child receives an education consistent with children who do not have special needs. EIS, on the other hand,

provides educational, medical, and social support services to address developmental delays.

Many parents reported losing needed services when they transitioned to school services (i.e., moved from EIS to school services). This is largely due to the different requirements schools have for providing services and the lack of viable alternatives for providing services that were lost. In addition, several families had experienced difficulties in receiving the services from school districts they were entitled to under law due to, among other things, overcrowded schools and a lack of resources (e.g., funding, qualified personnel).

Contributing factors:

- Lack of qualified professionals to fill school medical positions (e.g., nurses, speech therapists)
- Early intervention services are not provided consistently across the state
- Overcrowded schools and limited resources

Consequences:

- Lack of educational progress among children not receiving sufficient, timely services
- Frustration and dissatisfaction among parents
- Some parents stop pursuing services for the children

The BEIS and school districts are required to work together with families to prepare individual education plans (IEP) for each child to help them transition into the school setting. There is evidence to indicate, however, that this is not being done consistently in some, if not all, regions. Parents spoke of IEP being completed after the mandated deadline (by age 3 years) and some school district records indicate that they are not completing IEP in a timely manner.

Other Barriers

In addition to the universal barriers discussed above, children with special needs and their families experience barriers that are directly related to their levels of need, the regions where they live, or their ethnicity. These barriers are summarized in Table 8.

Table 8. Other Barriers for Selected Populations

Population(s)	Description
Developmentally disabled Medically fragile	Lack of vocational services, group homes, and financial assistance to help transition into adult, independent living
Foster parents and children	Families lose benefits when foster children are adopted
Non-English speakers and writers	Services providers and agency staff who are not bilingual, sometimes required to bring own interpreter
Native Americans	No telecommunication (remote reservations) Federal funding for medical services frozen at 1994 levels More severe shortages of medical and other service providers; more difficulty recruiting and retaining qualified professionals
Juvenile justice population	No residential treatment facilities in rural regions Families are unstable Diagnosis at late age cause problems to be more entrenched and difficult to treat

SERVICE DELIVERY SYSTEM

The service delivery system for children with special needs in Nevada encompasses a wide range of public and private sector organizations including:

- Early intervention services
- Public school districts
- Public health agencies (i.e., medical and mental health clinics)
- Community service organizations (e.g., advocacy groups, nonprofit service providers)
- Physicians and other medical service providers
- Mental health services providers
- Public assistance agencies (e.g., Medicaid)

Combined, these organizations provide a broad spectrum of services to address the financial, informational, medical and mental health, educational, transitional, and social support needs of children with special needs and their families. LeCroy & Milligan Associates generated four inventories of services offered by government agencies, medical and mental health providers, and advocate/community service agencies. These inventories, together with the primary data, were useful in identifying gaps in services at the state and regional levels (see Appendix H for summaries of the information contained in the directories). Excel[®] spreadsheets containing all the information collected were provided to the Bureau separately on compact disc.

Gaps in Services

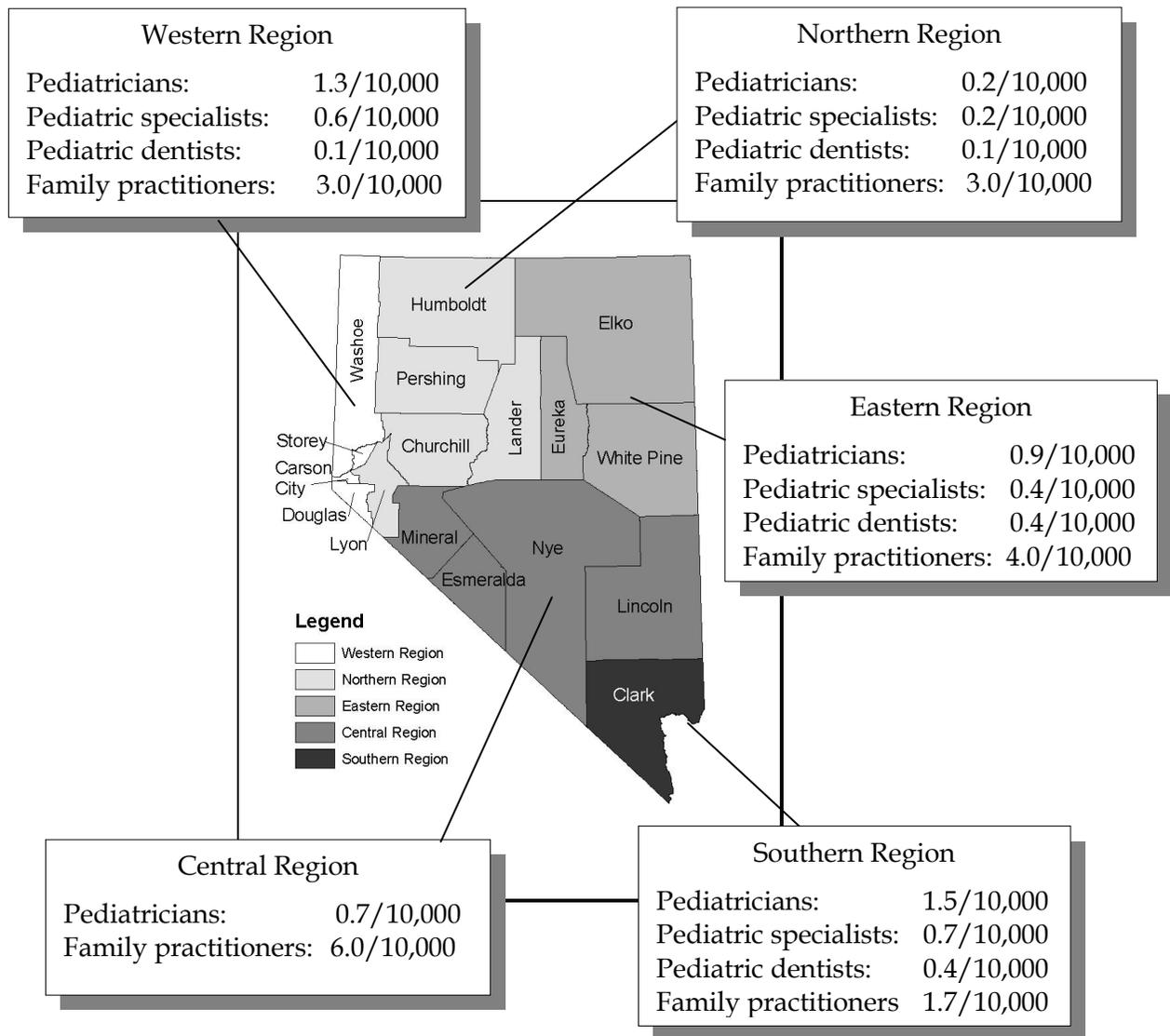
Although the consensus among the needs assessment participants was that there were not enough service providers to meet the demand in any regions of the state, there were some gaps in services that were more severe than others, including:

- Pediatric specialists: the rural regions have very few to no pediatric specialists and the urban regions have too few to meet the demand; some specialties are not represented at all in the state; the number of geneticists is also far too low to meet the demand
- Mental health providers, especially psychiatrists
- Respite care for families with medically-fragile children that require specialized medical care
- Childcare for medically-fragile children that require specialized medical care
- Dentists that accept Medicaid
- Very remote regions (including reservations) have little to no services of any kind

Figures 11-13 depict the number of physicians, mental health professionals, and other professionals providing care for children with special needs and their families. All figures represent services per 10,000 of Nevada's general population in each region based on U.S Census 2000 data.

According to the American Academy of Pediatrics, the recommended rate of pediatricians per population is 50/100,000, or 5/10,000. As can be seen in 11, no region comes close to this recommended rate.

Figure 11. Medical Providers per 10,000 General Population by Region (U.S. Census 2000 data)



The federal Health Resources and Services Administration designations of medically underserved areas in Nevada supports the above information (see Table 9).

Table 9. Federally-designated Medically Underserved Areas of Nevada

Region	Type of Designation			
	MUA/P ^a	Primary Care HPSA ^b	Dental HPSA	Mental Health HPSA
<i>Central Region</i>	ER ^c	ER	ER	ER
<i>Eastern Region</i>				
Elko County	PC ^d	PC	PC	EC ^e
Eureka County	EC	EC	EC	EC
White Pine County	None	EC	EC	EC
<i>Northern Region</i>				
Churchill County	None	Reservation	None	EC
Humboldt County	EC	PC	PC	EC
Lander County	EC	EC	EC	EC
Lyon County	EC	EC	EC	EC
Pershing County	None	EC	EC	EC
<i>Southern Region</i>	Low-income North LV	Low-income North LV	Low-income LV	Low-income
<i>Western Region</i>				
Carson City Cnty.	PC	Low income	None	Correctional facility
Douglas County	None	Indian health center	None	None
Storey County	EC	EC	None	EC
Washoe County	Indian service area	Low-income	Low-income	None

Data source: HRSA, Bureau of Primary Care, 2004

^a MUA/P = Medically underserved area/population

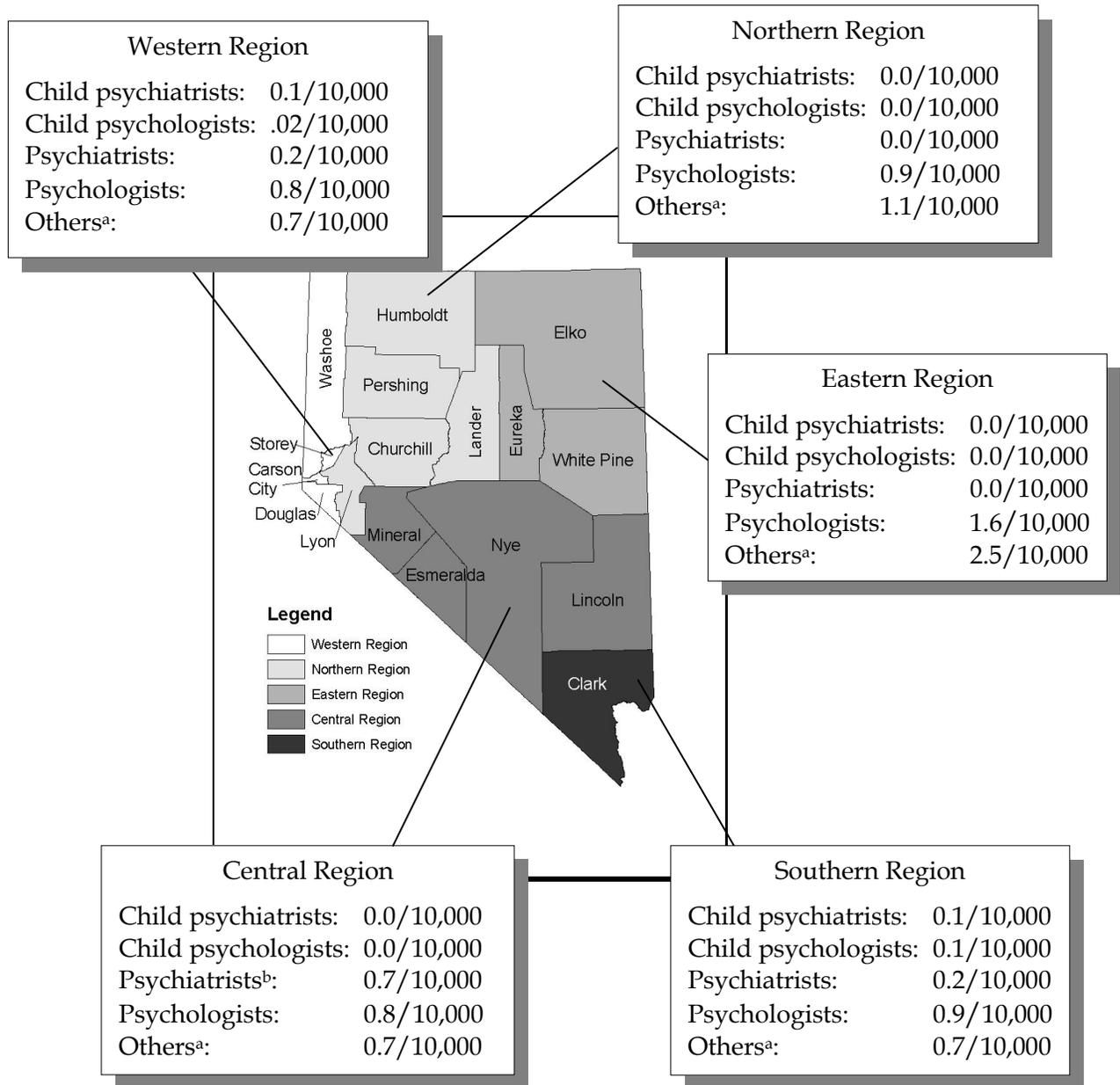
^b HPSA = Health professional shortage area

