



*What Does the National Survey of Children with Special Health Care Needs Tell Us About Arizona?*

September 2004



# National Survey of Children with Special Health Care Needs

The National Survey for children with special health care needs (CSHCN), conducted as a module of the State and Local Area Integrated Telephone Survey (SLAITS), is a broad-based, ongoing surveillance system available at the state and local levels for tracking and monitoring the health and well-being of children and adults.

The SLAITS is sponsored by the Centers for Disease Control and Prevention (CDC) and the National Center for Health Statistics (NCHS); and is funded by the Maternal and Child Health Bureau (MCHB) of the Health Resources and Services Administration.

The National Survey for CSHCN, which was designed to produce national and state-specific prevalence estimates of CSHCN, describes the types of services they need and use; assesses aspects of the systems of care; and provides health care coverage estimates.

SLAITS was conducted from October 2000 to April 2001 as part of the National Immunization Program's large-scale random digital-dial telephone survey.

The MCHB has developed six core outcomes (see sidebar) as part of the national action plan to achieve community-based service systems for CSHCN and their families. Four of the six core outcomes are presented here. (Core outcome #4 has not been measured by SLAITS and core outcome #6 is not presented here, as it does not meet the NCHS standard for reliability and precision).

## Core Outcomes for CSHCN

1. Families of CSHCN will partner in decision-making and will be satisfied with the services they receive.
2. CSHCN will receive coordinated, ongoing, comprehensive care within a medical home.
3. Families of CSHCN will have adequate private and/or public insurance to pay for the services they need.
4. Children will be screened early and continuously for special health care needs.
5. Community-based service systems will be organized so families can use them easily.
6. Youth with special health care needs will receive the services necessary to make transitions to adult life, including adult health care, work, and independence.

## PREVALENCE OF CSHCN IN ARIZONA (2000 - 2001)

In Arizona there were 8,542 children screened from 4,276 households to identify 774 CSHCN. The data is weighted to yield state and national estimates.

- ❖ Arizona has approximately 153,410 CSHCN age 0-17 years, comprising 10.8% of all Arizona children which is significantly lower than the national estimate of 12.8%.
- ❖ The proportion of all households with at least one child with a special health care need in Arizona is 17.8%.
- ❖ The prevalence of special needs is greater among males (13.1%) compared to females (8.4%). Both estimates are significantly lower than the national estimates for males and females.
- ❖ The prevalence of CSHCN increases with the age of the child, both nationally and in Arizona. This may reflect increasing identification and/or development of special health needs with age.
- ❖ Arizona has the highest prevalence of CSHCN (13.0%) in families with the income range of 200% to 300% of the Federal Poverty Level (FPL), while it has significantly lower prevalence of CSHCN (9.1%) in families with the income level of less than 200% of the FPL compared to the national prevalence of 13.6%.
- ❖ The prevalence of CSHCN is highest among Arizona families that have identified themselves as multi-racial (17.8%) followed by non-Hispanic Black families (16.0%) and non-Hispanic white families (13.8%). Arizona has significantly lower prevalence of CSHCN among Hispanic families (6.8%) compared to the national prevalence of 8.5%.

Prevalence of CSHCN by age, gender, federal poverty level, and race

	Arizona %	National %
0-5 years of age*	5.5	7.8
6-11 years of age*	12.0	14.6
12-17 years of age	15.0	15.8
Female*	8.4	10.5
Male*	13.1	15.0
< 200% FPL*	9.1	13.6
200% - 300% FPL	13.0	12.8
> 300% FPL	12.3	13.6
Hispanic*	6.8	8.5
White	13.8	14.2
Black	16.0	13.0
Multi-racial	17.8	15.1
Native American /Alaskan Native <sup>a</sup>	5.7	16.6

\* Statistically significant based on 95% Confidence Intervals.

<sup>a</sup> Estimates based on sample sizes too small to meet standards for reliability or precision. The relative standard error is greater than 30%.

