2014

Utah Survey of Children with Special Health Care Needs

Data Resources Program

Division of Family Health and Preparedness

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UTAH DEPARTMENT OF HEALTH

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The creation of this report was a collaborative effort between the Children with Special Health Care Needs Bureau and the Maternal and Child Health Bureau of the Utah Department of Health.

If you have any questions about this report or would like a copy, please contact Kathryn Crespin in the Data Resources Program at kcrespin@utah.gov or at 801-273-2866.

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Introduction

In conjunction with funding provided to state health departments by the Title V Maternal and Child Health (MCH) Block Grant, the federal Health Resources and Services Administration (HRSA) requires states to conduct a comprehensive assessment of the needs of the MCH populations they serve every five years. The information gathered as part of this needs assessment process is analyzed and used to shape the direction and focus of the state MCH programs over the next five years and to determine and prioritize what measures will be used to evaluate the impact and success of the programs. The Utah Children with Special Health Care Needs (CSHCN) Parent Survey was developed to assure that the concerns of families were included in the needs assessment process. The survey was designed to collect information not only about the children themselves, but also about the adults that care for them and the challenges they face in doing so. The purpose of this report is to present and summarize the findings of the CSHCN survey so that they may be effectively used in the needs assessment process.

Methods

The survey consisted of 29 questions and was developed by selecting questions from the National CSHCN Survey and a previous Utah Family Voices survey. Survey topics included type and level of disability, health insurance coverage, health care financial expenses, availability of care providers and services, quality of care, and challenges faced in obtaining care. Children and youth with special health care needs were defined as being any age between birth and 22 years old "who have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally." Either an email or postcard invitation was sent to 4,937 individuals identified by CSHCN clinic databases as those who were caregivers for special needs children or youth up to age 21, and one survey was allowed to be completed for each special needs child or youth within the family. The survey was administered online using the SurveyMonkey.com website. A toll-free telephone line with bilingual staff was provided to assist Spanish-speaking respondents and those without access to a computer. Basic demographic information was collected about both the survey respondents and the children in their care with special health care needs. Four demographic aspects of the children—gender, age, Hispanic ethnicity, and race—were used in cross-tabulation with other data to examine the nature of the relationship between a child's demographic status and the respondent's answers to other questions. A total of 804 surveys were returned and used for analysis for a response rate of 16.3%. The data was subsequently analyzed by the Data Resources Program using SAS 9.2 (32) and SPSS statistical software.

Results

Demographics of Children with Special Health Care Needs

Figure 1. Gender of Children

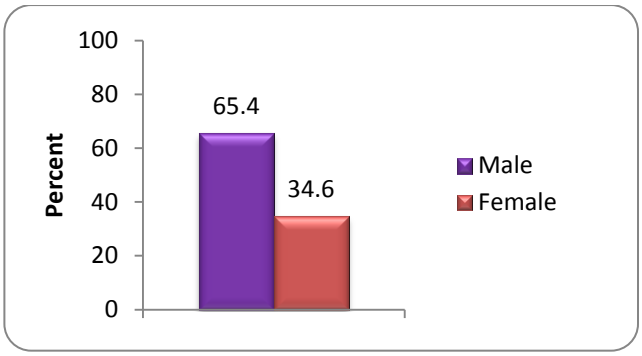


Figure 3. Hispanic Ethnicity of Children

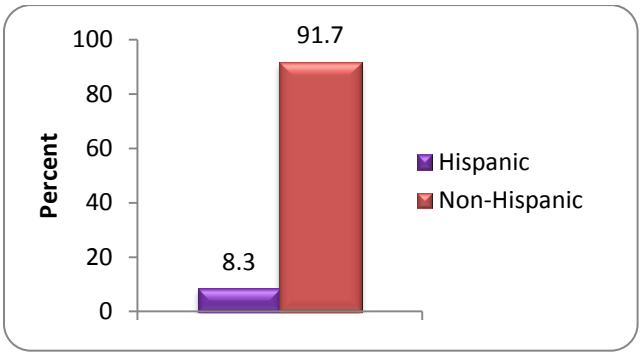


Figure 2. Age Category of Children

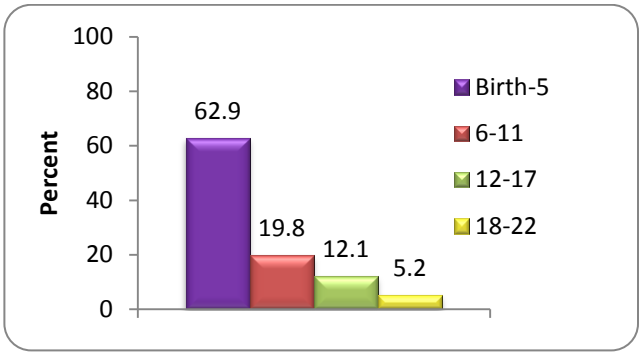


Figure 4. Race of Children

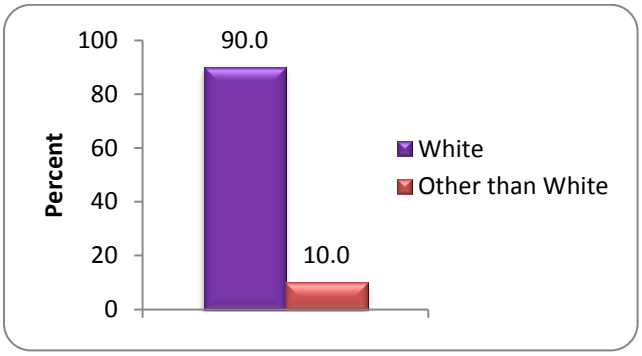


Table 1. Demographics of Children with Special Health Care Needs		
	%	n
Gender		
Male	65.4	451
Female	34.6	239
Age Category (Years)		
Birth-5	62.9	494
6-11	19.8	155
12-17	12.1	95
18-22	5.2	41
Hispanic Ethnicity		
Hispanic	91.7	57
Non-Hispanic	8.3	630
Race		
White	90.0	622
Other than White	10.0	69

Key Points

- Nearly two thirds (65.4%) of respondents' children with special health care needs were male.
- The majority of children (62.9%) were between the ages of birth and five years old.
- In the survey, respondents were able to identify their child's race using one or more of the following categories:
  - White/Caucasian
  - Black/African American
  - American Indian/Alaskan Native
  - Asian
  - Pacific Islander/Hawaiian
  - Other

  For cross-tabulation purposes, those children whose parents or guardians selected only "White/Caucasian" as their child's race (90.0%) were categorized as "White," and all other children (10.0%) were combined into a second category, "Other than white."

Demographics of Survey Respondents

Table 2. Demographics of Survey Respondents		
	%	n
Relationship to Child(ren)		
Father	5.8	40
Mother	91.1	626
Other	3.1	21
Marital Status		
Married	89.0	612
Divorced	5.2	36
Separated	1.3	9
Widowed	1.0	7
Single	3.5	24
2013 Pre-Tax Household Income		
< $20,000	9.7	66
$20,000-$39,999	19.9	135
$40,000-$59,999	27.4	186
$60,000-$99,999	29.5	200
≥ $100,000	13.5	92
Number of Income Dependents		
1-3	21.1	146
4-6	69.2	478
≥ 7	9.7	67

Key Points

- Roughly nine in ten survey respondents (91.1%) identified themselves as mothers.
- Over two thirds of respondents (69.2%) had 4-6 people depending on their household income.

"[One important improvement would be an] all-inclusive application process so that you find out about services that may be helpful before the child ages out of them."

-Respondent comment

"It would be great if there was a service that provided child care for other siblings. I'd be willing to pay for it. It's hard for us to find babysitters."