^c ER = Entire region

^d PC = Partial county

^e EC = Entire county

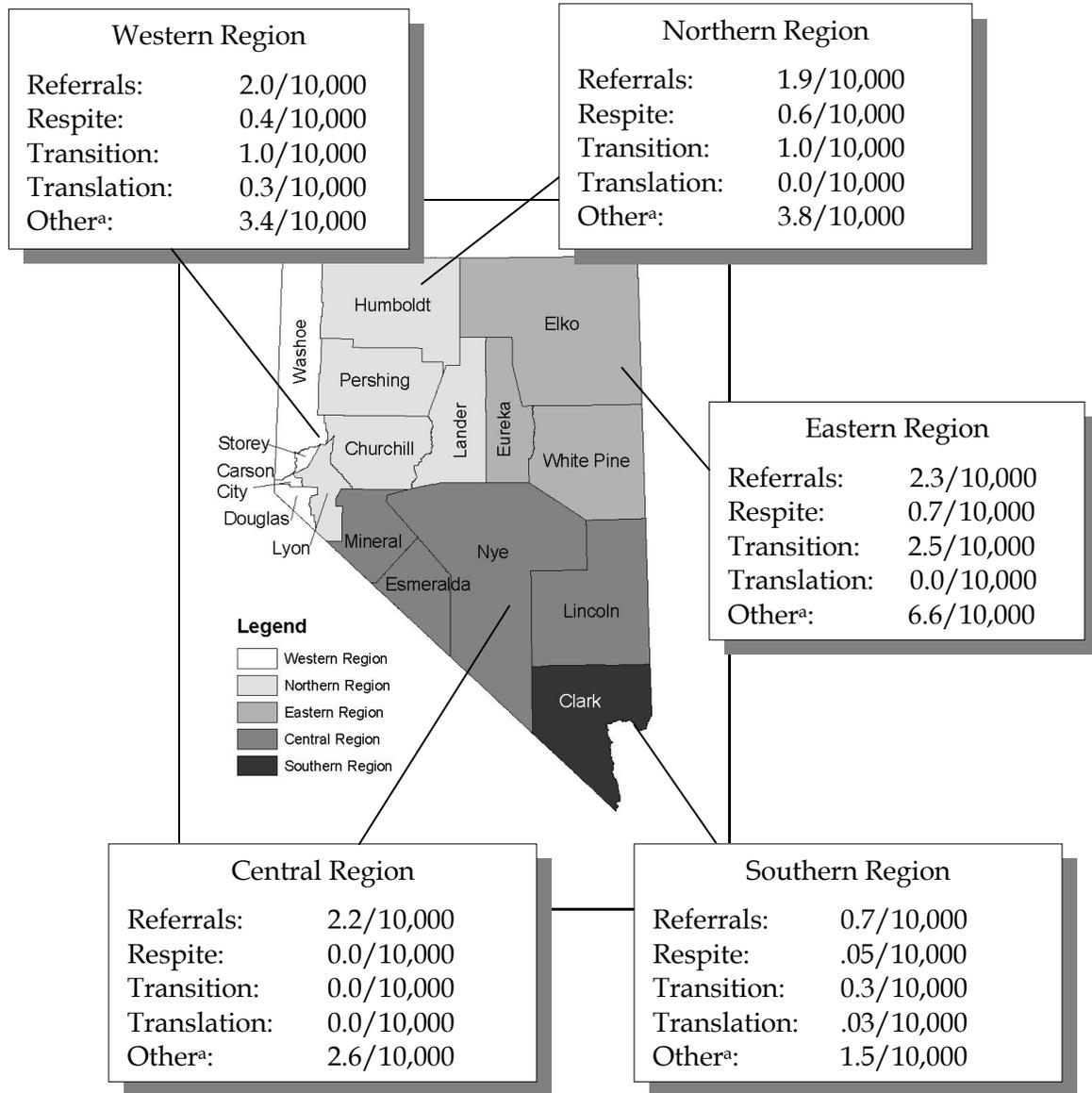
Figure 12. Mental Health Providers per 10,000 General Population by Region (U.S. Census 2000 data)



^a Others include licensed therapists and counselors and clinical social workers and clinics that employ more than one mental health professional (i.e., capacity may be slightly, but not significantly higher than presented)

^b Most are traveling psychiatrists who do not have permanent offices in the region

Figure 13. Social Support Service Agencies per 10,000 General Population (U.S. Census 2000 data)



^a Other services include: Advocacy (legal and service), child care, information and education/training, recreation programs, support groups, and transportation

It is important to note that because the information about social service providers shown in Figure 13 is presented on an agency, rather than individual, level it is not necessarily reflective of the capacity in each region. For example, one agency may be able to serve 100 families, while a different agency may only be able to serve 25.

It is important to consider the distribution of available services, as well as the number of service providers in each region. As can be seen in Figure 14, providers are very scarce in sections of the rural regions. In particular Humboldt, Lander, Pershing (northern region), Eureka, White Pine (eastern), and all central region counties have scarcities.

Figure 14. Distribution of Services in Rural Regions

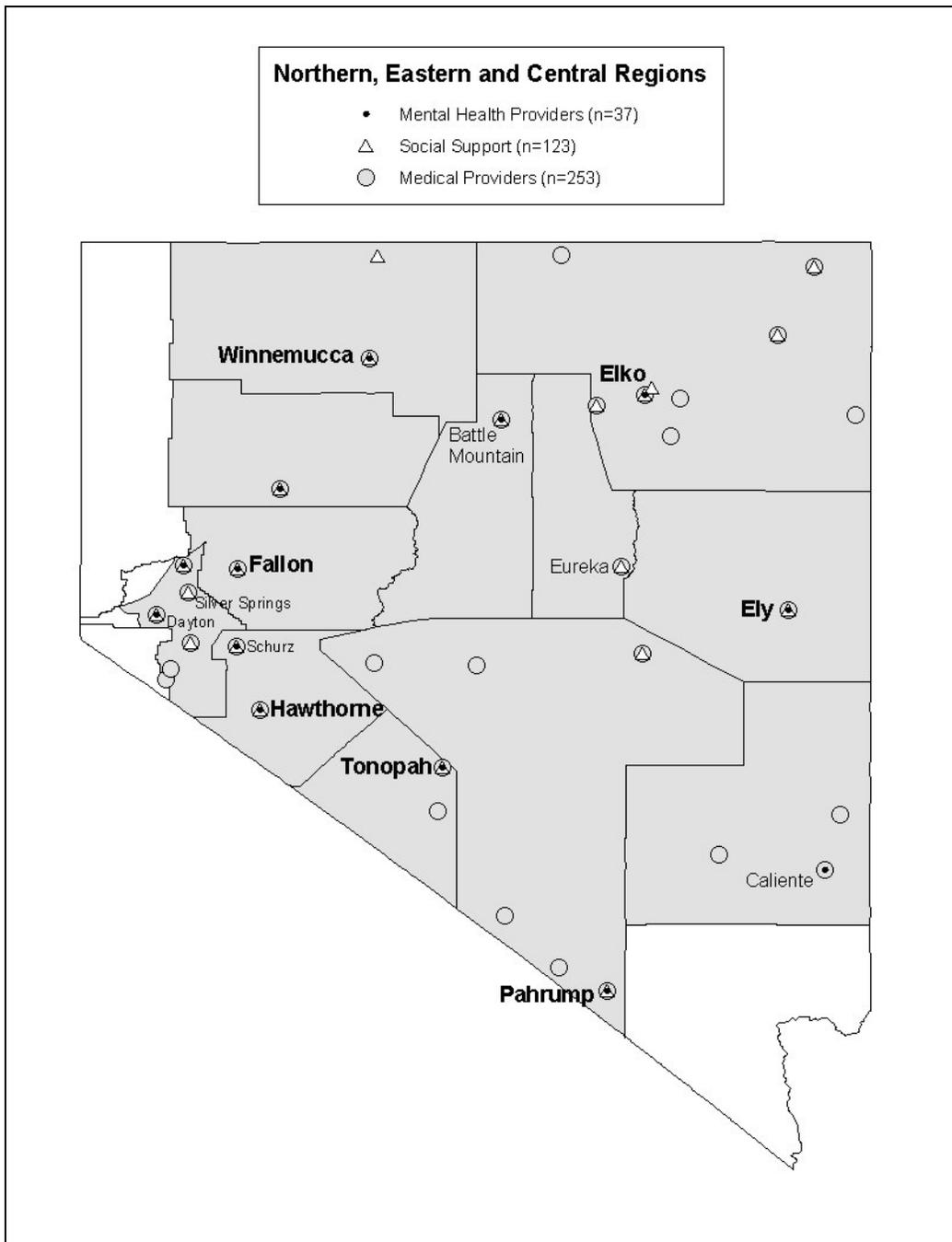
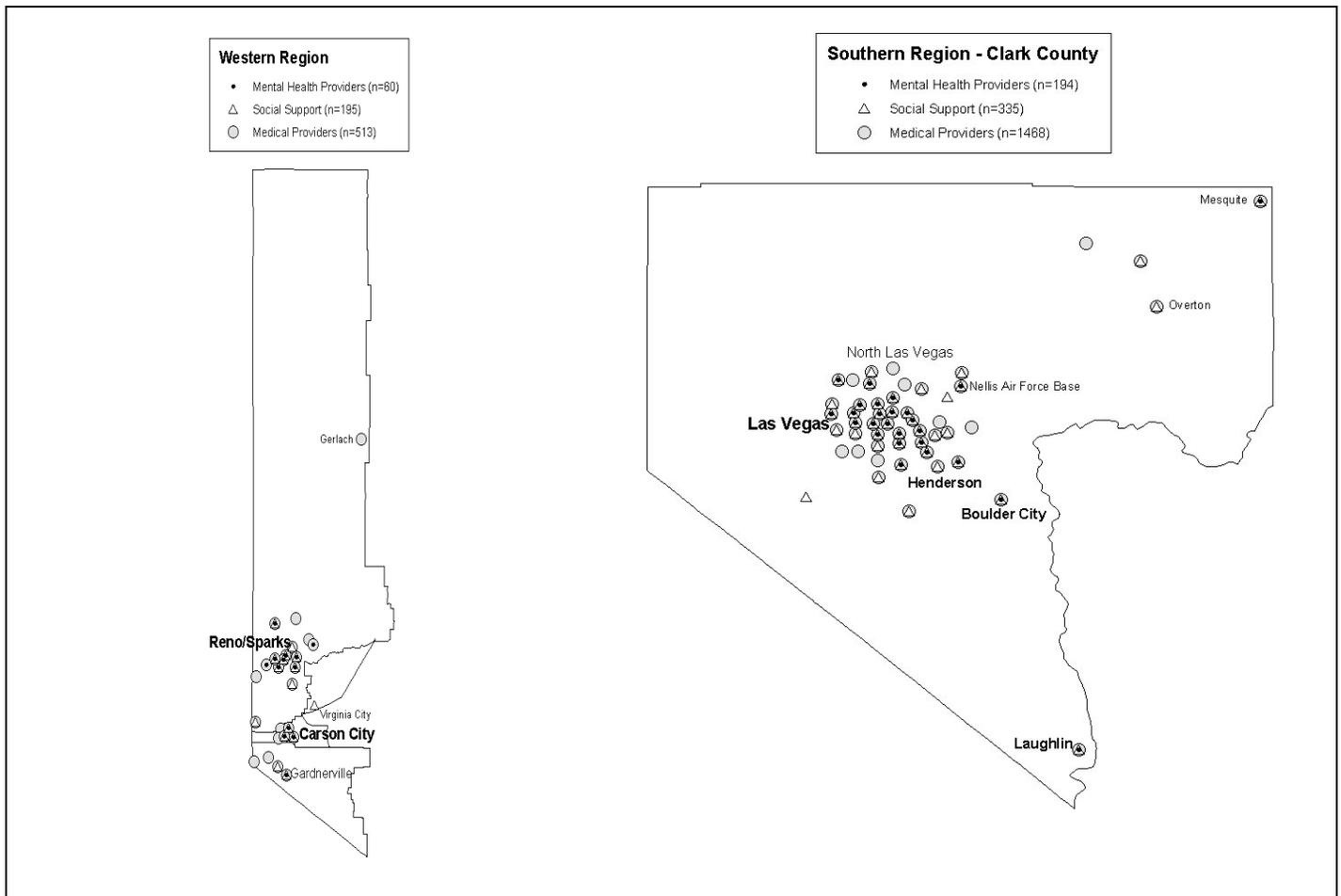


Figure 15 indicates that some areas of the southern and western regions also have few providers. As might be expected, the providers are clustered in the urban areas of Las Vegas and Reno/Carson City.

