

Appendix D. Investigation of the Utah Child Health Survey CSHCN Rate





Investigation of the Utah C. H. S. CSHCN Rate

At the time that the 2000 Utah Child Health Survey was being designed, the Foundation for Accountability (FACCT) instrument for assessing children for special health care needs was also under development. At the time the 2000 Utah Child Health Survey went into the field, the most current draft version of the FACCT survey was obtained, and embedded in the Child Health Survey instrument.

The FACCT survey instrument has been administered on several occasions, in different states, and to different survey populations. On all of these occasions, the FACCT survey has produced estimates for the prevalence of Children With Special Health Care Needs (CSHCN) that are substantially higher than what was found in Utah. Utah's rate of CSHCN was estimated by the survey to be 12.6%, while others' estimates around the country ranged from 16% to 19%. With a 95% confidence interval for the Utah survey of only $\pm 1.0\%$, the differences don't seem to be explainable as survey sampling error. However, there are other methodological issues that could account for Utah's low rate, and Utah desires to explore these potential causes for the difference, and, hopefully, rule them out.

An examination of the low rate, and all potential causes for the lower survey estimate, was undertaken. The examination took the form of several discussions, meetings, phone conference calls, data analyses, and sharing of data in an attempt to ascertain gauge the validity of Utah's lower-than-expected observed rate.

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DEFINITIONS:

CAHPS. Consumer Assessment of Health Plans Survey, a survey conducted with members of specific health plans to assess their satisfaction with various aspects of the plan.

Utah CHS2000. 2000 Utah Child Health Survey, a population-based telephone survey including 5,979 children, designed to be representative of all children living in Utah. To measure special health care needs among children, Utah adapted the October 1999 draft of the FACCT instrument. It looked at 10 conditions/behaviors:

1. Rx meds
2. Needs more care than most children
3. Restricted activity
4. Physical/speech/other therapy
5. Mental health problems
6. Durable medical equipment/special equipment
7. Life-threatening allergies
8. Special diet
9. IEP (Individualized Ed. Plan, Spec. Ed.)
10. Learning or behavioral difficulties

FACCT/LWI. (Living With Illness) instrument. The final version of the instrument that looks at 5 conditions/behaviors:

1. Rx meds
2. More care
3. Restricted activity
4. Physical/speech/other therapy
5. Mental health problems

FACCT Field Trial Survey. This survey was conducted in Oregon by the Foundation for Accountability (FACCT). We are using it as a comparison to explore reasons for our lower CSHCN rate.

VCU Survey. The Virginia Department of Health contracted with the Virginia Commonwealth University's Survey and Evaluation Research Laboratory to administer a telephone survey to a general population sample including 888 children in their state. Their questionnaire included a draft version of the FACCT questions that was very similar to the draft version administered as part of the 2000 Utah Child Health Survey. We are using it as a comparison to explore reasons for our lower CSHCN rate.

AT RISK vs. DURATION QUESTIONS. For each of the conditions/behaviors examined, there was a screener, or “at risk” question and one or two “duration” follow-up questions. The first question asks whether the condition currently applies to the child, the remaining question(s) ascertain whether the condition is chronic (has lasted or is expected to last 12 months).

CSHCN. A child in a surveyed household was defined as a Child with Special Health Care Needs (CSHCN) if, for any given condition or behavior, the survey respondent answered “yes” to BOTH the “at risk” and “duration” questions. For instance, if a child had an activity restriction (at risk) that had lasted or was expected to last for at least 12 months (duration), that child would be considered CSHCN. Alternatively, if the child had an activity restriction that was NOT expected to last a total of 12 months (e.g., broken arm in a cast) that child would not be categorized as a CSHCN.

HYPOTHESIZED REASONS FOR UTAH’S LOWER RATE:

1. Utah rate could be lower because of interviewers coding or respondents indicating “no” responses on the screener questions so they wouldn’t have to go through the follow-up questions.
2. Utah’s low rate could be due to the difference in question wording. The FACCT Utah Draft collapsed two follow-up questions, the FACCT/LWI broke them out.
3. Sampling frames are different. After a short time on the phone, it was discovered that the two survey samples were quite different. The age distribution of Utah kids may be more weighted toward the younger kids, and special health care needs are often not identified until a child is age two or older.
4. Utah has a lower rate of CSHCN.

Hypothesis 1: Poor interviewing techniques or respondent nea-saying.

If Pegus interviewers were opting out of the screener questions to save time, or if savvy parents were doing the same, we should have systematically fewer “yes” responses to the screener questions. There were two sources of data with which to compare our Utah survey results. FACCT had conducted a mail version of the FACCT Draft survey, and the Virginia Department of Health had conducted a general population telephone survey with a similar instrument. We compared the responses on the screener questions for most items in the FACCT Draft surveys (the three surveys were conducted at different points in the development of the questionnaire, so not all questions were administered across all three versions).

