

NEVADA NEEDS ASSESSMENT FOR CHILDREN WITH SPECIAL NEEDS

EXECUTIVE SUMMARY

LeCroy & Milligan Associates, Inc. conducted a needs assessment about children with special needs for the Nevada Bureau of Family Health Services. The multi-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 prioritization of needs and the design and implementation of 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.

First, prevalence, distribution, and demographic information about these children and their families was collected and reported. According to the U.S. Centers for Disease Control's National Survey of Children with Special Health Care Needs (National Survey) 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 use of 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.

Second, 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),

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

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)



- 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

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.

Third, 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).

Fourth, the inventories and the information collected from the needs assessment's 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.

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