Figure 15. Distribution of Services in Southern and Western Regions



Duplication of Services

The only service that people mentioned as being duplicated is assessment. In many cases, children have to be assessed several times to receive services from the various providers they must see in order to receive the full spectrum of services needed. One interviewee from a rural region also mentioned that some services (e.g., parenting classes) were underutilized because Hispanic parents were worried about immigration issues.

Challenges to Delivering Services

The variety and severity of the many conditions experienced by children with special needs present particular challenges for public and private health care and social service systems across the United States. Nevada faces additional challenges due to explosive population growth. According to the U.S. Census, Nevada has been the fastest growing state in the nation since 1960. From 1990 to 2000, the population increased by 66 percent (Nevada Department of Human Resources, 2001). The demand for services that has resulted from this growth has outstripped the social and medical systems' abilities to keep pace, leaving many families with unmet needs.

The distribution of the population across the state also presents challenges. Approximately 90 percent of the population lives in the urban centers of Las Vegas and Reno (see Figure 2). Consequently, there are vast rural areas that are classified as frontier areas (i.e., no more than 6 residents per square mile). Even though these areas are dotted with small towns, services are severely limited, particularly in the most remote areas of the state. It is very difficult to recruit and retain medical and education professionals who are qualified to serve children with special needs.

Specific challenges to delivering services that were identified through the interviews and surveys include the following:

- Lack of resources including funding and qualified personnel
- Medicaid reimbursements require extensive paperwork, take too long to receive, and are very low
- Parents who are not well-informed about eligibility criteria or scope of services offered (i.e., unrealistic expectations)
- Transient families
- High turnover rates in the education and medical professions
- Staff are overworked and do not always receive the support they need (e.g., equipment, funding)
- Language barriers

These challenges have similar consequences and contributory factors as those discussed in the previous section. However, underlying all these challenges is a systemic lack of funding to provide the comprehensive services needed to address all needs faced by children with special needs and their families.

Strengths of Service Delivery System

When asked about the strengths of the system, focus group participants and interviewees consistently mentioned the caring and committed professionals and advocates in Nevada who work with children with special needs. Many providers can be quoted as saying “whatever it takes” when discussing their role in addressing the needs of children with special needs and their families.

Another strength that was consistently mentioned is that the State is moving in the right direction. Many participants who had lived in Nevada for several years stated that there have been improvements in services; some also mentioned that a momentum for positive change has been building through the increased awareness around the state of children with special needs issues.

Several participants also stated that Medicaid, even with its limitations, was a strength and that they were grateful to have it because it provided better coverage than most private insurance plans. A few participants said that they thought communication among organizations had improved recently.

Regional strengths that were mentioned include:

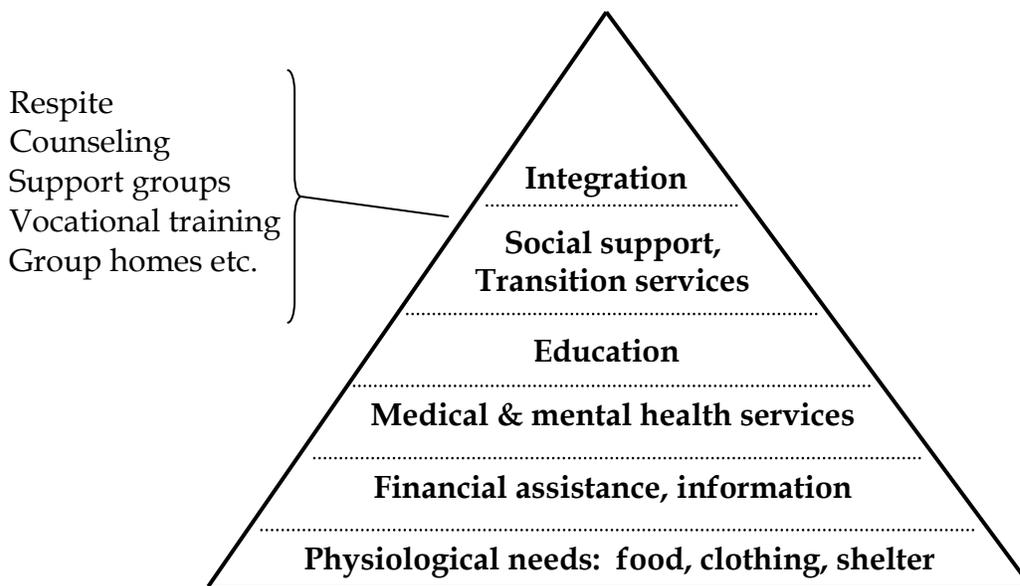
- Eastern region: Head Start program in Elko
- Southern region: Nevada PEP, Child Find, Milagro Escondidos, Desert Regional Center, Positively Kids, Reaching Our Community’s Kids (ROCK), partnerships between EIS and some schools, and some doctors
- Western: Therapists, partnership between EIS and school districts, Family Ties

DISCUSSION

The results presented above all point to the conclusion that Nevada faces serious challenges in its efforts to meet the needs of children with special needs and their families. The breadth and depth of needs and the complexity of the barriers to meeting those needs are daunting and raise the difficult question of where to begin.

One useful way to organize the information and to facilitate decision-making is to develop a needs hierarchy based on the categories of needs identified previously (i.e., financial assistance, information, medical and mental health services, education, social support, and transition). A visual depiction is presented in Figure 16. The pyramid is meant to convey the supposition that, in general, lower tiers act as a base for higher tiers and progression is in the upward direction. It is not a statement about the *relative importance of needs*. Rather, the tiers indicate that if lower-tier needs are met, it is more likely that the higher tier needs will be met as well.

Figure 16. Children with Special Needs & Their Families' Hierarchy of Needs

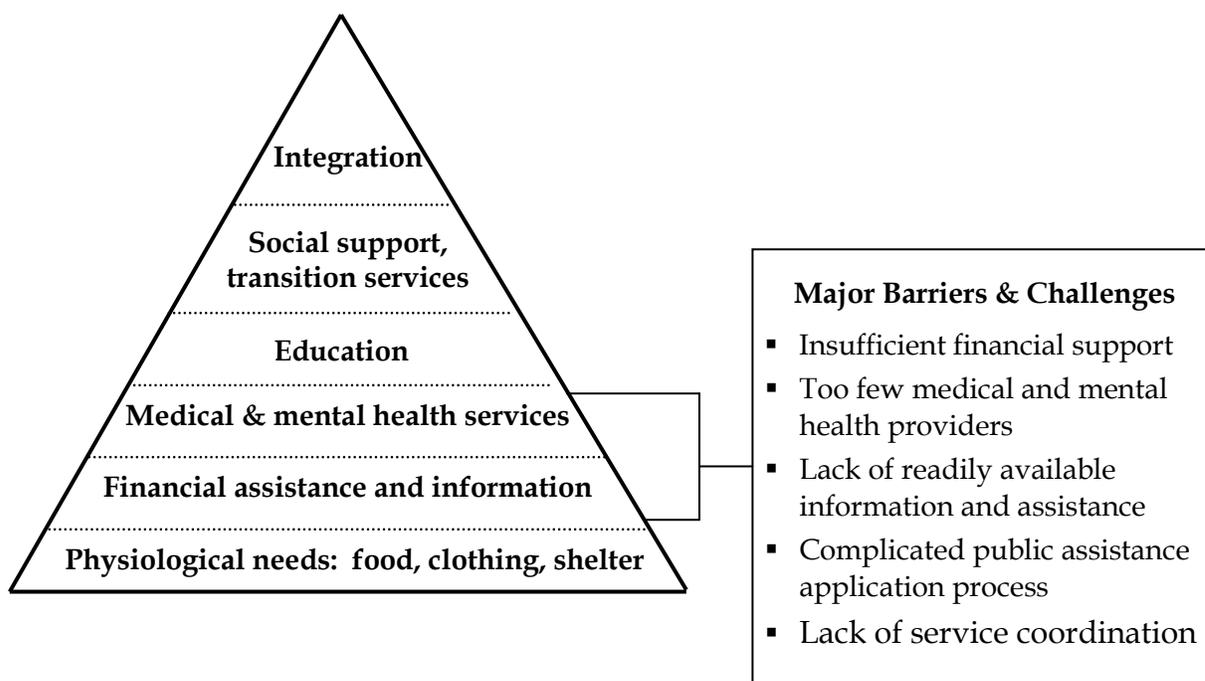


The first level of the pyramid corresponds to Maslow's Hierarchy of Needs first level because families with children with special needs who do not have these basic needs met will be unlikely to meet few, if any, of their children's special needs. Financial assistance and information were assigned to the second tier because these are both necessary conditions for families to pursue essential services such as medical and mental health care. Medical and mental health services seem to be obvious prerequisites for children with special needs and parents to participate in educational

activities. Finally, the ultimate goal for children with special needs is integration into their communities, be they school, work, or their local neighborhoods.

Most of the gaps in services and the resulting barriers and challenges discussed in the previous sections are directly related to the second and third tiers of the hierarchy (see Figure 17). This indicates that for the families that are impacted by these barriers, their path to integration is highly restricted.

Figure 17. Relationship between Hierarchy of Needs and Barriers



It is obvious from the information presented above, that much work is needed in order for the Bureau of Family Health Services to meet its ultimate goal of developing effective and enduring improvements in community that will increase accessibility to available services in the state. Some steps that will likely need to be taken include the following:

- The establishment of effective recruitment and retention efforts of medical and mental health professionals, particularly for the rural regions
- The implementation of effective and sustainable methods for educating parents about the scope and availability of resources and the public assistance application process

- The development of strong communication and collaboration networks between and among public and private agencies
- The establishment of financial safety nets for families who cannot meet obligations, particularly those at risk for bankruptcy or losing their homes
- Improved efforts to contact and support families who cannot meet their basic needs due to the parents' financial, mental/behavioral health, or medical difficulties
- The identification of additional strengths that can be built upon for program planning.

The following section provides information about how other states have addressed some of the same challenges and barriers that have been identified in Nevada.



SUMMARY OF SELECTED STATES' SERVICE DELIVERY MODELS

LeCroy & Milligan Associates, Inc. completed an assessment of selected states' service delivery models for children with special health care needs. The selection of states to be reviewed was determined by three criteria:

1. states that were ranked in the top five by the U.S. Centers for Disease Control (CDC) as having effective service models and are similar in size to Nevada,
2. western states that face similar challenges as Nevada in providing services to children with special needs and have a working model in place, and
3. states that had employed a particular strategy of interest (e.g., Kentucky's use of transition teams).

A total of 16 states were reviewed (see Table 10).

Table 10. States Reviewed for Summary

Arizona	Illinois	Michigan*	Utah
California	Iowa*	New Mexico	Washington
Florida	Kentucky	North Dakota	Wisconsin
Idaho	Maine	Oregon	Wyoming

* One of the CDC's top five states

As part of this process, the most innovative and effective planning and service model strategies from the states that were reviewed have been summarized and organized by the barriers to receiving and providing services in Nevada that were identified earlier in this report. In addition, an individual summary for each state that was reviewed is included in the remainder of this section.