Figure 5. 2013 Pre-Tax Household Income

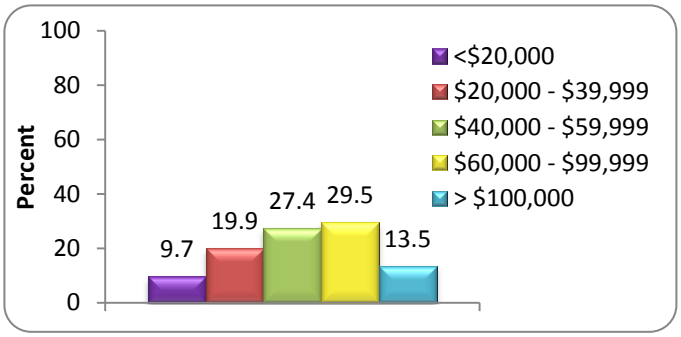


Figure 6. Number of Income Dependents by Income Category

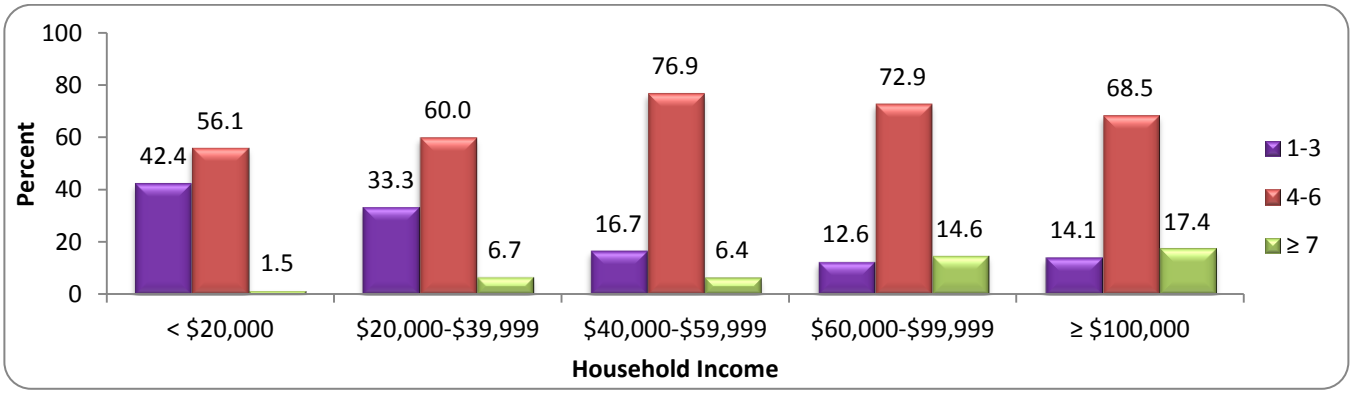


Table 3. 2013 Pre-Tax Household Income by Gender, Age, Hispanic Ethnicity, and Race of Child																
	<$20,000			$20,000-$39,999			$40,000-$59,999			$60,000-$99,999			>$100,000			
	%	95% CI		%	95% CI		%	95% CI		%	95% CI		%	95% CI		
		Lower Limit	Upper Limit		Lower Limit	Upper Limit		Lower Limit	Upper Limit		Lower Limit	Upper Limit		Lower Limit	Upper Limit	p-value
All	9.7	7.5	11.9	19.9	16.9	22.9	27.4	24.0	30.7	29.5	26.0	32.9	13.5	11.0	16.1	<.0001
Gender																
Male	8.7	6.5	10.8	20.1	17.1	23.1	27.2	23.8	30.5	29.7	26.2	33.1	14.4	11.7	17.0	0.7934
Female	11.2	8.8	13.5	20.2	17.1	23.2	27.9	24.5	31.3	28.8	25.3	32.2	12.0	9.6	14.5	
Age Category (Years)																
Birth-5	11.8	9.3	14.2	19.0	16.0	22.0	26.0	22.6	29.3	29.8	26.3	33.3	13.5	10.9	16.0	0.5785
6-11	5.2	3.5	6.9	23.1	19.9	26.3	29.9	26.4	33.3	28.4	24.9	31.8	13.4	10.8	16.0	
12-17	8.0	5.9	10.0	19.3	16.3	22.3	30.7	27.2	34.2	25.0	21.7	28.3	17.1	14.2	19.9	
18-22	6.3	4.4	8.1	18.8	15.8	21.7	25.0	21.7	28.3	40.6	36.9	44.3	9.4	7.2	11.6	
Hispanic Ethnicity																
Hispanic	25.0	21.7	28.3	21.4	18.3	24.5	21.4	18.3	24.5	19.6	16.6	22.6	12.5	10.0	15.0	0.0018
Non-Hispanic	8.5	6.3	10.6	19.7	16.7	22.7	28.1	24.7	31.5	30.2	26.8	33.7	13.5	10.9	16.1	
Race																
White	9.4	7.2	11.6	19.3	16.3	22.3	28.2	24.8	31.6	29.4	26.0	32.8	13.7	11.1	16.3	0.5497
Other than White	12.3	9.8	14.8	26.2	22.8	29.5	21.5	18.4	24.6	26.2	22.8	29.5	13.9	11.2	16.5	

Key Points

- More than half of survey participants (57.0%) reported household income below $60,000.
- A higher percentage of Hispanic children (25.0%) lived in households with 2013 pre-tax household income of less than $20,000 compared to non-Hispanic children (8.5%).

"[One of the biggest challenges our family has in relation to getting needed services for our child is] funding for equipment and therapies that would help but are not covered."

-Respondent comment

"[One of the biggest challenges our family has in relation to getting needed services for our child is] financial--our income is too high for assistance but the assistance doesn't see how much we pay in medical bills, prescriptions, and extra supplies bought at the store."

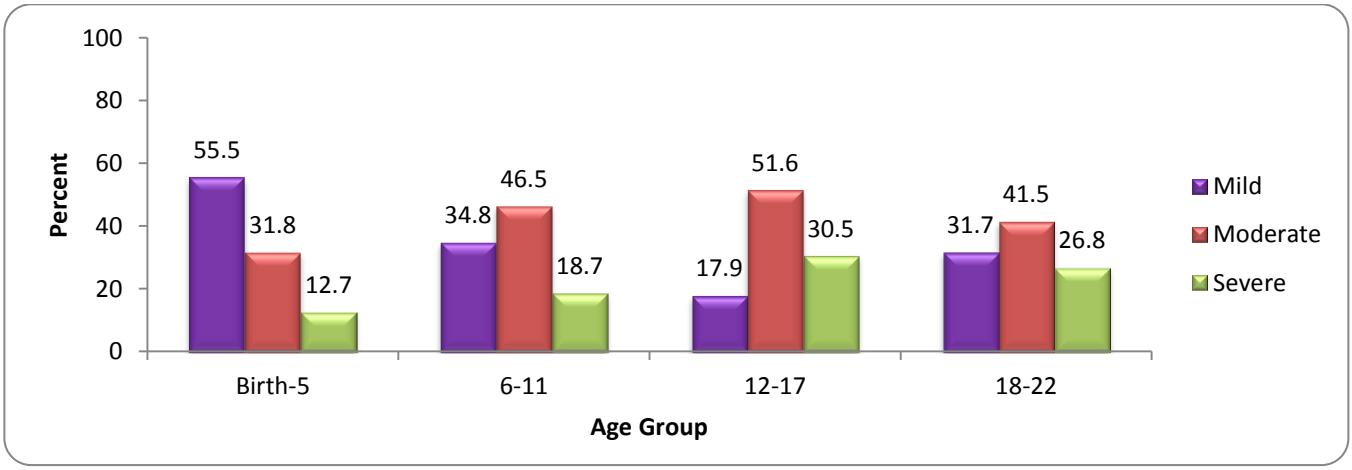
-Respondent comment

Level of Disability

Table 4. Level of Child's Disability by Gender, Age, Hispanic Ethnicity, and Race of Child