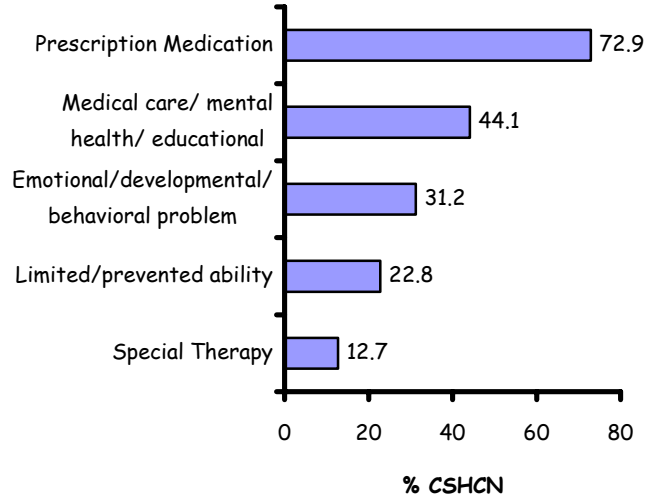
- o The prevalence of CSHCN in Arizona is 10.8%.
- o The proportion of all households with at least one child with a special health care need in Arizona is 17.8%.

## IDENTIFYING CSHCN

### Percentage of CSHCN in Arizona Based on Screening Criteria\*

The SLAITS survey identified CSHCN based on functional limitations and service needs. CSHCN were described as having a medical, behavioral, or other health condition that has lasted or is expected to last 12 months or longer, and met one or more of the following criteria:

- ❖ Need for prescription medicines;
- ❖ Increased use of medical care, mental health, or educational services;
- ❖ Need for treatment/counseling for an emotional, developmental, or behavioral problem.
- ❖ Limited or prevented in ability to do things; and
- ❖ Need for special therapy.

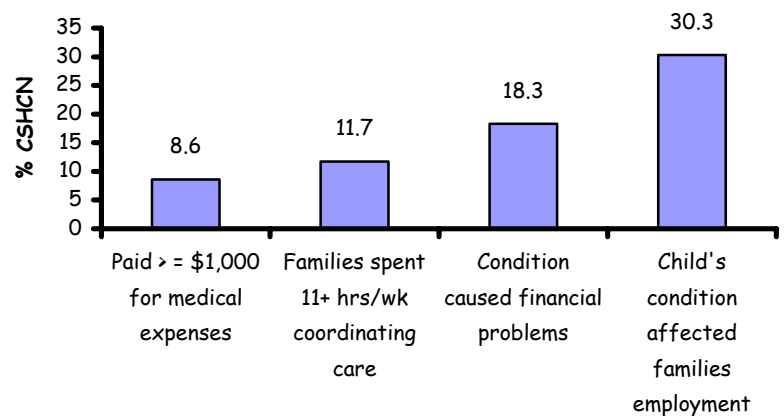


\* (Not mutually exclusive categories).

## IMPACT ON FAMILIES

### Proportion of Arizona Families with CSHCN Affected by Their Child's Condition

- ❖ 8.6% of Arizona families with CSHCN paid \$1,000 or more out-of-pocket for medical care in the past year.
- ❖ 11.7% of Arizona families with CSHCN spent 11 or more hours/week providing and/or coordinating health care for their child.
- ❖ 18.3% of Arizona families faced financial problems due to their child's condition.
- ❖ 30.3% of CSHCN had families whose employment was affected by the child's condition (reduced work hours or stopped working).



# CORE OUTCOMES

The Maternal and Child Health Bureau, Health Resources and Service Administration, has identified six core outcomes for measuring progress in implementing community-based systems of services for CSHCN. Four of the six core outcomes are presented here. Each core outcome was disaggregated into its essential elements or underlying concepts, and these essential elements or underlying concepts were then translated into measurable criteria using items contained in the survey. A core outcome is said to be met when participants responded to all essential elements or underlying concepts.