Innovative Strategies to Address Challenges and Barriers

Sufficient Financial Support

Although there were no strategies identified to directly help families with their financial burdens, there were two strategies in use that help to lower costs overall.

- Children's hospitals streamline referral, authorization, and billing processes to accelerate payments and reduce administrative costs (California, Washington)
- Electronic submission of claims to the state's fiscal intermediary significantly reduces administrative costs for the providers, local agencies, and state (California)

Information Dissemination

- A 'Virtual Hospital' (i.e., a digital health sciences library) helps meet health care providers and patients' information needs (Iowa)
- A toll-free hotline allows families to communicate with providers and agencies serving CSHCN and other families (Michigan)
- A web-based data collection system documents and evaluates public health activities and interventions at the individual, household, community, and system levels (Wisconsin)
- Parent-community teams connect people, build relationships, and provide educational opportunities (Arizona)
- Parent services consultants specialize in helping families find assistance and support, develop informative guides and brochures for parents, and help community-based groups enhance support and transitional services (Wyoming)
- Substantial interagency coordination increases interagency collaboration at the local level (Arizona, Florida)
- System building alliance creates partnerships with diverse organizations and individuals to strengthen the health care system (Wisconsin)

Sufficient Number of Medical and Mental Health Providers and Services

- Telemedicine programs increase services in isolated and underserved populations (Arizona, California)
- Medical residency programs connect future providers to underserved communities (Arizona, Kentucky)
- Interstate tertiary centers in rural and isolated communities increase services (Wyoming)
- Technology-based speech instruction provides speech instruction to children who are unable to travel (North Dakota)
- Traveling clinics of multidisciplinary teams work with the children's medical homes or primary health care providers to increase services (Utah)
- Parent-community teams increase the number of providers (Arizona)
- Strong public/private partnerships increase the number of medical residents and dental students working in underserved communities (Arizona)
- A electronic claims submission system permits payment to physicians within a few days (California)

Service Coordination

- CSHCN Bureau nurses co-locate with Division of Child and Family Services caseworkers to assist them in better coordinating foster children's health care (Utah)
- The departments of Education and Mental Health promulgate interagency regulations defining respective responsibilities in delivering medical therapy services to students eligible for special education (California)
- An Internet-based case management system allows doctors to see referred patients before medical charts are received and improves referral management (Kentucky)
- Parent-community teams increase coordination among existing programs (Arizona)
- A web-based application process reduces the number of application errors (nearly 40% reduction) and the time between application and final eligibility determination (reduced 21%) (California)
- Specialized managed care network consisting of a panel of providers that can only refer to other providers in the network, creating a closed system that reduces wait times and multiple applications (Florida)

Early Childhood Transitions

- The departments of Education and Mental Health promulgate interagency regulations defining respective responsibilities in delivering medical therapy services to students eligible for special education (California)
- Transition coordinators work in collaboration with special education cooperatives, the Department of Education, and other agencies that serve special populations to facilitate three transitional phases: 1) from pediatric to adult health care, 2) from school to work, and 3) from living at home to independent living (Kentucky)
- Parent services consultants specialize in helping families find assistance and support, develop informative guides and brochures for parents, and help community-based groups enhance support and transitional services (Wyoming)

The remainder of this section contains individual summaries for each of the 16 states reviewed. For the reader's clarification, an acronym box is included for states where more than two acronyms are used.

ARIZONA

Innovative Strategies

- **Telemedicine program.**

Providers and families in isolated rural communities have increasing access to this real-time audio/visual communications technique, as more physicians are able to conduct screenings and check-ups with children via the phone. The network also provides Arizona Department of Health Services (ADHS) staff access to continuing education opportunities that otherwise

would not be available. Over the past year, Children’s Rehabilitative Services (CRS) contractors and Arizona’s Office for Children with Special Health Care Needs (OCSHCN) staff completed training from the University of Arizona telemedicine program. Additional funding from ADHS allowed the purchase of compatible equipment by each of the CRS clinics. OCSHCN staff have also provided training for representatives from each office within the College of Medicine’s Community and Family Health Department.

The telemedicine program receives \$1.2 million annually from the state legislature and private companies pay membership fees. OCSHCN conducted a pilot in which equipment was installed in the home of an isolated family with a child with special needs so that the mother could receive care training through her television. The program was deemed highly successful; however, lack of funding has precluded additional efforts in this area.

ADHS:	Arizona Department of Health Services
AHCCCS:	Arizona Health Care Cost Containment System
ALTCS:	Arizona Long-Term Care System
CRS:	Children’s Rehabilitative Services
OCSHCN:	Arizona Office for Children with Special Health Care Needs

- **Parent-community teams.** Eight parent-led community teams (representing 21 communities) exist to assist parents in developing self-advocacy skills. Parent-community teams have improved service delivery for children with special health care needs (CSHCN) in their communities by expanding providers, coordinating existing programs, and obtaining new resources. Also, they have increased citizen skills, awareness, and interaction with CSHCN and their families by connecting people, building relationships, and providing educational opportunities. In addition to parents, there are representatives from medical, education, social services, public health, and community sectors. To facilitate involvement from the community, block grant funds are used to pay parents for



consultant services, travel expenses, and childcare. Sizable grants (~ \$30K) have been provided to rural communities to improve access and care coordination.

- **Development of strong public/private partnerships.** Strong public/private partnerships result in increased efficiency in serving CSHCN. For example, medical residents and dental students participate in a program where they spend a portion of their training years working in underserved communities.

Service Model Description

Delivery

OCSHCN does not provide direct services to families. Rather, a managed care system provides direct services through four CRS sites located in Phoenix, Tucson, Flagstaff, and Yuma. In addition, there are outreach clinics located in 27 smaller communities throughout the state. CRS coordinates with the Department of Economic Security to screen patients for Medicaid eligibility. Referrals are also made to Arizona's Long-Term Care System (ALTCS). CRS is payor of last resort and will bill insurance providers for covered services.

In 2003, OCSHCN developed a three-year strategic plan. As a consequence, staff members were re-organized to facilitate cross-team approaches among administration, data, clinical services, education/training, and community development departments and offices. This new organization has led to better communication and partnering among staff. OCSHCN has also experienced significant growth during the past year and has increased its office staff to about 50. For example, OCSHCN recently added a section devoted entirely to evaluation and assessment.

Screening

Identification and screening for children with special needs occurs through the Arizona Health Care Cost Containment System (AHCCCS) (i.e., the Medicaid system) and through screenings conducted by the Department of Economic Security through community clinics. There is now a universal application process and families have access to web-based enrollment. Through the Arizona Early Identification Program, which serves children ages zero to three, community forums are held to assist families in understanding eligibility to various funding streams. OCSHCN contains less stringent eligibility requirements for families that are not eligible for other services. A hearing screening program entitled Never Too Young has increased newborn hearing screening from 5 to 98 percent over the past 7 years.

Care Coordination

Care coordinators track CSHCN throughout individual systems. However, Arizona does not provide ‘super’ care coordinators that manage all systems of care for a particular child. Furthermore, AHCCCS utilizes a ‘carve-out’ system for mental health care and substance abuse needs, which are handled by ADHS. This has resulted in some significant barriers for families because of inadequate cross-system communication, boundary confusion, and inefficiency. In contrast, the ALTCS handles all of a child’s needs within one system, and thus has posed fewer challenges for families than for those in AHCCCS. However, ALTCS eligibility is limited to children with developmental disabilities.

Medical homes represent an encouraging systems model that is being used more frequently among Arizona physicians servicing CSHCN. The Leadership Institute developed curriculum modules to educate physicians serving CSHCN through a variety of methods, including the Internet. Physician education is still perceived as inadequate, as is the number of providers with sufficient CSHCN expertise. However, with Arizona’s increased physician education efforts, it is expected that many more physicians will acquire this expertise within the next two years.

Arizona participates in the SLAITS survey that is tracking 750 families with special needs children. OCSHCN distributes a SLAITS newsletter to providers and other interested parties throughout the state.

Sources of Information

Achieving Service Integration for Children with Special Health Care Needs: An Assessment of Alternative Medicaid Managed Care Models, Volumes I & II (1999). Health Systems Research, Inc.

Allison Hughes; Rural Health Office, 520.626.7946, ext. 248

Arizona Department of Health Services website:

<http://www.azdhs.gov/phs/ocshcn>

Arizona Telemedicine Program website: <http://www.telemedicine.arizona.edu/>

Arizona Title V narrative:

https://performance.hrsa.gov/mchb/mchreports/States_Narratives/AZ.htm

Cathryn Echeverria; Chief, Office for Children with Special Health Care Needs, 602.542.1860

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CALIFORNIA

Innovative Strategies

- **Telemedicine.** California Children's Services (CCS) has partnered with the University of California Davis (UCD) and Sutter Memorial Hospital to increase the use of telemedicine in delivering pediatric specialty level services to remote areas of northern California for children enrolled in the CCS program. Currently University of California Davis pediatric cardiologists use tele-echocardiography on a 24/7 basis with the CCS approved Mercy Medical Center Neonatal Intensive Care Unit (NICU) in Redding. Additional services being evaluated as appropriate for a telemedicine approach are endocrine disorders like diabetes control.

CCS:	California Children's Services
CHDP:	Child Health and Disability Prevention
CMS:	Children's Medical Services
NICU:	Neonatal Intensive Care Unit

- **Internet applications**
 - A collaborative initiative between the California HealthCare Foundation and the State of California led to the development of Health-e-APP, a web-based Healthy Families Program application process. An evaluation of the Health-e-App pilot project in San Diego suggests that Health-e-App reduced the number of application errors by nearly 40 percent and reduced the time between application and final eligibility determination by 21 percent. Health-e-App is now available to all California enrollment entities.
 - A contract has been awarded to develop CCS provider capacity serving CCS children to manage cases through the automated Children's Medical Services (CMS) Net system, which allows them to submit claims electronically to the State's fiscal intermediary. This change will: 1) significantly reduce administrative costs for the providers, local agencies, and state 2) permit payment within a few days of submission, and 3) provide for HIPAA compliance. This will be a major step towards retention and recruitment of the providers needed to serve the CCS population.
- **Family-centered credentialing.** Specialty clinics and hospitals that treat CSHCN and wish to become CCS-approved must meet specific criteria for approval. One of the criteria used in evaluation involves family-centered care.

During the center review, the following are considered: the level of parental involvement in treatment decision making; sharing of reports with families; the degree of parent/patient involvement in advisory committees that set policies and procedures; and availability of healthy sibling and parent visiting. Following the review of the Special Care Center, the CMS Branch sends a follow-up report to the facility with family-center care recommendations. Furthermore, county CCS programs budget for maintenance and transportation expenses for children with special health care needs (CSHCN) and their families. County CCS programs also work with hospitals and community agencies that contribute to expenses for family maintenance and transportation. County CCS programs also work with Special Care Centers, hospitals, and families to cluster appointments so more than one appointment can occur on the same day or over two days, and in this way assist families with arranging time away from home and travel time that can be exhaustive.

- **Inter- and intra-agency collaboration.** Inter- and intra-agency collaboration is vital for meeting the needs of CSHCN. CMS has numerous collaborative relationships in the public and private sectors and working relationships with organizations such as local foundations, medical professional associations, coalitions and children’s advocacy groups. Some examples include:
 1. The CCS program has been collaborating with the departments of Education and Mental Health to promulgate interagency regulations defining responsibilities for delivering medical therapy services to students eligible for special education.
 2. The CMS Branch coordinates efforts with the American Association of Pediatrics to develop guidelines for local CCS programs regarding the definition of a “medical home” and authorization of pediatricians and other primary care providers to provide these services for CSHCN.
 3. The CMS branch collaborates with the California Children’s Hospital on numerous issues, including standards for managed care compliance, the Newborn Hearing Screening Program, trainings on compensation, a “Best Practices Seminar”, and technical assistance and consultation on many areas of concern. Because Children’s Hospitals are experiencing budget shortfalls, CMS is working with them to increase revenues by streamlining CCS referral, authorization, and billing processes (thereby reducing costs) and accelerating payment.



