Does the FACCT Special Health Care Needs Screener Produce Biased Estimates of Children with Chronic Conditions?

During the past two decades, public health researchers have become increasingly interested in creating better survey-based instruments to identify children with chronic conditions. This subgroup of children has proven to be important to policymakers because their health care consumption is high relative to their numbers, and important to public health officials because children with chronic conditions are an especially needy group that can experience significant consequences if they do not receive adequate care. Exactly who is being referred to when "children with chronic conditions" are discussed has been contested. Over time, a dominant conceptualization of children with chronic conditions has emerged. This definition, the product of a Maternal and Child Health Bureau (MCHB)-sponsored workgroup formed in the early 1990's, defines these children as children with special health care needs (CSHCN):"those children who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally"[1].

Along with competing definitions of the population of interest have come competing survey-based methods of identifying these children. In general, these methods have relied upon parental report to identify CSHCN and all have left aside the question of how to identify children who are at risk of developing chronic conditions. In recent years, the most commonly used operationalization of the special health needs concept has been the screener developed by the Foundation for Accountability (FACCT). FACCT'S screener is based on MCHB's definition of CSHCN, as well as the empirical methodology of the Questionnaire for Identifying Children with Chronic Conditions – Revised (QuICCC-R)[2,3]. Although there is no acknowledged "gold-standard" method for identifying children with chronic conditions, the FACCT screener is becoming the de facto preferred method of providing population estimates of children with chronic health conditions. The FACCT has already been employed by several well-known population-based surveys to provide population based estimates of children with chronic conditions, including the 2001 National Survey of Children with Special Health Care Needs, the 2002 National Health Interview Survey and the 2003 National Survey of Child Health. The FACCT screener is shown in Table One below.

Table One. The FACCT Screener Items (adapted from the 2002 NHIS Child Questionnaire)

(1) Does [CHILD] need or use any medications prescribed by a doctor (excluding vitamins)?
      (a) **[IF (1) IS YES]** Is this need/use due to a medical condition?
      (b) **[IF (1) IS YES AND (A) IS YES]** Has this condition lasted or is this condition expected
         to last for 12 months or longer?
(2) Does [CHILD] need or use more health care, educational or mental health services than
   [HIS/HER] peers?
      (a) **[IF (2) IS YES]** Is this need/use due to a medical condition?
      (b) **[IF (2) IS YES AND (B) IS YES]** Has this condition lasted or is this condition expected to last for 12 months or
         longer?
(3) Is [CHILD] limited in [HIS/HER] ability to do things most children [HIS/HER] age can do?
      (a) **[IF (3) IS YES]** Is this limitation due to a medical condition?
      (b) **[IF (3) IS YES AND (B) IS YES]** Has this medical condition lasted or is this condition expected to last for
         12 months or longer?
(4) Does [CHILD] need or use any special therapy (such as speech or occupational therapy)?
      (a) **[IF (4) IS YES]** Is this need/use due to a medical condition?
      (b) **[IF (4) IS YES AND (A) IS YES]** Has this medical condition or is this condition expected to last for 12
         months or longer?
(5) Does [CHILD] have an emotional, behavioral, or developmental problem?
      (a) **[IF (5) IS YES]** Has this problem lasted or is this problem expected to last for 12 months or longer?

[1] Kogan, Michael D. and Peter C. van Dyck. 2005. "The National Survey of Children with Special Health Care Needs: Using State-Level Data to Improve Systems of Care for Children". *Maternal and Child Health Journal* 9S(2): s1-s2.

[2] Bethell, Christina D.; Debra Read; Ruth E.K. Stein; Stephen J. Blumberg; Nora Wells; and Paul W. Newacheck. 2002. "Identifying Children with Special Health Care Needs: Development and Evaluation of a Short Screening Instrument". *Ambulatory Pediatrics* 2(1): 38-48.

[3] Stein, Ruth E.K.; Ellen Johnson Silver; and Laurie J. Bauman. 2001. "Shortening the Questionnaire for Identifying Children with Chronic Conditions: What is the Consequence?" *Pediatrics* 107(4): 61-65.