	Mild				Moderate				Severe				
	%	n	95% CI Lower Limit	95% CI Upper Limit	%	n	95% CI Lower Limit	95% CI Upper Limit	%	n	95% CI Lower Limit	95% CI Upper Limit	p-value
All	45.9	369	42.5	49.3	37.4	301	34.1	40.8	16.7	134	14.1	19.2	<.0001
Gender													
Male	44.1	199	40.4	47.8	38.4	173	34.7	42.0	17.5	79	14.7	20.4	0.3150
Female	47.3	113	43.5	51.0	32.6	78	29.1	36.1	20.1	48	17.1	23.1	
Age Category (Years)													
Birth-5	55.5	274	52.0	58.9	31.8	157	28.5	35.0	12.7	63	10.4	15.1	<.0001
6-11	34.8	54	31.5	38.2	46.5	72	43.0	49.9	18.7	29	16.0	21.4	
12-17	17.9	17	15.2	20.6	51.6	49	48.1	55.1	30.5	29	27.3	33.7	
18-22	31.7	13	28.4	35.0	41.5	17	38.0	44.9	26.8	11	23.7	29.9	
Hispanic Ethnicity													
Hispanic	56.1	32	52.4	59.8	31.6	18	28.1	35.1	12.3	7	9.8	14.7	0.2275
Non-Hispanic	44.9	283	41.2	48.6	36.4	229	32.7	39.9	18.7	118	15.8	21.6	
Race													
White	44.7	278	41.0	48.4	37.0	230	33.4	40.6	18.3	114	15.4	21.2	0.4662
Other than White	52.2	36	48.4	55.9	30.4	21	27.0	33.9	17.4	12	14.6	20.2	

Figure 7. Level of Child's Disability by Age Group of Child

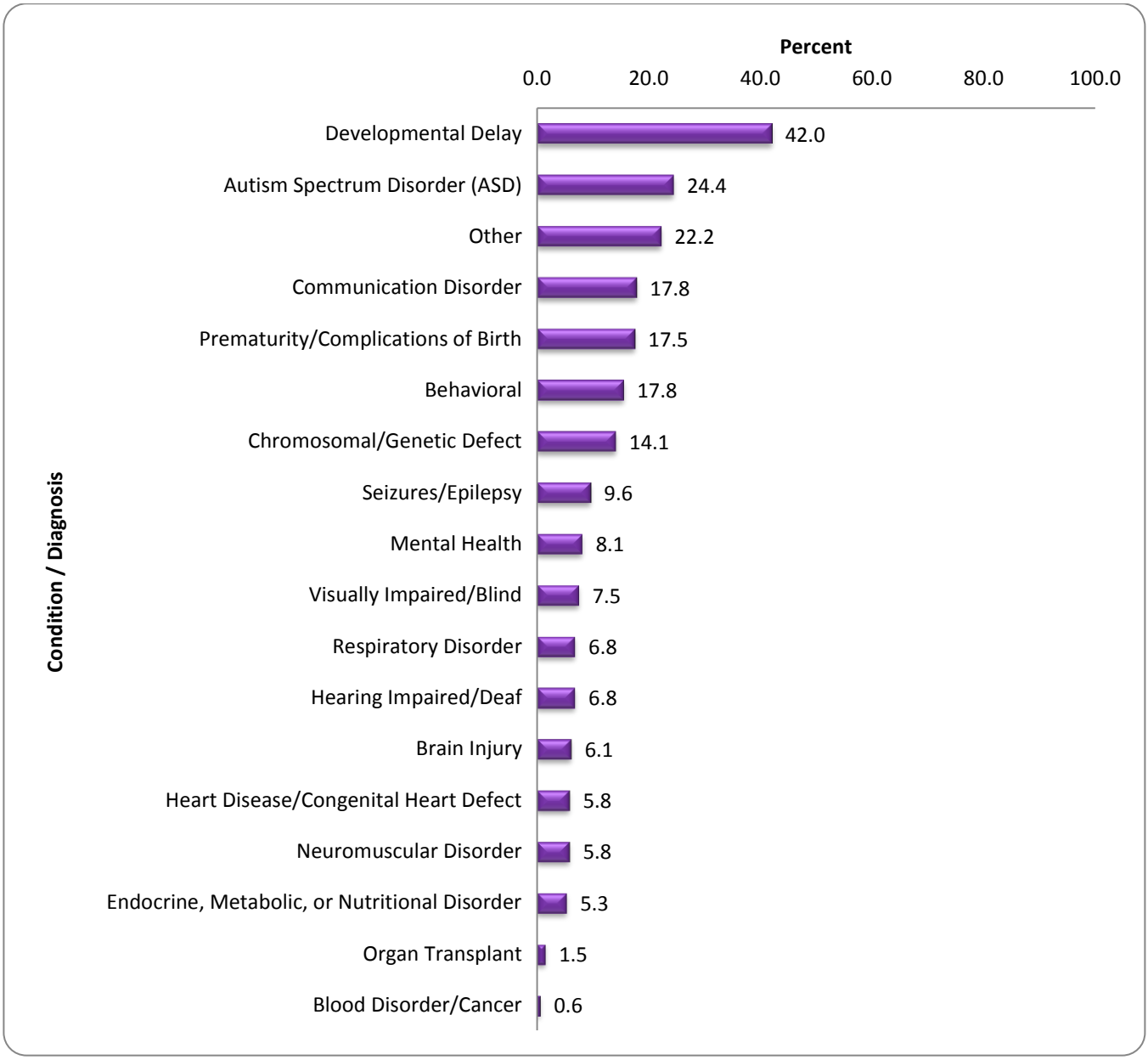


Key Points

- 45.9% of respondents characterized their child's disability as mild, 37.4% as moderate, and 16.7% as severe.
- A higher percentage of parents and guardians of older-age children reported that their child had a moderate or severe disability.
  - Close to one third of children ages 12-17 (30.5%) and more than a quarter of young adults ages 18-22 (26.8%) were reported to have a severe disability compared to children ages birth-5 (12.7%) and ages 6-11 (18.7%).

Conditions / Diagnoses

Figure 8. Conditions / Diagnoses



Note: Respondents were able to select as many conditions/diagnoses as apply

"[One of the biggest challenges our family has in relation to getting needed services for our child is] not having a diagnosis."