Service Model Description

Delivery

The designated Title V CSHCN program is CCS. Their services are ‘carved out’ in Medi-Cal and the state Children’s Health Insurance Plan, Healthy Families. Thirty-one county health departments fully administer their own CCS program and are designated as independent counties. The remaining 27 dependent counties share the administrative and case management activities with CMS branch regional offices located in northern and southern California.

CCS provides access to quality specialty and subspecialty providers for CSHCN. Special care centers, which are located in the outpatient departments of tertiary care hospitals, address health needs and provide coordinated care using multidisciplinary teams to CCS beneficiaries. CCS manages Medi-Cal beneficiaries and authorizes Medi-Cal reimbursement for medical and dental services, including EPSDT (Early and Periodic Screening, Diagnosis, and Treatment) supplemental services.

Although most services are offered through the CMS branch, the private sector is the principal provider of California’s health services, including services for low-income populations. Programs such as the Child Health and Disability Prevention (CHDP), Comprehensive Perinatal Services, and Family Planning Access Care and Treatment offer services through a broad network of providers in private practice, community health centers, and other private non-profit clinics.

The CCS Medical Therapy Program provides physical and occupational therapy services to children with CCS-eligible conditions. There is no financial eligibility requirement. Over 22 new medical therapy units or therapy satellites are currently undergoing remodeling, in the process of construction, or in the design phase throughout southern California. The facility expansion is necessary to accommodate the overcrowding at existing medical therapy units and to extend outpatient services to communities with new school construction.

Screening

The CMS branch administers the Child Health and Disability Prevention program (CHDP), which is the screening and preventive component of EPSDT. CHDP provides health assessments for children from families having incomes less than 200 percent of the federal poverty level. CHDP also assures preventive services such as health assessments, immunizations, screening tests, dental screening, and referral for further diagnosis and treatment for Medi-Cal funded children up to 21 years of age. There is also a state-funded component that extends these same services to children up to 19 years of age. The CHDP gateway offers electronic eligibility screening,

enrollment of children receiving CHDP assessments into two months of no-cost full-scope Medi-Cal benefits, and an “extended enrollment” process into continuing Medi-Cal/Healthy Families coverage if a formal application is submitted within the two month initial period. Families can obtain medical or dental care immediately following the Gateway enrollment.

The CMS Branch has two programs that address the needs of high-risk infants. The first allows infants that are discharged from CCS-approved neonatal intensive care units (NICUs) to be followed in NICU high-risk infant follow-up clinics. Three multidisciplinary outpatient visits are authorized by CCS during the first three years of life to identify problems, institute referrals, and monitor outcomes. Visits include a comprehensive history and physical examination, developmental testing, and ophthalmologic, audiologic, and family psychosocial evaluations. The second program, the Medically Vulnerable Infant Program, has used a network of community-based contractors to provide home-based services to high-risk infants from NICUs and their families. Services have been provided to infants up to three years of age. Infants are eligible for the Medically Vulnerable Infant Program if they have required medical care in a CCS-approved NICU, are at risk of developing a CCS-eligible condition, and were premature or had a defined, serious neonatal health problem.

Transition Services

The CMS Branch is adding standards for initiating transition services at 14 years at the outpatient specialty care centers. Instruction letters are sent to county CCS programs on the subjects of family-centered care and transitional issues. During site reviews of new specialty care centers and county CCS programs, transition issues are emphasized for the future delivery of medical care and services to the CSHCN. During both types of reviews, staff is made aware of the availability of transitioning resources such as the California Department of Rehabilitation and the Centers of Independent Living to assist youth in transitioning to independence.

Sources of Information

California’s Title V Narrative:

https://performance.hrsa.gov/mchb/mchreports/States_Narratives/CA.htm

Children’s Medical Services Home Page: <http://www.dhs.ca.gov/pcfh/cms/>

Dr. Marian Dalsey; Chief, Children’s Medical Services, 916.327.3076

FLORIDA

Innovative Strategies

- **Specialized managed care network for CSHCN.** The providers that comprise the Children’s Medical Services (CMS) network panel include primary and specialty care providers, all of whom have met credentialing criteria to demonstrate expertise in the care of children with special health care needs (CSHCN). These providers can only refer to other providers in the network, creating a *closed system* that is monitored by the state. To reduce multiple referrals, CMS encourages primary care providers to provide time-limited blanket authorizations to facilitate service delivery.
- **Substantial interagency coordination.** Florida’s CMS enjoys uniquely strong partnerships with many agencies. Most importantly, Title V/CMS and Medicaid agencies are closely linked, resulting in a maximization of resources. Also, CMS is the lead agency for Part C, which serves children 0-3 who have a genetic or metabolic disorder, neurological abnormalities, severe attachment disorder, significant sensory impairment, or developmental delays. The two agencies have agreements to recognize evaluations and programs throughout the state and to designate case managers to serve as liaisons. Strong interagency collaboration at the state level has led to greater interagency collaboration at the local level.

Service Model Description

Delivery

CMS manages a care network specifically designed for CSHCN that provides a family-centered, comprehensive, and coordinated statewide managed system that links community-based health care with multidisciplinary, regional, and tertiary pediatric care. This statewide, integrated system of care includes services ranging from prevention and early intervention programs to primary and specialty care programs including long-term care for medically complex, fragile children. The benefit package mirrors Florida’s Medicaid range of services plus additional supporting services such as respite services, parenting support services, early intervention, genetic testing, and genetic and nutritional counseling.

Patients receive medical and support services through 22 CMS area clinics or practices and hospitals and other regional and statewide specialty programs. CMS, in coordination with Medicaid, has established 16 children’s multidisciplinary assessment teams to staff the needs of children and families who require long-term

care services such as medical day care or foster care, nursing home care, and in-home, wrap-around services. All CMS services are provided through a panel of CMS consultant physicians who meet specific credentialing requirements to ensure quality pediatric care.

Screening

CMS identifies children for their network through tertiary care centers with neonatal intensive care units. Referrals are also received from physicians, parents, and other programs serving CSHCN. Before 1998, families entering the system through Medicaid had difficulty accessing the CMS network because enrollment staff did not routinely assess children's special health care needs. Consequently, many CSHCN were assigned to mainstream HMOs that offered inadequate services. However, the state revised the enrollment script to inquire about special needs, and to inform eligible families about the CMS network.

CMS PCPs are expected to provide preventive and primary care services to CSHCN families in accordance with the rules of Medicaid's Child Health Check-Up program, and CMS case managers ensure that families receive routine well-child care. However, there is a dearth of pediatricians due to low reimbursement rates from Medicaid. The state is attempting to counteract this shortage by requiring each local CMS office to develop a plan for recruiting, credentialing, and enrolling PCPs with expertise in serving CSHCN. Recruitment has been successful because of the case management support that is provided through CMS. Credentialing entails two criteria for physicians: 1) board certified in pediatrics or family medicine; and 2) have hospital privileges at a designated CMS facility or have an arrangement with another physician who does.

Care Coordination

A central component of the CMS enrollment process is assignment to a case manager. Several strategies are used for assignment including level of need, condition type, and geographic proximity. All CMS offices have a case manager that coordinates care for children who are dually eligible for CMS and Part C. Case managers also play an active role in advocating to the Medicaid agency for services. Moreover, because of CMS's link with the public agency that serves as the Title V grantee, CMS can draw on general revenue or Title V funds to pay for additional care when Medicaid does not cover services. These case management services are supplemented by peer supports from parents who have participating children and who are paid by the CMS program.

For statewide tracking, the University of Florida's Institute for Child Health Policy (<http://www.ichp.ufl.edu/>) evaluates the KidsFirst program, which serves CSHCN

through CMS and other programs. In addition, the Institute publishes a series of policy briefs focusing on financing and reimbursement strategies for CSHCN.

Supportive Legislation

The Florida Legislature has been active in facilitating service access and coordination to CSHCN. In 1996, they passed legislation making the CMS network available as a recognized managed care choice for Medicaid recipients who are required to choose a managed care option [i.e. Medicaid HMO or MediPass (managed fee-for-service)].

In 1998, the Florida Legislature extended CMS network benefits to CSHCN who are enrolled in Florida's KidCare program, which covers uninsured children through the Children's Health Insurance Program (Title XXI). This program is capitated and operates within enrollment limits established by the Legislature. In addition, it includes a joint partnership with Children's Mental Health to provide coordinated physical and behavioral health care for school-age children with mood, psychiatric, or anxiety disorders; severe emotional disturbance; or substance dependence or abuse.

Sources of Information

Achieving Service Integration for Children with Special Health Care Needs: An Assessment of Alternative Medicaid Managed Care Models, Volumes I & II (1999). Health Systems Research, Inc.

Florida Title V narrative:

https://performance.hrsa.gov/mchb/mchreports/States_Narratives/FL.htm

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IDAHO

Innovative Strategies

- **Specialty health clinics:** Until late 2004, the Children's Special Health Program (CSHP) contracted with physician providers to organize and staff an average of 200 annual clinics across the state, covering 8 diagnostic categories. However, CSHP will only continue to sponsor PKU and Cystic Fibrosis clinics due to funding cutbacks.
- **Community/ migrant clinic centers.** There are 24 community/ migrant clinics in Idaho (21 are in southern Idaho) to serve isolated communities.
- **Community collaboration.** CSHP staff collaborates with major advocacy organizations, including Co-Ad, the State Independent Living Council, the Consortium of Idahoans with Disabilities (an umbrella group composed of a variety of programs), and agencies and organizations located throughout Idaho that are focused on disability issues.

Service Model Description

Delivery

CSHP, which is housed within the Bureau of Clinical and Preventive Services, provides consultation, information, technical assistance, and referral services to families of children who have chronic illnesses and disabilities. CSHP works with families, providers, and communities to: 1) help establish and maintain a system of information, referral, and follow-up services, 2) promote parent-to-parent support networks to ensure that all families have access to support services and health benefits counseling, and 3) build systems of care in collaboration with other child/ family efforts to link community-based health, social services and education agencies.

Core functions of public health (assessment, policy development, and assurance) are provided to the entire state through the collaboration of the state and seven district health departments. The directors of the public health departments meet monthly with the Division of Health Administration.

Screening

Children with qualifying medical conditions are most often referred to CSHP by neonatal intensive care units and pediatricians. Referrals may also come from the 35

certified rural health clinics and 5 registered free medical clinics across the state. As of October 2004, the family must also be determined to have “no creditable insurance” to qualify for enrollment in CSHP. After an insurance determination has been made, the family is contacted by a CSHP care coordinator to explain program enrollment or to be referred to other providers or programs.

Sources of Information

Brett Harrell; Manager, Children's Special Health Program, 208.334.5962

Idaho Department of Health and Welfare website:

<http://www.healthandwelfare.idaho.gov/>

Idaho Title V Narrative:

https://performance.hrsa.gov/mchb/mchreports/States_Narratives/ID.htm



ILLINOIS

Innovative Strategies

- **Multi-agency collaboration at state and regional Levels.** The University of Illinois at Chicago's Division of Specialized Care for Children (DSCC) staff participate on state level interagency boards, councils, and task forces, while regional office staff participate in numerous community working groups that involve local leaders and parent groups. This interagency collaboration leads to enhanced planning for services.

Service Model Description

Delivery

DSCC manages the programs for children with special health care needs (CSHCN). DSCC's goal is to ensure community-based, family-centered, culturally sensitive, and comprehensive care coordination services for all CSHCN and their families. They collaborate with the Illinois Chapter of the American Academy of Pediatrics, Illinois Academy of Family Physicians, Shriner's Hospitals for Children, and Illinois Department of Public Aid to identify and train PCPs to serve as the medical home providers for CSHCN.

Children receive diagnostic and care coordination services without regard to a financial means test. Families of those children requiring financial support for treatment services must demonstrate a total income below 285 percent of the federal poverty level, adjusted for family size. All families must utilize existing health insurance benefits before financial assistance can be provided. Children with severe, long-term disabilities receive continued DSCC assistance in programming and coordinating care regardless of family income.

The DSCC Core Program provides comprehensive evaluation, medical care, habilitative services, and financial support to those families who meet the financial eligibility requirements and who fall within the following impairment categories: orthopedic, nervous system, cardiovascular, craniofacial deformities, hearing, organic speech, cystic fibrosis, hemophilia, inborn errors of metabolism, eye and urinary system. DSCC also operates the Title XIX waiver program to provide home and community-based services for children that require complex medical treatments or who are at risk of prolonged institutionalization.