Table 1. Percentage of "Yes" Responses to the Screener Question

ITEM	UTAH %	FACCT FIELD TRIAL %	VIRGINIA %
Rx meds	12.1	23.3	21
Needs more care than most children	6.0	10.0	7
Restricted activity	4.6	5.8	7
Physical/speech/other therapy	3.3	2.9	6
Mental health treatment/counseling	3.1	4.7	4
Durable medical/special equipment	2.1	4.9	3
Life-threatening allergies	3.3	n/a	n/a
Special diet	1.6	2.3	2
IEP (Individualized Ed Plan, Spec Ed.)	4.7	4.1	5
Learning or behavioral difficulties	4.8	8.5	n/a

From examining the Table 1, it is clear that for certain items (prescription medications and learning or behavioral difficulties) the Utah sample had fewer “yes” responses, but for other items Utah had similar or higher responses. There was no easily discernible pattern of “nea-saying” among the Utah respondents or the interviewers. The data do not support hypothesis #1.

This finding is interesting in light of the conventional wisdom that Utah is a state that uses medications such as antidepressants and Ritalin to a greater extent than other places.

Since Utah’s rate for use of prescription medications was so much lower than that found in the FACCT field trial (12.1% in Utah versus 23.3% in FACCT Field Trial), we wanted to look at the use of prescription medicines by age and health insurance. While it is true that the uninsured group had much lower rates of prescription medication use (7.0% for uninsured children versus 12.2% for children covered by health insurance), the proportion of children in Utah who were without health insurance was quite small (6.5%, overall), and the lower prescription medication use rates did not change the overall prescription use rate substantially (insured children only, 12.2%, all children, 12.1%, see Table 2).

Table 2. Percentage of Children Who Used Prescription Medications (Q2A) by Age Group and Insurance Status

Age Group	Insured (n=2,332)	Not Insured (n=187)
Age 0-1	8.9	5.7
Age 2-4	5.6	3.3
Age 5-7	6.7	13.0
Age 8-10	11.6	8.5
Age 11-13	16.6	7.9
Age 14-18	19.4	5.7
All Ages	12.2	7.0

Hypothesis 2: Difference in question wording/structure.

The FACCT Utah Draft collapsed two follow-up questions, the FACCT/LWI broke them out.

Utah follow-up question: “Is this because of ANY medical, behavioral or other health condition lasting or expected to last for AT LEAST 12 months?”

FACCT Field Trial follow-up questions: “Is this because of ANY medical, behavioral, or other health condition?” “Is this a condition that has lasted or is expected to last 12 months or longer?”

Two sources of evidence speak against this hypothesis. First, if Utah’s lower CSHCN rate was due to the question structure, then we would have had similar rates on the screener questions, and differences in the follow-up questions. But it appears that we start out with different rates on the screener questions.

In addition, Debra Ried and Christina Bethell indicated that they have tested for effects of this methodological difference in their work, and the two question structures yielded very similar results. They indicated that the wording change would not make a difference in phone surveys. They have also tested the two- versus one-question follow up with behavior coding¹, and said that the one-question follow-up version held up well.

Hypothesis 3: Different sampling frames.

The Utah sample was a random sample of all children age 0 through 18 in the general population, whereas the FACCT Field Trial sample (and similar surveys that had been yielding the 18% estimates) was a CAHPS sample - all the children had health insurance, and had been enrolled in their current health insurance plan for at least 12 months. This alone should account for much of the difference in the two rate estimates, as CSHCNs are more likely to have health insurance. To test this hypothesis, we looked at the CSHCN rate among children in the 2000 Utah Child Health Survey who had been continuously insured for the past 12 months. Although these children were not necessarily on the same health plan during that time, they should be similar to the group in the CAHPS sample.

Had this hypothesis accounted for the difference, we would expect the Utah CSHCN rate among this group of children to increase to a level near 16%. Instead, the CSHCN rate among these children increased only modestly, so we continued to pursue the other hypotheses for the lower Utah estimate.

¹ Behavior coding is a process in which survey questions are pilot tested while a coder listens-in and codes for certain interviewer or respondent behaviors that would indicate a problem with the question. The coder would typically look for behaviors such as respondents asking for clarification, hesitating, giving irrelevant answers, interviewers needing to clarify a question, reread a question, etc.

Table 3. Percentage of Children in the Utah CHS2000 Who Were Considered CSHCN by Health Insurance Status

	Index Kids With Health Insurance Throughout Last 12 Months(1)
All Index Kids	
12.7%	13.1%

(1)Not necessarily the same health plan the entire 12 mos.

Hypothesis 4: Age distribution of Utah children.

The age distribution of Utah children may be more weighted toward the younger kids, and special health care needs are often not identified until a child is age two or older. Here is the age distribution of children in the CHS2000 survey compared with the age distribution of kids in Utah and kids in the U.S.