-Respondent comment

Key Point

- The five most frequently reported conditions/diagnoses were:
  1) Developmental delay (42.0%)
  2) Autism Spectrum Disorder (24.4%)
  3) Other (22.2%)
  4) Communication disorder (17.8%)
  5) Prematurity/Complications of birth (17.5%)

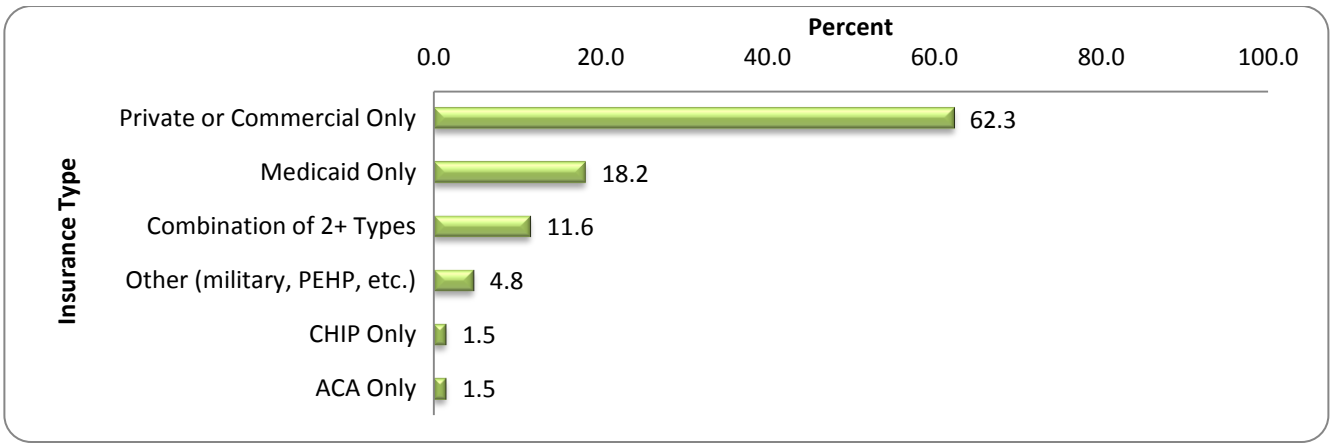
Health Insurance Coverage and Costs

Table 5. Percent of Children Having Health Insurance by Gender, Age, Hispanic Ethnicity, and Race of Child

	Yes				No				
	%	n	95% CI		%	n	95% CI		p-value
			Lower Limit	Upper Limit			Lower Limit	Upper Limit	
All	95.6	734	94.1	97.0	4.4	34	3.0	5.9	<.0001
Gender									
Male	95.5	428	94.0	97.1	4.5	20	2.9	6.0	0.6880
Female	96.2	227	94.8	97.6	3.8	9	2.4	5.2	
Age Category (Years)									
Birth-5	95.8	456	94.4	97.2	4.2	20	2.8	5.6	0.9476
6-11	95.3	141	93.8	96.8	4.7	7	3.2	6.2	
12-17	96.7	**	95.5	98.0	3.3	*	2.0	4.5	
18-22	95.0	**	93.4	96.5	5.0	*	3.4	6.5	
Hispanic Ethnicity									
Hispanic	93.0	**	91.1	94.9	7.0	*	5.1	8.9	0.2484
Non-Hispanic	96.1	600	94.7	97.6	3.9	24	2.4	5.3	
Race									
White	96.4	595	95.0	97.8	3.6	22	2.2	5.0	0.0089
Other than White	89.7	61	87.4	92.0	10.3	7	8.0	12.6	

* The observed number of events is very small and not appropriate for publication.
** The estimate is suppressed because it could be used to calculate the number in a cell that has been suppressed.

Figure 9. Type of Insurance



Note: Respondents were able to select more than one type of insurance if applicable

Key Points

- The majority of respondents (62.3%) said they carry private or commercial health insurance only; however, more than one in ten respondents (11.6%) reported that they carry a combination of two or more types of health insurance.
- A higher percentage of families of non-white children (10.3%) were uninsured compared to families of white children (3.6%).

The top two most frequently mentioned challenges in the respondent comments in relation to caring for a special needs child were:

1) **Financial costs**
2) **Insurance coverage issues**

Table 6. Percent of Children Having Adequate Health Insurance Coverage by Gender, Age, Hispanic Ethnicity, and Race of Child

	Always				Usually				Rarely				
	%	n	95% CI		%	n	95% CI		%	n	95% CI		p-value
			Lower Limit	Upper Limit			Lower Limit	Upper Limit			Lower Limit	Upper Limit	
All	23.6	169	20.5	26.7	55.6	399	52.0	59.3	20.8	149	17.8	23.7	<.0001
Gender													
Male	21.0	89	17.9	24.2	55.1	233	51.2	58.9	23.9	101	20.6	27.2	0.0386
Female	27.6	62	24.1	31.0	56.0	126	52.2	59.8	16.4	37	13.6	19.3	
Age Category (Years)													
Birth-5	30.0	134	26.7	33.4	53.6	239	49.9	57.3	16.4	73	13.6	19.1	<.0001
6-11	12.1	17	9.7	14.5	52.9	74	49.2	56.5	35.0	49	31.5	38.5	
12-17	12.6	11	10.2	15.1	63.2	55	59.7	66.8	24.1	21	21.0	27.3	
18-22	14.3	*	11.7	16.9	68.6	**	65.1	72.0	17.1	**	14.4	19.9	
Hispanic Ethnicity													
Hispanic	35.8	19	32.1	39.5	49.1	26	45.2	52.9	15.1	8	12.3	17.8	0.0573
Non-Hispanic	21.7	129	18.6	24.9	56.5	335	52.7	60.3	21.8	129	18.6	24.9	
Race													
White	23.1	136	19.9	26.4	56.3	331	52.5	60.1	20.6	121	17.5	23.7	0.2936
Other than White	29.5	18	26.0	33.0	45.9	28	42.1	49.7	24.6	15	21.3	27.9	

* The observed number of events is very small and not appropriate for publication.
** The estimate is suppressed because it could be used to calculate the number in a cell that has been suppressed.

Key Points

- Though 79.2% of respondents reported their health insurance coverage was "always" or "usually" adequate to meet their child's special health care needs, approximately one in five (20.8%) said they "rarely" have adequate coverage.
- A higher percentage of male (23.9%) than female (16.4%) children were reported to "rarely" have adequate health insurance coverage.
- More than one third (35.0%) of parents or guardians of 6-11-year-olds reported that their health insurance coverage was "rarely" adequate to meet their child's special health care needs.

"[It is] difficult to find a quality provider who works with your insurance, is close to home, [and] has appointments before or after school."

-Respondent comment

Table 7. Out-of-Pocket Costs During the Past Year in Relation to Child's Health Care Needs by Gender, Age, Hispanic Ethnicity, and Race of Child													
	< $1,000 per year			$1,000 to $4,999 per year			$5,000 to $10,000 per year			>$10,000 per year			
	%	95% CI		%	95% CI		%	95% CI		%	95% CI		p-value
		Lower Limit	Upper Limit		Lower Limit	Upper Limit		Lower Limit	Upper Limit		Lower Limit	Upper Limit	
All	39.9	36.4	43.4	38.3	34.8	41.8	15.0	12.4	17.5	6.8	5.0	8.6	<.0001
Gender													
Male	37.6	33.9	41.2	39.6	35.9	43.3	16.5	13.8	19.3	6.3	4.4	8.1	0.2410
Female	44.5	40.8	48.2	35.6	32.0	39.2	12.7	10.2	15.2	7.2	5.3	9.1	
Age Category (Years)													
Birth-5	42.8	39.2	46.3	35.2	31.8	38.7	15.5	12.9	18.2	6.5	4.7	8.3	0.1476
6-11	34.3	30.8	37.7	45.4	41.8	49.0	11.9	9.5	14.2	8.4	6.4	10.4	
12-17	39.1	35.6	42.7	38.0	34.5	41.5	16.3	13.6	19.0	6.5	4.7	8.3	
18-22	23.7	20.6	26.7	57.9	54.3	61.5	13.2	10.7	15.6	5.3	3.6	6.9	
Ethnicity													
Hispanic	53.6	49.8	57.3	33.9	30.4	37.5	7.1	5.2	9.1	5.4	3.7	7.0	0.1085
Non-Hispanic	38.3	34.6	41.9	39.3	35.6	42.9	15.7	13.0	18.4	6.7	4.8	8.6	
Race													
White	39.5	35.9	43.2	38.1	34.4	41.7	15.6	12.8	18.3	6.8	4.9	8.7	0.7055
Other than White	43.3	39.6	47.0	40.3	36.6	44.0	10.4	8.2	12.7	6.0	4.2	7.7	

Table 8. Child's Utah Medicaid Waiver Status				
	Yes		On Waiting List	
Waiver Type	%	n	%	n
Community Supports Waiver through DSPD	4.0	27	6.5	44
Technology Dependent (Travis C.) Waiver	1.5	10	1.1	7
Autism Waiver	3.2	21	1.7	11

Key Point

- Close to 1 in 10 (8.4%) parents or guardians of children ages 6-11 reported paying more than $10,000 of out-of-pocket expenses during the past year for their child's health care needs.