The Title V program works closely with the state's early intervention program, which provides coordinated, comprehensive, multi-disciplinary services to children from 0-

3 who have developmental disabilities and delays. Services also include case coordination, developmental therapy (special instruction), physical therapy, occupational therapy, speech therapy, assistive technology, nursing services, nutrition services, vision services, audiologic services and medical diagnostic services for purposes of eligibility determination.

Screening

Identification and screening for CSHCN occurs primarily through the 13 field offices and 40 satellite locations operated by DSCC, and through private physicians and other clinics. The clinic system allows medical specialists and professional staff to provide early evaluation of children with medical conditions potentially eligible for DSCC services.

An individual service plan is developed for each child following the initial evaluation process to summarize the care coordination services needed and the financial support required for treatment. The individual service plan reflects the perceived needs and priorities of the child and family, the medical needs as articulated by the managing physician, and the plan by which the needs will be addressed. In order to coordinate efforts to meet the total needs of the children, DSCC professional staff housed in the 13 regional offices work closely with other community, public, and private entities.

Care Coordination

DSCC care coordinators help to develop care coordination plans for children enrolled in programs. These plans help to promote better care through improved communication among the health care professionals by keeping everyone informed about what each partner is doing.

Sources of Information

Dr. Charles N. Onufer; Director, Division of Specialized Care for Children,
217.793.2340

Illinois Title V Narrative:

https://performance.hrsa.gov/mchb/mchreports/States_Narratives/IL.htm

IOWA

Innovative Strategies

- **Virtual Hospital.** The Virtual Hospital is a digital health sciences library created in 1992 at the University of Iowa to help meet the information needs of health care providers and patients. It contains hundreds of books and brochures for health care providers and patients.

CSHC:	Child Health Specialty Clinics
IDPH:	Iowa Department of Public Health
IEPC:	Integrated Evaluation and Planning Clinics
PCN:	Parent Consultation Network

- **Family-centered services.** Child health specialty clinics (CSHC) offer family-centered services through the CHSC Parent Consultant Network (PCN), which consist of 16 individuals serving 14 regional centers. The family participation coordinator initiated monthly PCN meetings designed to boost networking and to increase parent participation in CHSC decision-making.
- **Grassroots outreach.** An effective collaboration between the Department of Public Health and the Department of Human Services has resulted in grassroots outreach and enrollment for hawk-i (Iowa's Children's Health Insurance Program). Outreach efforts coordinated through IDPH and the local child health agencies have been very successful. Initial outreach efforts focused on four areas: schools, faith-based, medical Providers, and underserved populations. These efforts have expanded to areas of businesses, workforce, tax preparation sites, and many other areas.

Service Model Description

Delivery

The Iowa Department of Public Health (IDPH) administers Title V and maternal and child health programs. The Bureau of Family Health, housed within IDPH, provides resources for health care services through public and private collaborative efforts. The University of Iowa, Department of Pediatrics, under contract with IDPH, coordinates Iowa's program for children with special health care needs (CSHCN). Within the University of Iowa, child health specialty clinics (CHSC) have responsibility for delivering services.



The CHSC help families to evaluate their children's needs and obtain services. CHSC also assists with care coordination for CSHCN who are eligible for the Medicaid home and community-based services waiver. CHSC offers care coordination services to children applying for benefits under the SSI program.

The CHSC manage several funding opportunities under the Iowa Medical Home Initiative that strive to ensure that all Iowa CSHCN are enrolled in a medical home. The Iowa Part C Program (Early ACCESS) also supports the IMHI through a contract with CHSC under the Early ACCESS Comprehensive System of Personnel Development Program.

Screening

Identification and screening for CSHCN occurs primarily through 14 regional special outreach service clinics and through integrated evaluation and planning clinics (IEPC) located throughout the state. Once eligibility is determined, the regional clinics provide community-based, coordinated specialty services such as cardiac; orthopedic; ear, nose and throat; cystic fibrosis; muscle disorder; cleft lip and palate; diabetes-endocrine; hemoglobinopathy; Down syndrome; and gastrointestinal that are otherwise unavailable in local areas or inaccessible to low-income families. Fees are based on a sliding scale. Effective in 2005, CHSC support for the regional outreach clinics will be terminated because of budget reductions. Alternative providers are being sought.

The IEPC provide multidisciplinary clinical evaluations and care planning services. Staffing varies, but usually includes a pediatric nurse practitioner, a contracted medical consultant, a psychology and/or speech and hearing professional, a social worker, and others.

Care Coordination

CHSC includes a care coordination services program, the Health and Disease Management Unit, that is designed to help families evaluate their children's needs and to obtain services. Other care coordination services include: 1) a hemoglobinopathy comprehensive care program, 2) a Prader-Willi syndrome community outreach program, 3) early and periodic screening, diagnosis and treatment (EPSDT) care coordination service, 3) a hemophilia care coordination service, and 4) a new coordination program called "Continuity of Care" that seeks to improve outcomes for CSHCN discharged from the Children's Hospital by improving linkages to community-based services.

Sources of Information

Child Health Specialty Clinics website: <http://www.medicine.uiowa.edu/chsc/>

Dr. Jeffrey G. Lobas; Director, Iowa Child Health Specialty Clinics, 866.219.9119

Iowa Department of Public Health website: <http://www.idph.state.ia.us/>

Iowa Title V Narrative:

https://performance.hrsa.gov/mchb/mchreports/States_Narratives/IA.htm



KENTUCKY

Innovative Strategies

- **Transition teams.** Transition coordinators work in collaboration with special education cooperatives, the Department of Education, and other agencies that serve special populations to centralize efforts to facilitate three transitional phases: 1) from pediatric to adult health care, 2) from school to work, and 3) from living at home to independent living.
- **Partnerships with medical schools.** After reviewing availability of doctors and specialists to serve all areas of the state, the Commission for Children with Special Health Care Needs (CSHCN) works with the state's medical schools to make recommendations for possible career paths.
- **Parent involvement.** KY SPIN (Kentucky Special Parent Involvement Network) receives training from the U.S. Department of Education to train parents to serve as resources for parents of children with special health care needs. Training is not limited to parents, and other providers will send representatives to also receive training.
- **Internet-based database.** The Computer Utility Program is an internet-based case management system that allows doctors to see referred patients even before their medical charts are received. The system also allows for referral management.

Service Model Description

Delivery

The Commission for CSHCN is housed in the Cabinet for Health and Family Services, the state government agency that promotes mental and physical health. The Commission's role is to assure a system of care for CSHCN. In 2001, the Commission was reorganized to include First Steps, the state's early intervention program (IDEA Part C), which continues to shape the program planning and system changes for the Commission.

Extensive collaboration exists between the Commission and the Adult and Child Health Department, as well as the Department for Medicaid Services. The collaboration between the Commission and Medicaid Services includes their children's health insurance plan, which extends Medicaid coverage to eligible

children, and Kentucky's managed care program, Kentucky Patient Access Care. More recently, the Commission has partnered with the Cabinet for Families and Children to identify Title V/ CSHCN program enrollees who are residing in foster care to assure services to those children. Finally, the Commission collaborates with the state's Parent Training Institute, KY SPIN, the Division of Exceptional Education, and the KY Transition Project to plan collaborative activities and review opportunities for grants to support and enhance systems development.

Screening

Identification and screening for children with special needs occurs primarily in 14 regional offices, specialty clinics, school health nurses, and primary care physicians. Financial eligibility is not needed for diagnostic tests. Once a course of treatment is set, financial eligibility is determined and a sliding fee schedule is used.

Care Coordination

During the pre-eligibility phase, referred children are assigned an intake nurse to coordinate their care. Once determined to be eligible, a care coordinator is assigned to manage the treatment plan and work with doctors and specialists throughout the treatment phases. When appropriate, transition coordinators, who serve as a liaison with the community, work with community groups to ensure smooth transition.

Representatives from the Commission for CSHCN, KY SPIN, the Interdisciplinary Human Development Institute's Early Childhood Transition Project, and the Health And Read to Work National Center attend monthly meetings to address transition issues across the lifespan for people with disabilities.

Sources of Information

Kentucky SPIN web page: <http://www.kyspin.com/>

Kentucky Title V Narrative:

https://performance.hrsa.gov/mchb/mchreports/States_Narratives/KY.htm

Theresa Glore, MS; Executive Staff Assistant, Commission for Children with Special Health Care Needs, 502.595.4459 ext. 317

MAINE

Innovative Strategies

- **Youth Advisory Council.** In 2000, Maine received a Healthy Ready to Work grant that stipulated they create a Youth Advisory Council. Children with special health care needs (CSHCN) were recruited, and the current members are between 15 and 22. The council meets six times per year with the state program manager, and the primary topics include transitioning to adult health care and obtaining employment. A maternal and child health block grant now funds the council, and youth are provided stipends, transportation, and any special needs they may require to attend the meetings.
- **Family-centered care.** Maine has consistently involved families on boards, councils, and in the planning process for improving services for CSHCN. Similar to the Youth Advisory Council, a Family Advisory Council meets monthly with the state program manager. Parents are provided stipends and transportation for their attendance.

Service Model Description

Delivery

Maine's rural nature and town meeting format of local government essentially preclude any significant county government structure or influence. The three largest cities maintain local health departments. However, there are no other health departments in Maine. Most public health functions are concentrated at the state level with minimal staffing and funding. The absence of local health departments and county government is further complicated by issues of uneven provider distribution, economic disparity, and a large rural population. Although efforts are being made to promote collaboration between the 3 health departments, there continues to be significant disconnect between them. There is a lack of health services in the state, and there are only three cities with pediatric specialists.

Screening

The state program manager stated that screening for CSHCN is inadequate due to the highly rural population. However, community outreach efforts are perceived to be working, and public health nurses deliver numerous workshops to Maine's rural communities. The state program manager also stated that families learn about services through word of mouth. One strategy that has helped increase the number of CSHCN who access services is changing the Medicaid form so that parents are

explicitly asked, “Does your child have a disability.” Although benefits have been reduced due to budget cuts, MaineCare has more flexible eligibility to serve more CSHCN.

Care Coordination

Just as there is a lack of specialty services, there is also a lack of case management. There are no regional offices so families in isolated areas generally receive case management services via the phone. Because of their reliance on the telephone, the state has considered pursuing telehealth technologies. However, the state program manager expressed ambivalence about pursuing this strategy because of the separation it fosters between families and the providers.

Sources of Information

Maine Title V narrative:

https://performance.hrsa.gov/mchb/mchreports/States_Narratives/ME.htm

Toni Wall; State Program Manager, Children with Special Health Needs,
207.287.3311

MICHIGAN

Innovative Strategies

- **Parent participation program.** Parent consultants are paid to develop community-based networks of parent-to-parent support, provide parent input about Children’s Special Health Care Services (CSHCS) program and policies, and assists families in need. The program is inclusive of all parents of children with special health care needs (CSHCN), not just those who are enrolled in CSHCS. Furthermore, parents with children with special health care needs are employed at various levels throughout the CSHCS Program:
 1. CSHCS is headed by a parent who has a child with special health care needs.
 2. The liaison between CSHCS and the Michigan Department of Educator Early-On program, which assists families with very young children (0-3) with development delays and other difficulties, is a parent of a child with special needs.
 3. The care coordination component maintains two parent positions to ensure that plans’ services are family-centered and that the plan’s policies meet the families’ need. Both of these positions are by parents of CSHCN.
- **Toll-free hotline.** The CSHCS hotline allows families to communicate with CSHCS staff, providers, other agencies serving CSHCN, and other families. The hotline is used for referral and to check on the status of CSHCS applications. Calls are analyzed quarterly to “determine areas of special concern and to identify needed policy or procedural changes.”
- **Data warehousing.** The CHSCS, along with 11 other state agencies, is contributing data to a warehousing effort operated by the Michigan Department of Community Health for the purpose of gathering comprehensive data about the department’s overlapping populations. One of the primary roles for the warehouse is to provide quarterly managed care “report cards” to primary care physicians to evaluate their performance and compare it to their peers in the same specialty.