Core Outcome	Arizona (%) <sup>*</sup>	National (%)
Core Outcome #1	51.4	57.5
Core Outcome #2	50.5	52.6
Core Outcome #3	60.8	59.6
Core Outcome #5	70.9	74.3

(\* Not statistically significant from national data).

## Arizona Families Respond to Their Role as Decision Makers

When children and families are fully informed and understand the options available, better decisions can be made regarding individual treatment and services. When key stakeholders such as children, families, and community leaders are fully informed and empowered, decisions lead to more effective use of systems of care.

(The percentage for the Core Outcome #1 is derived from the following two indicators).

- ❖ 82.2% of the families of CSHCN say that their doctors usually or always made the family feel like a partner.
- ❖ 54.4% of the families of CSHCN are very satisfied with the services they received.

**Core Outcome #1**

**51.4% of Arizona families with CSHCN partner in decision-making and are satisfied with the services they receive.**

# Arizona Families Respond to Their Child's Medical Home

Every child deserves a medical home. A medical home is not a building, house, or hospital, but rather an approach to providing accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally competent health care services in a high-quality and cost-effective manner as defined by the American Academy of Pediatrics.

## Core Outcome #2

In Arizona, 50.5% CSHCN receive coordinated, ongoing, comprehensive care within a medical home.

(The percentage for the Core Outcome #2 is derived from the following four indicators).

### 1. Healthcare System Indicator:

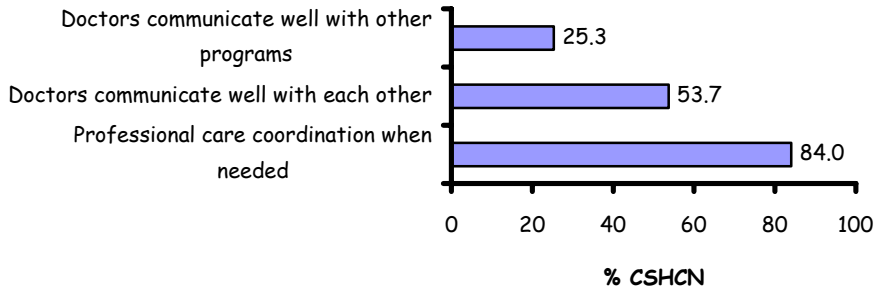
- 91.7% CSHCN had a usual source for sick care.
- 98.4% CSHCN had a usual source of preventive care.
- 88.2% CSHCN had a personal doctor or nurse.

### 2. Referrals Indicator:

74.4% CSHCN had no problems obtaining referrals when needed.

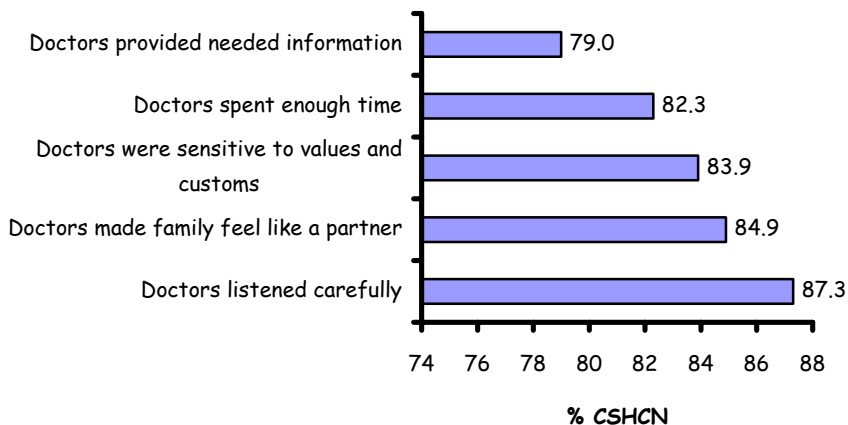
### 3. Care Coordination Indicator:

30.5% CSHCN received effective care coordination.



### 4. Family-Centered Care Indicator:

63.7% CSHCN received family-centered care.