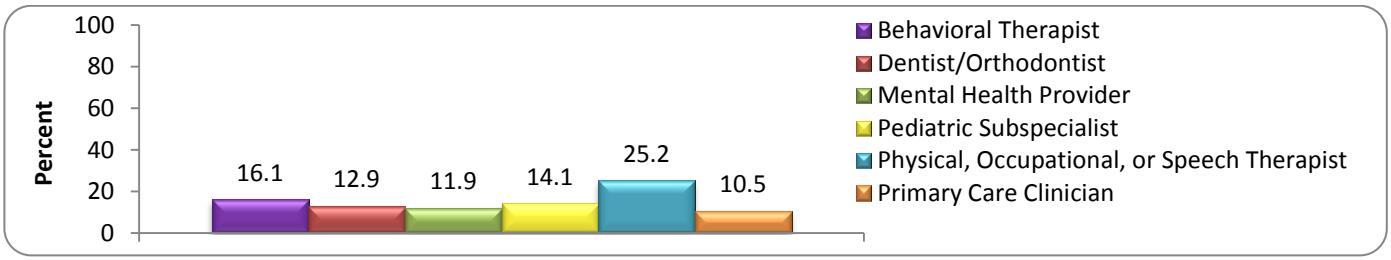
Availability of Providers and Services

Table 9. Percent of Children Having a Primary Care Clinician by Gender, Age, Hispanic Ethnicity, and Race of Child

	Yes			No			
	%	95% CI		%	95% CI		
		Lower Limit	Upper Limit		Lower Limit	Upper Limit	p-value
All	97.3	96.2	98.5	2.7	1.5	3.8	<.0001
Gender							
Male	97.5	96.4	98.7	2.5	1.3	3.6	0.6982
Female	97.0	95.8	98.3	3.0	1.7	4.2	
Age Category (Years)							
Birth-5	98.5	97.6	99.4	*1.5	0.6	2.4	0.0047
6-11	95.9	94.5	97.3	4.1	2.7	5.5	
12-17	96.7	95.4	98.0	3.3	2.0	4.6	
18-22	89.2	86.9	91.4	10.8	8.6	13.0	
Hispanic Ethnicity							
Hispanic	98.2	97.3	99.2	1.8	0.8	2.7	0.7088
Non-Hispanic	97.4	96.2	98.6	2.6	1.4	3.7	
Race							
White	97.2	96.0	98.5	2.8	1.5	4.0	0.5198
Other than White	98.6	97.7	99.4	*1.4	0.6	2.3	

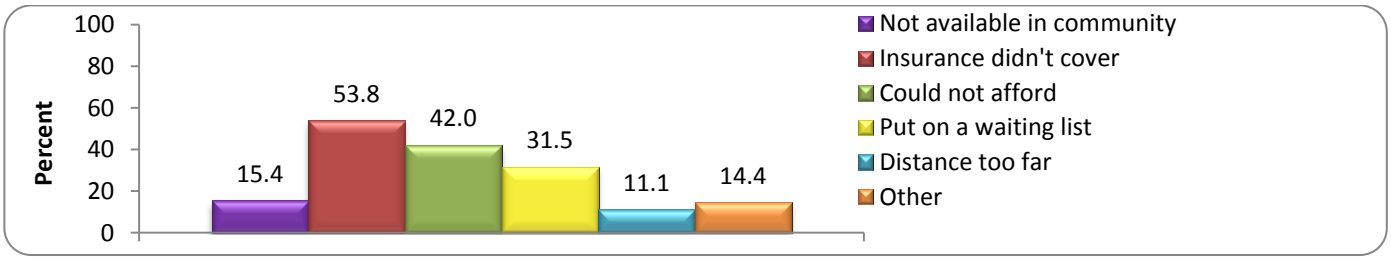
* Use caution in interpreting; the low counts in these instances may deem the estimate to be unreliable.

Figure 10. Percent of Respondents Having Difficulty Seeing Providers in Last 12 Months (by Provider Type)



Note: Respondents were able to select as many that apply

Figure 11. Reason for Difficulty in Seeing Providers in Last 12 Months



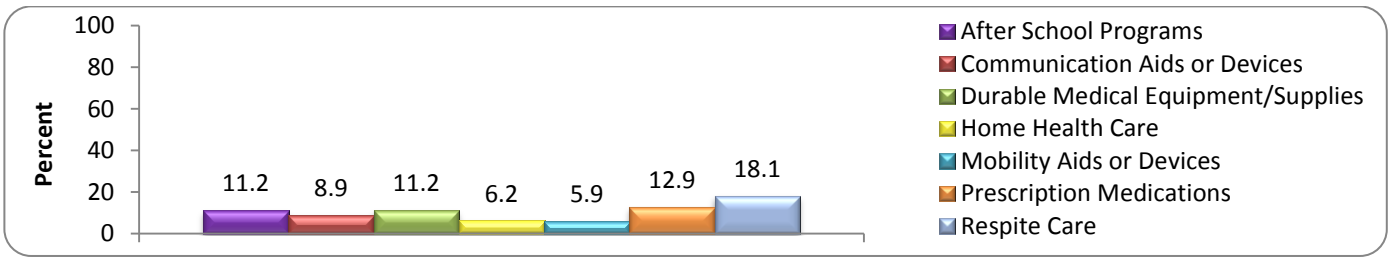
Note: Respondents were able to select as many that apply

Key Points

- One in four respondents (25.2%) reported difficulty in seeing a physical, occupational, or speech therapist within the past year.
- More than half of survey participants (53.8%) indicated that one of the reasons for difficulty in seeing a provider within the past 12 months was that insurance did not cover the provider.

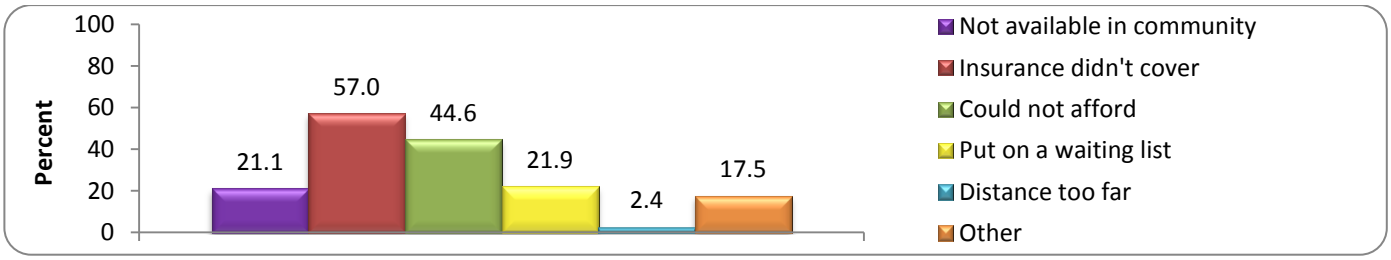
Table 10. Percent of Children Who Had or Are Scheduled For an Appointment at Any Children with Special Health Care Needs Clinic by Gender, Age, Hispanic Ethnicity, and Race of Child									
	Yes				No				
	%	n	95% CI Lower Limit	95% CI Upper Limit	%	n	95% CI Lower Limit	95% CI Upper Limit	p-value
All	41.7	291	38.0	45.3	58.3	407	54.6	62.0	<.0001
Gender									
Male	39.0	172	35.3	42.7	61.0	269	57.3	64.7	0.0299
Female	47.7	112	43.9	51.4	52.3	123	48.6	56.1	
Age Category (Years)									
Birth-5	43.9	188	40.2	47.6	56.1	240	52.4	59.8	0.2182
6-11	40.3	56	36.6	43.9	59.7	83	56.0	63.4	
12-17	39.3	35	35.7	43.0	60.7	54	57.0	64.3	
18-22	26.5	9	23.2	29.8	73.5	25	70.2	76.8	
Hispanic Ethnicity									
Hispanic	47.3	26	43.5	51.0	52.7	29	49.0	56.5	0.4427
Non-Hispanic	41.9	260	38.2	45.7	58.1	360	54.3	61.8	
Race									
White	41.9	257	38.2	45.6	58.1	356	54.4	61.8	0.6998
Other than White	44.4	28	40.7	48.2	55.6	35	51.8	59.3	