Service Model Description

Delivery

CSHCS is operated by the Medical Services Administration, which also administers Medicaid and MICHild, the state's child health insurance program. CSHCS became part of the Bureau of Children and Family Programs under the Health Services Administration in 2002.

CSHCS supports core public health functions that are accessible through local health departments. CSHCS has incorporated family-centered, community-based, culturally competent, and coordinated practices into its program development and service delivery structure. Local health departments partner with the state in order to provide a unified system of statewide health care, shifting the responsibility of providing personal care services from the local public health entities to the qualified health plans.

The CSHCS collaborates with various state agencies including the Michigan Department of Educator Early-On program, which assists families with young children (under 3 years of age) with special needs.

Screening

Identification and screening of children with special health care needs occurs through physician/specialist referrals or a referral from a local health department (though a diagnostic visit with a specialist). The diagnostic report is sent to the state CSHCS program office for a determination of eligibility. The qualifying family will complete an application for enrollment. A financial review is conducted to determine level of cost sharing.

Care Coordination

Once enrolled in the program, the youth's treatment is managed through two case managers: the plan-based care coordinator and the local care coordinator. The plan-based care coordinators review and authorize services and respond to questions. They are the first contact with the families to identify their children's immediate needs and help them choose a local care coordinator. The local coordinators develop the individualized health care plans and provide ongoing coordination for the child and family.

Sources of Information

Achieving Service Integration for Children with Special Health Care Needs: An Assessment of Alternative Medicaid Managed Care Models, Volumes I & II (1999).
Health Systems Research, Inc.

Kathleen Stiffler; Director, Children's Special Health Care Services Plan Division,
Michigan Department of Community Health, 517.335.5008

Michigan Department of Community Health website:
<http://www.michigan.gov/mdch/>

Michigan Title V Narrative:
https://performance.hrsa.gov/mchb/mchreports/States_Narratives/MI.htm



NEW MEXICO

Innovative Strategies

- **Medical home partnership.** Several partnerships have facilitated statewide efforts to bring families into medical homes and to educate providers and families about the medical home concept. Children’s Medical Services (CMS) and its partners planned and delivered medical home training for providers. Two major statewide training events were delivered to the children with special health care needs (CSHCN) program staff and to parents of CSHCN attending the Parents Reaching Out Conference.

CMS:	Children’s Medical Services
CYSHCN:	Children and Youth with Special Health Care Needs
EPICS:	Educating Parents of Indian Children with Special Health Care Needs
SCHIP:	State Children’s Health Insurance Program

A report on a medical home survey of family practice physicians and pediatricians was included in the Epidemiology Newsletter reaching 4,000 organizations and individuals in New Mexico. Steps have been taken to include medical home training in the pediatrics and family practice residency program at the University of New Mexico School of Medicine. CMS continues to work with partners to implement the medical home project in ten sites throughout the state. CMS provides the social work component of the medical home team in clinics that are receiving training.

Service Model Description

Delivery

The Family Health Bureau of the Public Health Division, in the New Mexico Department of Health is the lead Title V agency. CMS is the specific program for CSHCN. Due to limited funding, new enrollment was curtailed in January 1999; income eligibility guidelines of 300 percent of poverty were implemented and the program operates on 50 percent of its budget. The fund now primarily serves immigrant children and children who are ineligible for Medicaid and the state’s child health insurance program.

CMS provides care coordination/EPSTD case management for CSHCN on Medicaid; it assures ongoing evaluations and referrals for periodic evaluations and EPSTD case management billing resumed to meet CSHCN’s increasing medical costs with ongoing level funded budgets.

The University of New Mexico is the main tertiary care center in the state with pediatric specialists in multidisciplinary outreach clinics coordinated and funded by CMS. Clinics include Pulmonary, Neurology, Genetics/Dysmorphology, Cleft Palate, and Endocrine. UNM and CMS are collaborating regarding medical home training for 5 pediatric clinics in New Mexico. Pediatric nephrology will be added to the Endocrine outreach clinics. Metabolic specialists conduct staff outreach.

CMS participated in a Medicaid redesign initiative: The SALUD! Under this initiative, managed care organizations reimburse CMS for specialty clinic services and up to two hours of case management. CMS requested that the existing CSHCN purchasing specifications be included in the Medicaid redesign and the state health plan. Healthier Kids Fund and CSHCN programs are supported, but no additional funding is available.

Care Coordination

The University of New Mexico's Newborn Intensive Care Unit (NICU) Developmental Care Program continues to maintain coordination of follow-up, referral tracking, and communication between NICU staff and families in need of service. Infants with a high environmental risk are referred to CMS for prevention and tracking for developmental delay. A new follow-up and tracking form was implemented in 2004, improving the average response rate by CMS 50 percent.

New Mexico participates in the SLAITS survey that is tracking 750 families with CSHCN.

Transition Services

One of the goals of the CMS program is to raise awareness of adolescent transitions with client families and local communities. The Healthy Transition New Mexico coordinating committee (HTNMCC) and CMS has sponsored two statewide "Tools for Transitions" conferences. HTNMCC has applied for additional funding to hold more regional trainings focused on transition issues. Recent efforts have also focused on infrastructure building so that information can be generated among community partners from the ground up rather than being generated by the state government agencies.

Sources of Information

Bruce Blair; State Planner; Children's Medical Services, 505.476.8868

New Mexico Department of Health website:
<http://www.health.state.nm.us/mch.html>

New Mexico Title V Narrative:

https://performance.hrsa.gov/mchb/mchreports/States_Narratives/NM.htm



NORTH DAKOTA

Innovative Strategies

- **Sponsorship of clinics for specialist services.** In 2002, the Children's Special Health Services (CSHS) supported 96 clinics addressing multiple disciplines (cleft lip and palate, scoliosis/orthopedic, cardiac care, metabolic disorders, cerebral palsy, developmental assessment, myelodysplasia, and diabetes) with two more in the works (neurorehabilitation and asthma). Representatives from each discipline are available at the clinics for screening and referral services.
- **Speech instruction for children in remote areas.** Children requiring speech instruction but who are unable to travel to speech clinics can receive technology-based speech instruction.

Service Model Description

Delivery

CSHS is a health program located within the Medical Services Division in the Department of Human Services. The purpose of CSHS is to provide services for children with special health care needs (CSHCN) and their families and promote family-centered, community-based, coordinated services and systems of health care.

CSHS partners with the Center for Persons with Disabilities to implement First Sounds – North Dakota's Early Hearing Detection and Intervention program – and is collaboratively developing a birth defects monitoring system. CSHS also works on an asthma initiative to decrease hospitalization rates for children with asthma and administers a birth defects monitoring system.

Comprehensive pediatric care is provided through the Multidisciplinary Clinic Program. The program assists families with children with chronic health care needs and whose treatment is best managed through a team approach. Multidisciplinary clinics and care coordination activities are the primary mechanisms by which comprehensive health components are successfully coordinated.

Screening

Identification and screening for children with special health care needs occurs primarily through the county social services (CSS) offices. Referrals to the program

also take place through the primary care physicians. CSS staff are responsible for determining eligibility for the CSHS program. The CSHS program supports both diagnostic and treatment services. To get diagnostic care, families complete an application for services at their county social service office, which is then reviewed by the CSHS Medical Director. There are no financial eligibility requirements for the diagnostic services; however, there are financial eligibility requirements for treatment services. The CSHS Medical Director also reviews the application for treatment services.

Care Coordination

In the eastern part of the state, there is a separate care coordination program. In the western part of the state, the CSS offices manage care coordination. Care Coordination activities vary, but may include: eligibility determination, assessment, service planning, case monitoring and coordination, referrals, information and training, etc.

Much of the state uses a multi-county health district rather than a single-county health department. North Dakota has 7 multi-county health districts, each of which contain as few as 2 and as many as 8 counties. Referrals for participation in the CSHS program can take place through the Health Departments, but screening for eligibility still requires the CSS office.

Transition Services

There are limited transition programs available at the local level, however, the CSHS is involved in a Transition Steering Committee at the state level and has plans to bring similar collaborations at the local level.

Sources of Information

North Dakota Department of Health website:

<http://www.health.state.nd.us/localhd/>

North Dakota Department of Human Services website: <http://www.state.nd.us>

North Dakota Title V Narrative:

https://performance.hrsa.gov/mchb/mchreports/States_Narratives/ND.htm

Tamara Gallup-Millner, R.N., M.P.A.; Unit Director, CSHS Unit, 701.328.2436

OREGON

Innovative Strategies

Family Involvement Network.

Historically, there has been very little family involvement in policy development, implementation, or oversight. However, with the advent of the Family Involvement Network, parents are becoming more active. There are now three parents in paid positions in the central office of the Child Development and Rehabilitation Center (CDRC).

CDRC:	Child Development and Rehabilitation Center
OHSU:	Oregon Health and Science University
OSCSHN:	Oregon Services for Children with Special Health Care Needs

Service Model Description

The Oregon Services for Children with Special Health Needs (OSCSHN) Title V Program is administered by CDRC at the Oregon Health and Science University (OHSU). The agencies work together under an interagency agreement to achieve the goals set forth by the Title V legislation. CDRC serves as an education and research center for health professionals; provides interdisciplinary clinical services for persons with developmental disabilities and other special health care needs; and supports the philosophy of partnership with families, health care providers, and the community. CDRC also administers two community-based programs for children with special health care needs (CSHCN). The first, the CaCoon (CAre COOrdinatiON) is a statewide program that provides public health nursing services in communities. The second, Community Connections Network, coordinates community clinics in 14 sites that are staffed with a multidisciplinary team, including a physician (pediatrician or family practice), care coordinator, mental health specialist, and a special education representative.

Workforce Education

CDRC continues to expand the scope and service of its outreach program and to improve collaboration with other units and programs at OHSU and in the community. The OHSU School of Nursing and the Area Health Education Center participated with CDRC community-based programs in providing continuing education for community providers. CaCoon staff joined three other OHSU programs and applied for a Ford Family Foundation grant to develop an OHSU Rural Health Initiative. The Oregon Department of Education, the Oregon Pediatric Society, Family Voices, the Oregon Office of Family Health, and other community

agencies provided joint conferences during the year. Staff are actively developing the capacity to conduct distance learning and telemedicine consultation for improved outreach and service to rural areas throughout Oregon.

CDRC continues to provide ongoing training for professionals who work with CSHCN and their families. A series of self-directed learning modules for nurses who coordinate care for children with special health needs are being developed through grants from four foundations. Each module focuses on a specific disability and the series is designed to improve continuing education opportunities and better prepare Public Health Nurses to provide care coordination services.

Sources of Information

Achieving Service Integration for Children with Special Health Care Needs: An Assessment of Alternative Medicaid Managed Care Models, Volumes I & II (1999).
Health Systems Research, Inc.

Dr. Robert Nickel, Director, Child Development and Rehabilitation Center,
503.494.6961

Oregon Title V Narrative:

https://performance.hrsa.gov/mchb/mchreports/States_Narratives/OR.htm

UTAH

Innovative Strategies

- **Traveling clinics.** Specialty services are delivered through multidisciplinary teams that travel to 9 sites across the state. These clinics work in collaboration with the child's Medical Home or Primary Health Care Provider. Provided in collaboration with the University of Utah Department of Pediatrics.
- **Collaborative efforts at state, community, and private levels.** The Utah Children with Special Health Care Needs Bureau (CSHCNB) 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. CSHCNB staff serve on several working and advisory committees.
- **Services for CSHCN in foster care.** CSHCNB staff participates on the Health Care Advisory Council for the Division of Child and Family Services, Utah's child welfare agency, which advises the Division's Board on health issues for children in their system. Through the Fostering Healthy Children Program (FHCP), CSHCN Bureau nurses co-locate with Division of Child and Family Services 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.

Service Model Description

CSHCNB is housed within the Utah Department of Health, Division of Community and Family Health Services. CSHCNB provides direct care, newborn screening, and case management. The CSHCN Bureau maintains 7 types of clinics that provide a range of services. They are: ABLE (school-age youth); Baby Watch (youth aged 0-3); Child Development Clinic (youth aged 0-5 years); Hearing, Speech, and Vision service (youth under age 18); Neonatal Follow up (birth to 2½ years); specialty clinics (all ages), and traveling clinics (all ages). Specialty clinics provide services for the following diagnoses: Cleft Lip and Palate, Genetics Neurology, Occupational & Physical Therapy Evaluations, Orthopedic/Therapy Clinics, and Spina Bifida.