## Arizona Families Respond to the Adequacy of Health Insurance Coverage for CSHCN

CSHCN must have adequate, quality insurance coverage in order to have access to coordinated medical, educational, and social services which can lead to the best outcomes and highest quality of life.

(The percentage for this outcome measure is derived from the following five indicators).

1. 94.9% CSHCN had public or private health insurance coverage at the time of interview.
2. 86.4% CSHCN had no gaps in coverage during the year prior to the interview.
3. 86.7% CSHCN had insurance that usually or always met their needs.
4. 75.4% families of CSHCN believe that costs not covered by insurance are usually or always reasonable.
5. 86.0% families of CSHCN believe that insurance usually or always permits the child to see needed health care providers.

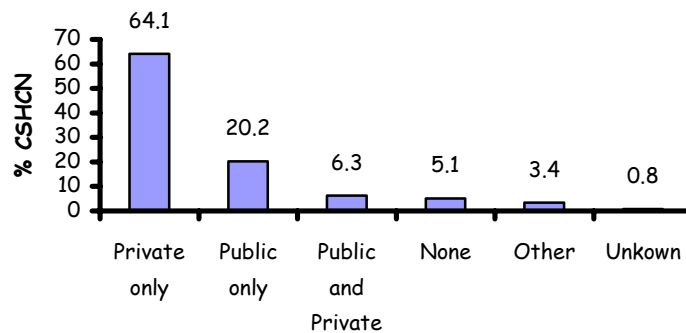
### Core Outcome #3

**60.8% of Arizona families with CSHCN have adequate private and/or public insurance at time of the interview.**

### Arizona Families Find Problems with Insurance

- ❖ Among CSHCN currently insured, 30.4% of families with CSHCN believe insurance is not adequate.
- ❖ 29.5% of families with CSHCN, if had a chance, would switch to a different health plan.
- ❖ 13.6% of families with CSHCN called or wrote to any of the child's health plan with a complaint or problem.
- ❖ 12.6% of families with CSHCN believe their child's health plan is not good for CSHCN.
- ❖ 8.1% of families with CSHCN do not have enough information about how their child's health plan works.

## Types of Health Insurance Coverage



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Public only includes - Medicaid, State Children's Health Insurance Program (SCHIP), Title V, and Indian Health Service.

Private only includes - Private, military insurance, and Single Service Plan (Dental, Vision, Prescription, etc).

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## Arizona Families Respond to the Community-based Service System

Children and families have the ability to reach their potential when they have access to a comprehensive array of services and support designed to meet the individual special needs of the child and their family in the context of their community and living environment.

### Core Outcome #5

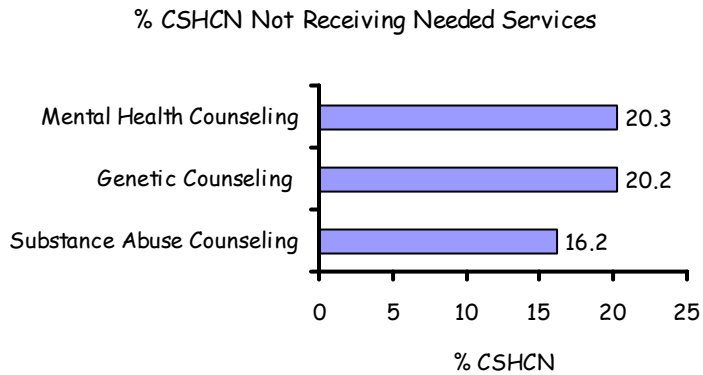
**70.9% of Arizona families with CSHCN report community-based service system is organized so they can use them easily.**

## Unmet Need for Specific Health Care Services

Approximately 19.1% of Arizona families with CSHCN have at least one unmet need for specific health care services.