Figure 12. Percent of Respondents Having Difficulty Obtaining Services or Equipment in the Last 12 Months



Note: Respondents were able to select as many that apply

Figure 13. Reason for Difficulty in Obtaining Services or Equipment in the Last 12 Months



Note: Respondents were able to select as many that apply

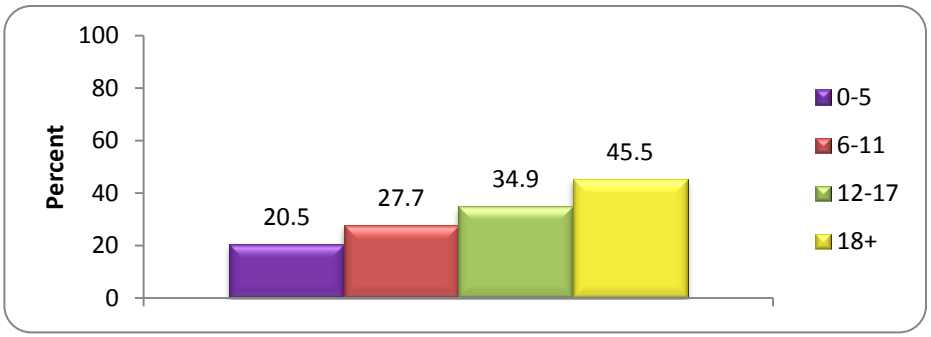
Key Points

- Less than half of respondents (41.7%) said their child has had or was scheduled for an appointment at one of the CSHCN Clinics, with a lower percentage of male (39.0%) versus female (47.7%) children having scheduled appointments.
- Almost one in five survey participants (18.1%) had difficulty obtaining respite care.
- More than half of survey participants (57.0%) indicated that one of the reasons for difficulty in obtaining services or equipment over the past year was that insurance did not cover them.

Quality of Care

Table 11. Percent Concerned About Quality of Care by Gender, Age, Hispanic Ethnicity, and Race of Child									
	Yes				No				
	%	n	95% CI Lower Limit	95% CI Upper Limit	%	n	95% CI Lower Limit	95% CI Upper Limit	p-value
All	25.1	170	21.8	28.4	74.9	507	71.6	78.2	<.0001
Gender									
Male	25.6	113	22.3	28.9	74.4	328	71.1	77.7	0.6492
Female	24.0	55	20.8	27.2	76.0	174	72.8	79.2	
Age Category (Years)									
Birth-5	20.5	86	17.4	23.5	79.5	334	76.5	82.6	0.0007
6-11	27.7	36	24.3	31.1	72.3	94	68.9	75.7	
12-17	34.9	30	31.3	38.5	65.1	56	61.5	68.7	
18-22	45.5	15	41.7	49.2	54.5	18	50.8	58.3	
Hispanic Ethnicity									
Hispanic	16.4	9	13.5	19.2	83.6	46	80.8	86.4	0.1155
Non-Hispanic	26.0	159	22.6	29.3	74.0	453	70.7	77.3	
Race									
White	24.3	147	21.1	27.6	75.7	457	72.4	78.9	0.2875
Other than White	30.3	20	26.8	33.8	69.7	46	66.2	73.2	