CSHCNB provides enabling services that allow or provide for access to, and the derivation of, benefits from the array of basic health care services and includes: transportation, translation services, outreach, respite care, health education, family support services, purchase of health insurance, case management, coordination of Medicaid, WIC and education.

Screening

Children with qualifying medical conditions are most often referred to the CSHCN Program through local health departments, community health centers, specialty clinics and local community health nurses. There are 12 local health departments, 10 specialty clinics and 9 traveling clinics provided across the state.

Children are eligible for diagnostic services if they have (or may have) a physical or developmental disability, special medical needs, or an associated behavioral problem. The CSHCN Bureau works closely with the child's Medical Home (primary health care provider) and provides only specialty care, not primary, acute or emergency care. Information and referral services are available to all families at no charge.

Care Coordination

The move to managed care has made tracking of services for maternal and child health populations very difficult, if not impossible. For example, tracking prenatal, family planning, EPSDT services, or immunizations is almost impossible because of the shift in data ownership from Medicaid to the Managed Care Organizations. Medicaid is working with the managed care organizations to improve access to needed data to track outcomes, costs, services provided, etc.

Transition Services

The Systems Development Program houses CSHCN transition efforts. In addition to establishing the full time SSI Specialist/Program Manager, 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 above), and training and consultation to CSHCN Bureau staff, other agencies and health professionals. This specialist also assists individuals and their families in developing and implementing individual transition plans.

Sources of Information

Dr. Vera Frances Tait; Director Children with Special Health Care Needs,
800.829.8200

Utah Children With Special Health Care Needs website:
<http://health.utah.gov/cshcn/>

Utah Title V Narrative:
https://performance.hrsa.gov/mchb/mchreports/States_Narratives/UT.htm

WASHINGTON

Innovative Strategies

- **Interagency partnerships.** The manager of the Office for Children with Special Health Care Needs (OCSHCN) noted that establishing personal connections with other agencies is critical to building and maintaining partnerships. OCSHCN has partnerships with local health jurisdictions (LHJ), private and non-private agencies, the University of Washington Children’s Hospital and Regional Medical Center in Seattle, other tertiary care centers, and family organizations. These contracts and partnerships significantly extend the capacity of programs for children with special health care needs (CSHCN) in policy development, assessment, quality assurance, and provider education.
- **Parent support networks.** Parents who attend support network meetings are provided stipends for transportation and childcare. In addition, OCSHCN has hired a full-time parent position to promote parental leadership.
- **Promotion of cultural competence.** The Office of Maternal and Child Health (OMCH) plans to train LHJ providers on how to interview families of CSHCN in a culturally competent manner. This training will assist in program development by improving the quality of data collected from families by local CSHCN providers.

LHJ:	Local Health Jurisdictions
OCSHCN:	Office for Children with Special Health Care Needs
OMCH:	Office of Maternal and Child Health

Service Model Description

According to the OCSHCN manager, Washington provides great benefits to CSHCN. Washington’s Title V agency, OMCH, has intentionally moved toward a “core functions” model of public health during the past several years. This involved increasing infrastructure building services and decreasing direct services. The cornerstone of infrastructure building services is collaboration with other partners to achieve shared goals for MCH populations. Meanwhile, the OCSHCN promotes integrated systems of care that assure the population of children with special health care needs and their families the opportunity to achieve the healthiest life possible and to develop to their fullest potential. CSHCN staff provide leadership in addressing health system issues that impact this population; work with families and other leaders to influence priority setting, planning and policy development; and



support community efforts in assessing the health and well-being of children with special health care needs and their families.

In addition to the OCSHCN, there are 35 LHJ with care coordinators who provide case management services to CSHCN aged 0-18. OMCH program staff work closely with LHJ to oversee contract activities and provide consultation and technical assistance. OMCH administrators and staff meet regularly with the Nursing Directors of LHJ, and with other local OMCH staff through quarterly MCH Regional Meetings. The Department of Health maintains close relationships with the Department of Social and Health Services programs to best serve the overlapping population. The agencies collaborate to: maximize federal administrative match, build on the strengths of each department to promote the best outcomes for clients, generate and utilize data needed by both agencies, provide coordinated program services for clients, and provide complementary services and avoid duplication.

An interagency agreement between Medical Assistance Administration and OMCH has existed for 12 years and developed with the mutual goal of assuring quality health services for pregnant women, infants, children, and adolescents served by Medicaid. OMCH staff participate on the Medicaid External Quality Review Organization Contract committee, the MAA EPSDT Improvement Committee, and the MAA Immunization Partnership Committee.

Sources of Information

Maria Nardella; Manager, Office for Children with Special Health Care Needs,
360.236.3573

The Center for Children with Special Needs Website: <http://www.cshcn.org/>

Washington Title V Narrative:

https://performance.hrsa.gov/mchb/mchreports/States_Narratives/WA.htm

WISCONSIN

Innovative Strategies

- **Web-based data collection.** During 2003, a state-of-the-art web-based application called Secure Public Health Electronic Record Environment (SPHERE) was implemented. SPHERE is used for collecting data on children with special health care needs (CSHCN) and other important health areas. SPHERE is a comprehensive public health tool to document and evaluate public health activities and interventions at the individual, household, community, and system levels. In addition, SPHERE has been connected to the birth registry.

Access to SPHERE is limited to public health authorities and their authorized agents who have signed a Confidentiality and Security Agreement. Demographic (i.e., non-health) information is shared in a statewide registry database. All health information is maintained in a secure local organization database.

- **System building alliance.** The Children's Health Alliance of Wisconsin, housed at Children's Hospital of Wisconsin in Milwaukee, aims to build partnerships with diverse organizations and individuals to strengthen the health care system.

Service Model Description

Delivery

Wisconsin's designated Title V MCH/CSHCN Program is the Department of Public Health Bureau of Family and Community Health, Family Health Section. BadgerCare, Wisconsin's Title XXI, Children's Health Insurance Program, enrolls families with dependent children who lack insurance and whose incomes do not exceed 185 percent of federal poverty guidelines. The state negotiated a waiver with the Centers for Medicare and Medicaid Services for its program design.

In January 2001, the Title V MCH/CSHCN Program awarded contracts totaling \$1,370,000 to continue funding the five regional CSHCN centers. The regional CSHCN Centers have contracts to provide service coordination to 93 percent of the counties, with the ultimate goal being to subcontract with every county statewide. The centers' service goals are to: 1) provide a system of information, referral, and follow-up services, 2) promote a parent-to-parent support network, 3) increase the capacity of the local public health departments, 4) work to establish a network of

community providers of local service coordination, and 5) initiate formal working relationships with local public health departments and establish linkages for improving access to local service coordination.

The regional CSHCN centers provide outreach, information and referral, training, and parent support opportunities. They also provide materials, posters, and other information to make families aware of available services and supports. Each center has developed a website to facilitate the dissemination of information.

Sources of Information

Children's Health Alliance of Wisconsin: <http://www.chawisconsin.org/>

Title V Narrative:

https://performance.hrsa.gov/mchb/mchreports/States_Narratives/WI.htm



WYOMING

Innovative Strategies

- **Interstate tertiary centers.** Because Wyoming has few pediatric specialists, tertiary centers have been established at hospitals in Colorado, Utah, Montana, and South Dakota.
- **Parent services consultant.** A parent services consultant specializes in helping families find assistance and support, develops informative guides and brochures for parents, and helps community-based groups to enhance support and transitional services.
- **Database for tracking maternal outcomes.** The Maternal Outcomes Monitoring System provides a database for use by Maternal and Child Health Bureau (MCHB) to connect interventions to outcomes and to decrease duplication of information required from families when applying for additional programs.
- **Community health planning boards:** In collaboration with the state and local agencies, MCHB established Community Health Planning Boards to serve as central health planners for local health issues.

Service Model Description

Delivery

Public health nurses provide services ranging from family planning to specialty clinics for children with special health care needs (CSHCN). Because of their unique role, the public health nurses received funding from the MCHB Community Capacity Grants to assist communities in the development, delivery, and quality evaluation of maternal and child health services. Families must meet eligibility requirements as established by the Title V Children's Special Health Program. Funds for translation services are available.

Screening

Identification and screening for CSHCN occurs primarily through the local public health nurses, who are the first contact for families in need of maternal and child health services, making appropriate referrals according to families' needs.

The tertiary centers established at hospitals in Colorado, Utah, Montana, and South Dakota also make referrals of CSHCN into the CSH program. The MCHB maintains a strong relationship with these centers by making periodic visits to promote referrals of Wyoming families.

Further, referrals can be received from one of the three specialty clinics/programs in operation in the state: the Cleft Palate Clinic (held once a year in two locations), Pediatric Specialty Outreach Clinics (staffed by pediatric sub specialists from Tertiary Care Centers), and the Deaf/Blind Clinic (held twice a year in one location).

Sources of Information

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Wyoming Title V Narrative:

https://performance.hrsa.gov/mchb/mchreports/States_Narratives/WY.htm



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- U.S. Census Report on *Children's Living Arrangements and Characteristics, March 2002*, as accessed on 11/24 at: <http://www.census.gov/prod/2003pubs/p20-547.pdf>

U.S. Census Report on *General Population Characteristics, 1990 – Nevada Report*, as accessed on 11/24 at: <http://www.census.gov/prod/cen1990/cp1/cp-1-30.pdf>

- Table 3. Race and Hispanic Origin - Nevada: 1990.
- Table 5. Race and Hispanic Origin - County: 1990.

U.S. Census Report on *Income, Poverty, and Health Insurance Coverage in the United States: 2003*

- Table 7. Money Income of Households by State Using 2- and 3-Year Average Medians: 2002-2003.
- Table 9. Percentage of People Without Health Insurance Coverage by State Using 2- and 3-Year Averages: 2001-2003.

U.S. Census Quick Facts:

- People – Nevada, <http://quickfacts.gov>, as accessed on 11/22/04.
- People – USA, <http://quickfacts.gov>, as accessed on 11/24/04.
- Census 2000 Housing Unit: County – Nevada, <http://quickfacts.gov>, as accessed on 11/22/04.

U.S. Census tables:

- Table DP-1. Profile of General Demographic Characteristics: 2000 – United States.
- Table DP-1. Profile of General Demographic Characteristics: 2000 – Nevada.
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- Low Income Uninsured Children by State: 2001, 2002, 2003, as accessed on 11/22/04.

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APPENDIX A: REAL CHOICES SYSTEMS CHANGE GRANT INFORMATION





APPENDIX B: STATE OF NEVADA GOVERNMENT ORGANIZATION CHART





APPENDIX C: DEMOGRAPHIC INFORMATION ABOUT NEVADA'S GENERAL POPULATION





APPENDIX D: FOCUS GROUP MATERIALS

Focus Group Locations and Attendance	D-1
Parent Protocol and Questions	D-2
Advocate/Provider Protocol and Questions	D-5
Summary of Parent Focus Groups	D-8
Summary of Advocate/Community Service Organizations Focus Groups	D-16





APPENDIX E: PHYSICIAN SURVEY MATERIALS

Physician Survey Cover Letter	E-1
Physician Survey	E-3
Physician Survey Results	E-5
Summary of Written Comments From Physician Survey	E-7





APPENDIX F: KEY STAKEHOLDER INTERVIEW MATERIALS

Nevada CSHCN Needs Assessment Key Information Interview Protocol	F-1
Nevada CSHCN Needs Assessment Key Information Interview Questions	F-2
Nevada CSHCN Needs Assessment Key Stakeholders Juvenile Justice/CPS Interview Questions	F-3
Summary of Key Stake Holder Interviews	F-4





APPENDIX G: SECONDARY DATA SOURCES





APPENDIX H: RESOURCE INVENTORY SUMMARIES

Advocate/Community Service Organizations	H-1
Government Agencies	H-3
Medical Providers	H-10
Mental Health Providers	H-13