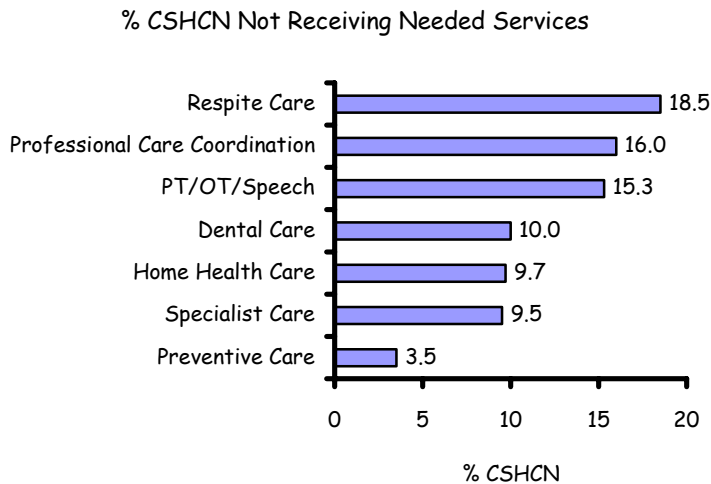
### Access to Care: Counseling

The greatest unmet need is mental health care counseling. 20.3% of Arizona families with CSHCN reported that they did not receive mental health care counseling when needed.



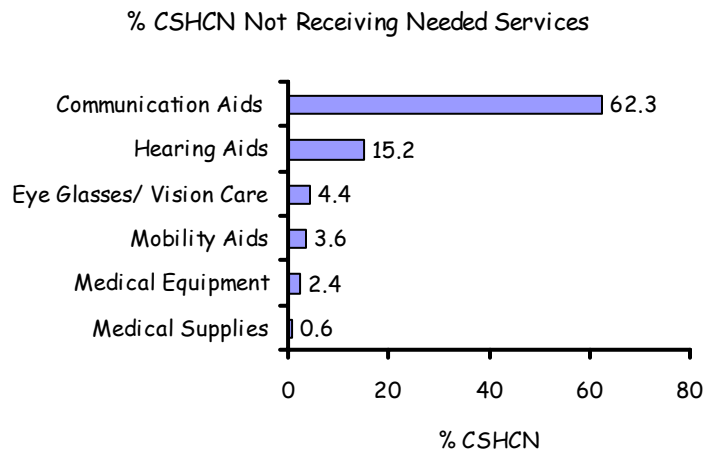
### Access to Care: Service Delivery and Coordination

The greatest unmet need is respite care. 18.5% of Arizona families with CSHCN reported they did not receive respite care when needed.



## Access to Care: Ancillary Services

The greatest unmet need is Communication Aids. 62.3% of Arizona families with CSHCN reported they did not receive communication Aids or devices when needed.



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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.

## Office for Children with Special Health Care Needs Arizona Department of Health Services

The Office for Children with Special Health Care Needs (OCSHCN) within the Arizona Department of Health Services was formed in 1993. Since its inception, OCSHCN has operated on the principal that the family is the center, the most important participant in the system of care for children with special health care needs. The philosophy along with a belief that services are enhanced in a system that is accountable, cost effective and responsive to multiple stakeholders is embedded in its mission:

*To continuously improve comprehensive systems of care which enhance the health, future, and quality of life for children with special health care needs, their families, and the communities in which they live.*

### Websites for More Information

Arizona Department of Health Services - OCSHCN: [www.azdhs.gov](http://www.azdhs.gov)  
Data Resource Center for Child and Adolescent Health - [www.cshcndata.org](http://www.cshcndata.org)  
Family Voices - *families speaking on behalf of CSHCN*: [www.familyvoices.org](http://www.familyvoices.org)  
Healthy and Ready to Work National Center - *transition to adult life*: [www.hrtw.org](http://www.hrtw.org)  
Maternal and Child Health Bureau - *Title V, Block Grant, CSHCN*: [www.mchb.hrsa.gov/programs](http://www.mchb.hrsa.gov/programs)  
National Center for Health Statistics - *National Survey of Children with Special Health Care Needs*:  
[www.cdc.gov/nchs/about/major/slraits/cshcn.htm](http://www.cdc.gov/nchs/about/major/slraits/cshcn.htm)



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*There's nothing so powerful as the potential of a child*