Figure 14. Percent Concerned About Quality of Care by Age of Child



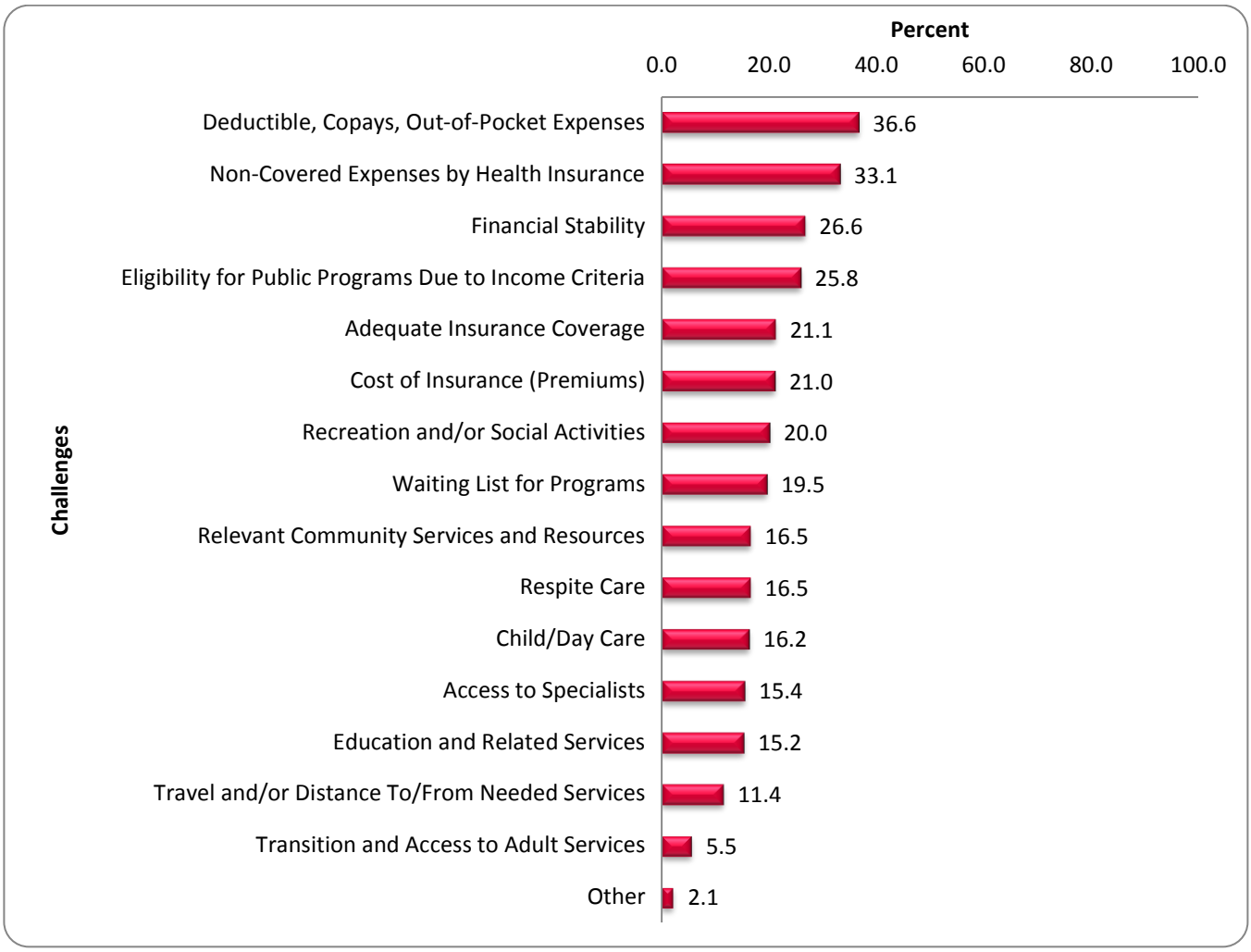
Key Points

- Overall, one in four parents (25.1%) had concerns about quality of care.
- The top five concerns about quality of care were:
  1) Lack of care provider knowledge about child's condition and/or needs
  2) Care provider skills not a good match for child's needs
  3) Concerns about quality of care within the school system
  4) Lack of concern for child's needs by care provider(s)
  5) General concerns about overall quality of care for child
- Parents and guardians of older-age children tend to have more concern about quality of care than parents and guardians of younger-age children.
  - Nearly half of respondents (45.5%) with children ages 18-22 years old had concerns about quality of care for their child.

We have loved the services we have received through the neonatal follow-up clinic! They are fantastic. What a great service. Thanks!!!

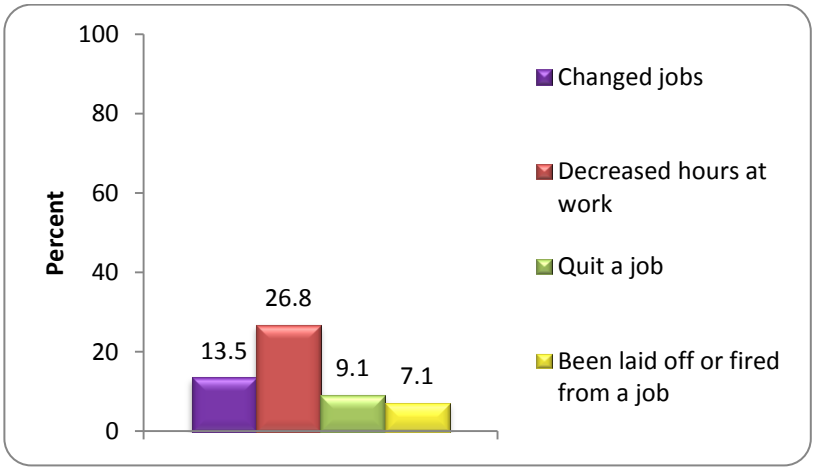
Challenges and Adverse Experiences

Figure 15. Challenges Faced by Child or Family



Note: Respondents were able to select as many challenges as apply

Figure 16. Adverse Employment Experiences in Past 12 Months



Key Points

- The top three challenges reported by families were financial:
  1) Deductibles, copays, out-of-pocket expenses (36.6%)
  2) Expenses not covered by insurance (33.1%)
  3) Financial stability (26.6%)
- Slightly more than one in four respondents (26.8%) indicated that at least one member of the household had to decrease his or her work hours in the past 12 months due to their child's special health care needs.

- **Respondents were asked in an open-ended question to name the biggest challenge their family has faced in getting needed services for their child. Though many more than this were mentioned, 11 challenges stood out as being the most frequently mentioned (in decreasing order of frequency):**
  1) **Financial cost/income-based qualification for assistance**
  2) **Insurance/Medicaid coverage, especially for behavioral, respite, and speech therapies**
  3) **Provider and/or service availability**
  4) **Scheduling/time issues, especially in relation to appointments with providers**
  5) **Distance to providers and/or travel and transportation issues**
  6) **Lack of information regarding available resources**
  7) **Access to appropriate educational services**
  8) **Ability to get an appropriate needs assessment for their child**
  9) **Issues with need-based qualification for assistance**
  10) **Access to affordable childcare (for both children with and without special health needs)**
  11) **Access to or coverage for equipment and/or supplies**

- **Respondents were also asked in an open-ended question to state what they believe is the most important area that needs improvement in relation to obtaining services for special health care needs in Utah. Though, again, many more than this were mentioned, several suggestions stood out as being the most frequently mentioned (in decreasing order of frequency):**
  1) **Improve insurance coverage, especially for mental health care, behavioral therapies, respite care, and equipment/supplies**
  2) **Help families with financial costs / Expand income-based qualification for assistance**
  3) **Improve availability of services and providers, especially in rural areas / Reduce wait list times**
  4) **Provide better/more centralized/more streamlined/more widely distributed access to information regarding what services and assistance are available**
  5) **Improve coordination of and/or consolidate services between agencies and/or providers**
  6) **Increase program funding**
  7) **Improve access to appropriate educational services**
  8) **Widen the range of ages for which programs and services are available / Improve availability of adult transition services**
  9) **Expand provider and service appointment hours**

Conclusions

In support of the MCH Block Grant Five-Year Needs Assessment process, the primary purpose of this report is to summarize the findings of the 2014 CSHCN Parent Survey so that the suggestions and concerns of families of children with special health care needs in Utah can be used to help state Title V programs prioritize and tailor future program activities. It is clear from the results that many families struggle with the financial requirements associated with caring for a child with special health care needs. The cost of participating in health insurance (premiums, deductibles, co-pays, and expected out-of-pocket expenses) is often prohibitive for many families. Additionally, five of the ten most frequently mentioned diagnoses (developmental delay, Autism Spectrum Disorder, communication disorders, behavioral disorders, and mental health issues) are conditions that health insurance and other types of assistance programs often do not cover at all, cover only partially or inadequately, or cover only for children of certain ages. Furthermore, many of these conditions require multiple types of therapies (behavioral, physical, occupational, and speech, for example) or specialized types of care (respite, for example) for which adequate insurance coverage is often difficult to obtain.

In addition to expressing concerns about health care costs and insurance coverage, respondents indicated a desire to have more access to recreational and/or social activities, more centralized and streamlined information regarding what community services and resources are available, and more help finding affordable child/daycare. They also desired improved availability of services and providers outside (and inside) the greater Salt Lake City area, improved coordination and consolidation of services between agencies and/or providers, and expanded provider and service hours. In addition to conveying respondents' directly stated challenges and hopes for improvement, this report also highlights differences among subgroups of the CSHCN population in relation to many of the survey topics that were addressed that will help Title V programs define relevant, realistic, and measurable goals for future activities.

Limitations

Like all surveys, this survey has some limitations that should be noted. First, because potential respondents were selected from CSHCN clinic databases, results may not be generalizable to the entire CSHCN population. Second, survey results based on self-reported information are limited by respondent recall capacity and may be susceptible to recall bias. Third, the survey response rate was considerably low (16.3%). Though this response rate produced a sample size that was adequate for analysis of the group as a whole, the statistical reliability of some of the analyses of certain subgroups within the population may have been negatively affected because the number of people included within these subgroups was small. A final limitation of the survey is that some of the statistics pertaining to age group might be explained by children with milder conditions moving out of the survey sample as they age and their conditions improve. Thus, only those older children whose more severe conditions warrant continuing care remain in the sample, which might affect the results of some of the analyses.

Appendix A

Utah Survey of Children with Special Health Care Needs

Utah Survey of Children with Special Health Care Needs, 2014

The Utah Department of Health is interested in your thoughts about the needs that your child has with a health or developmental issue. The information you provide will be very valuable in planning for services for children and youth with special needs in Utah.

Children and youth (ages Birth - 22) with special health care needs are defined by the Federal Government as: "those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotion condition and who also require health and related services of a type or amount beyond that required by children generally".