Table 4. Age Distribution of Utah Survey Subjects Compared With That of the Utah Population and FACCT Field Trial Subjects

Age Group	CHS2000 Survey (1)	Utah Pop (2)	FACCT Field Trial (3)
Age 0-1	14.1%	16.5%	4.0%
Age 2-4	19.8%	23.0%	26.5%
Age 5-7	24.6%	20.9%	24.2%
Age 8-10	21.3%	20.4%	23.7%
Age 11-13	20.2%	19.2%	21.5%

(1) Weighted survey data, kids insured for at least 12 mo., (2) GOPB Jan 2000 projections for July 2000, (3) FACCT field trial sample (3 health plans: 2 commercial, 1 Medicaid)

Table 5. Age Distribution of Utah Survey Subjects Compared With That of the Virginia Children’s Health Access Survey

Age Group	Utah CHS2000 Survey	Virginia Child Health Survey
Age 0-5	33.3%	31.1%
Age 6-9	20.9%	23.5%
Age 10-14	25.7%	24.7%
Age 15-18	20.0%	20.7%

Both surveys reported weighted survey data for all children, regardless of insurance

Table 6. Comparison of Age-Specific CSHCN Rates: Utah CHS2000 and FACCT Field Trial Surveys (% CSHCN in Each Age Group)

Age Group	Utah Age-Specific CSHCN (1)	FACCT Field Trial (2)
Age 0-1	5.2%	3.7%
Age 2-4	8.1%	11.9%
Age 5-7	8.6%	18.6%
Age 8-10	14.7%	20.9%
Age 11-13	19.5%	19.2%

(1) Weighted survey data, kids insured for at least 12 mo., (2) FACCT field trial sample (3) health plans: 2 commercial, 1 Medicaid

Table 7. Utah CSHCN Estimates Age-Adjusted to FACCT Field Trial Survey Standard Age Distribution

Age Group	Utah Age-Specific CSHCN (1)	FACCT Field Trial Age Distribution	Utah Rate Age-Adjusted to FACCT Field Trial Survey
Age 0-1	5.2%	4.0%	0.0021
Age 2-4	8.1%	26.5%	0.0215
Age 5-7	8.6%	24.2%	0.0208
Age 8-10	14.7%	23.7%	0.0348
Age 11-13	19.5%	21.5%	0.0419

Utah Age-Adjusted Rate: 12.11%

(1) Includes only index kids who were insured at the time of the survey and at all times during the previous 12 months.

Table 8. Comparison of Age-Specific CSHCN Rates: Utah CHS2000 and VCU Surveys (% CSHCN in Each Age Group)

Age Group	Utah Age-Specific CSHCN	Virginia Age-Specific CSHCN
Age 0-5	7%	12%
Age 6-9	12%	18%
Age 10-14	17%	26%
Age 15-18	17%	24%

Both surveys reported weighted survey data for all children, regardless of insurance

The prevalence of CSHCN increased substantially with age in the Utah sample. Table 4 shows the Utah survey sample contained more children aged 0-1 than the FACCT Field Trial sample, which could lower Utah's CSHCN rate. However, the proportion of children age five and under in the Utah survey was very similar to that in the Virginia survey (Table 5).

In comparing age-specific rates of CSHCN, the Utah survey identified fewer children as CSHCN in the 2 to 10 year age groups compared with the FACCT Field Trial. By the time the child is age 13, Utah appears to have "caught up" with the FACCT Field Trial sample rate (Table 6). We adjusted the Utah CSHCN rate to the FACCT Field Trial age distribution (Table 7) to see what effect the different age distribution would have on the Utah rate (i.e., what would the rate look like if the Utah survey age distribution was identical to the FACCT Field Trial age distribution?). After adjusting the Utah rate to the FACCT Field Trial age distribution, using only those children who were insured at the time of the survey and at all times during the previous 12 months, the Utah rate was 12.1%, still quite different from the FACCT Field Trial rate. Compared with age-specific rates from the Virginia Child Health Access Survey, Utah's rates appear to be lower for every age group.

CONCLUSIONS:

Although there was evidence to support the hypotheses for methodological and age distribution differences between Utah and other survey data, the differences were slight. It is unlikely that methodological or age distribution differences were responsible for Utah's lower CSHCN rate.

Examination of the age-specific rates did suggest that Utah rates may be lower in the younger age groups, but are almost identical to the FACCT Field Trial sample in the 11 to 13 year age group. This pattern of results suggests some possible explanations.

- (1) Utah has fewer CSHCN than other places
- (2) Younger children are less likely to be recognized by parents and identified by the health system as having a health problem. Children who have not been diagnosed with a special health care need will be less likely to be identified by the FACCT instrument as a CSHCN.
- (3) We could have fewer of the types of problems that affect young children, but the same amount of the types of problems that affect older children.

Compared with the Virginia survey data, however, the Utah survey sample yielded lower CSHCN rates in every age group, suggesting that Utah has lower CSHCN rates overall. Utah will continue to examine age-specific rates of various types of problems to attempt to address these questions further.