This survey is designed to be completed for one child or youth with special health care needs. Feel free to complete another survey if you have more than one child or youth with special health needs.

Thank you for your participation!

Please click the "Next" button below to continue with the survey.

1. How old is your child? (Please select the age from the drop down menu provided below)

***2. How would YOU describe the degree of your child's disability or of his/hers special health care need(s)?**

- ◯ Mild
- ◯ Moderate
- ◯ Severe

Other (please specify)

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Utah Survey of Children with Special Health Care Needs, 2014

3. Please indicate your child's diagnosis(es) or conditions(s)? (check all that apply)

- ☐ Autism Spectrum Disorder (ASD)
- ☐ Behavioral
- ☐ Blood Disorder / Cancer
- ☐ Brain Injury
- ☐ Chromosomal/Genetic Defect
- ☐ Communication Disorder
- ☐ Developmental Delay
- ☐ Endocrine, Metabolic or Nutritional Disorder
- ☐ Heart Disease / Congenital Heart Defect
- ☐ Mental Health
- ☐ Neuromuscular Disorder
- ☐ Organ Transplant
- ☐ Prematurity / Complications of Birth
- ☐ Respiratory Disorder
- ☐ Seizures / Epilepsy
- ☐ Visually Impaired / Blind
- ☐ Hearing Impaired / Deaf

Other (please specify)

4. Does your child have health insurance?

- ○ Yes
- ○ No

5. What type of health insurance(s) does your child have? (check all that apply)

- ☐ Medicaid
- ☐ CHIP
- ☐ Private or Commercial
- ☐ Insurance purchased through the Affordable Care Act (ACA)
- ☐ Other, please specify

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Utah Survey of Children with Special Health Care Needs, 2014

6. Does your child's health insurance provide adequate benefits or cover services that are needed to meet his/her special health care needs? (check one)

- ◯ Always
- ◯ Usually
- ◯ Rarely

7. Please indicate how much you spent out of pocket over the past year related to your child's health care needs? (include insurance premiums, co-pays, deductibles, non-covered items, out of pocket expenses, etc.) (check one)

- ◯ < $1000 per year
- ◯ $1000 to $4999 per year
- ◯ $5000 to $10,000 per year
- ◯ > $10,000 per year

8. Does your child have a primary health care clinician who provides for your child's ongoing medical needs, such as immunizations, well check-ups, sick visits, etc?

- ◯ Yes
- ◯ No

9. In the last 12 months, did your child have any difficulties in seeing any of the following health care providers? (check all that apply)

	Yes	No	Not applicable
Behavioral Therapist	◯	◯	◯
Dentist/Orthodontist	◯	◯	◯
Mental Health Provider	◯	◯	◯
Pediatric Subspecialists (Neurology, Cardiology, etc.)	◯	◯	◯
Physical, Occupational or Speech Therapist	◯	◯	◯
Primary Care Clinician	◯	◯	◯

10. If your child had difficulties in seeing any of the above providers, what was the reason? (check all that apply)

- ☐ Not available in my community
- ☐ Insurance did not cover the provider
- ☐ Could not afford to have our child seen by the provider
- ☐ We requested that our child be seen and she/he was put on a waiting list.
- ☐ Distance to travel for appointment was too far.

Other (please specify)

_____

11. In the last 12 months, did your child have any difficulties in obtaining any of the following services/equipment? (check all that apply)

	Yes	No	Not applicable
After school programs	◯	◯	◯
Communication aids or devices	◯	◯	◯
Durable medical equipment or supplies	◯	◯	◯
Home health care	◯	◯	◯
Mobility aids or devices	◯	◯	◯
Prescription medications	◯	◯	◯
Respite care	◯	◯	◯

12. If your child had difficulties in receiving any of the above services/equipment, what was the reason? (check all that apply)

- ☐ Not available in my community
- ☐ Insurance did not cover the services/equipment
- ☐ Could not afford the services/equipment
- ☐ We requested services/equipment and she/he was put on a waiting list.
- ☐ Distance to travel for appointment was too far.

Other (please specify)

_____

Utah Survey of Children with Special Health Care Needs, 2014

13. Does your child or family face challenges related to any of the following areas? If YES, check all that apply.

- ☐ Access to specialists
- ☐ Adequate insurance coverage
- ☐ Child/day care
- ☐ Cost of insurance (premiums)
- ☐ Deductible, co-pays, out of pocket expenses
- ☐ Non covered expenses by health insurance
- ☐ Education and related services
- ☐ Eligibility for public programs due to income criteria
- ☐ Financial stability
- ☐ Waiting lists for programs
- ☐ Relevant community services and resources
- ☐ Recreation and/or social activities
- ☐ Respite care
- ☐ Transition and access to adult services
- ☐ Travel and/or distance from needed services

Other (please specify)

14. Is your child on a Medicaid Waiver in Utah? (Please check one)

	Yes	No	On waiting list
Community Supports Waiver through DSPD	◯	◯	◯
Technology Dependent (Travis C.) Waiver	◯	◯	◯
Autism Waiver	◯	◯	◯

15. Has your child received services or is scheduled for an appointment at any of the Children with Special Health Care Needs clinics, such as Neonatal Follow-up Clinic (NFP), Child Development Clinic (CDC), Speech and Hearing, etc?

◯ Yes

◯ No

16. In the past 12 months, have you or any family member experienced any of the following due to your child's special health care needs?

	Yes	No
Changed jobs	◯	◯
Decreased hours at work	◯	◯
Quit a job	◯	◯
Been laid off or fired from a job	◯	◯

Utah Survey of Children with Special Health Care Needs, 2014

17. What is the biggest challenge your family has for getting needed services for your child?

18. In your opinion, what would be the most important area to improve in obtaining needed services related to special health care needs in Utah?

19. Have you been concerned about the quality of the care your child receives from any of her/his providers?

- ◯ Yes
- ◯ No

If yes, please explain briefly:

20. What is your child's gender?

- ◯ Male
- ◯ Female

21. Is your child of Hispanic or Latino origin?

- ◯ Yes
- ◯ No
- ◯ Don't know

22. Which of the following best describes your child? (check all that apply)

- ☐ White/Caucasian
- ☐ Black/African American
- ☐ American Indian/Alaskan Native
- ☐ Asian
- ☐ Pacific Islander/Hawaiian
- ☐ Other, please specify

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Utah Survey of Children with Special Health Care Needs, 2014

23. What was your total household income from all sources before taxes in 2013?

- ◯ < $20,000
- ◯ $20,000-$39,999
- ◯ $40,000-$59,999
- ◯ $60,000-$99,999
- ◯ > $100,000

24. Including yourself and your child with special health care needs, how many people usually depend upon this income?

[ ]

25. If you are a parent/guardian of more than one individual with special health care needs, please select the number for the appropriate age group(s):

	# of children
Birth to 18 years old	
18 to 22 years old	
23 and older	

Other (please specify)

26. What is your current marital status?

- ◯ Married
- ◯ Divorced
- ◯ Separated
- ◯ Widowed
- ◯ Single

27. What is your home zip code?

28. How are you related to your child with special health care needs?

- ◯ Father
- ◯ Mother
- ◯ Other, please specify

Utah Survey of Children with Special Health Care Needs, 2014

29. Do you have any additional comments that you would like to share with us?

If you have any questions or concerns regarding the survey, please contact Stephanie Robinson at: stephanierobinson@utah.gov

For additional information about resources that may be helpful for the needs of your child and family please contact Gina Pola-Money at gpolamoney@utah.gov or visit www.medicalhomeportal.org

Thank you for helping us determine important health issues for children and adolescents of special health care needs in Utah!