To date, the focus of most analyses of CSHCN has been an applied one, mainly serving the planning needs of policy makers and public health officials. Moreover, the majority of scholarship in this area employs certain assumptions that have become reified and taken for granted in work around CSHCN. Use of the FACCT is the result of a shift in the measurement of children with chronic conditions from a using checklists of diagnosed conditions to a focus on a consequences-based framework. The major consequence the FACCT is intended to measure is heightened reliance on specialty health care services as a consequence of having a chronic condition. However, the assumption underlying the FACCT screener's reliance on measuring consequences in this way is that all children with chronic conditions can be identified equally well through the assessment of needs for specialty health care services. The problem with such an assumption, however, is the premise that all children have an equal chance of being identified as "needy" in the first place. This premise involves a number of smaller assumptions: 1) that identification of need can precede access to appropriate personnel for all children with chronic conditions; 2) that given access to appropriate personnel, a diagnosis of the underlying condition will occur; and 3) that the diagnosis will be translated into the perception of an elevated need for specialty health care services on the part of parents and children. The second two assumptions hinge on the quality of the health care received by children with chronic illness or disability.

Sociologists can contribute to the ongoing discussion of how best to identify CSHCN by analyzing how the boundaries and categories created by our health care system intersect with socioeconomic and ethnic dimensions of health and well-being for children with chronic conditions.[4] Previous research in both the social sciences and public health have repeatedly provided evidence of racial, ethnic, and socioeconomic disparities across a number of health-related outcomes that are integral to the assumptions underlying the FACCT screener. Because minority and low-SES groups have historically had higher levels of poor health, and *if the FACCT screener is not biased by issues of health care access and quality, we would expect that low-SES and minority children will be identified at higher levels than other children (1)*. However, *if the FACCT screener is influenced by access to quality health care, we would expect that low-SES and minority children will be identified at lower rates than other children (2)*. In this paper, I will use population data to investigate whether the FACCT screener differently identifies children belonging to groups who have historically had poorer access to good quality health care and with higher levels of poor health outcomes. By first providing a thorough description of which children are identified as having chronic conditions and their access to health care and family contexts, and then examining whether racial, ethnic, or socioeconomic characteristics contribute to the probability of children being identified as having chronic conditions, the work done here can help clarify whether the current FACCT screener provides biased estimates of children with chronic conditions.

Data and Methods

To answer the questions raised here, this study uses the 2002 National Health Interview Survey (NHIS) Child Sample. The NHIS is an annual population-based survey conducted through personal household interviews with the adult most knowledgeable about the health of everyone in the family. The child sample includes one randomly selected child from each household that serves as a focal child. The 2002 NHIS child survey had a response rate of 88.1%, yielding a sample size of 12,524 children between 0 and 17 years of age. 1,811 of these children are identified by the FACCT screener as having a special health care need. In addition to the FACCT screener, the 2002 NHIS also includes sociodemographic information, in-depth questions about access to health care, health care utilization, health status, functional limitations, and the child's family context. To measure access to health care, I use the American Academy of Pediatrics (AAP)'s concept of the medical home[5] using measurements similar to those suggested by Bethell, Read, and Brockwood (2004)[6].

Preliminary Findings

Preliminary analyses focused on two substantive areas: (1) The prevalence of diagnosed chronic conditions among children who were not identified by the FACCT screener and their characteristics and (2)

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[4] Haritos, Rosa and Thomas R. Konrad. 1999. "A Timely Partnership: Sociology and Health Services Research". *Contemporary Sociology* 28(5): 529-536.

[5] American Academy of Pediatrics. 2002. "The Medical Home". *Pediatrics* 110(1): 184-186.

[6] Bethell, Christina D.; Debra Read; and Krista Brockwood. 2004. "Using Existing Population-Based Data Sets to Measure the American Academy of Pediatrics Definition of Medical Home for All Children and Children with Special Health Care Needs". *Pediatrics* 113(5): 1529-1536.

Socio-demographic and health-related characteristics of children by whether or not they were positively identified by the FACCT screener.

Among children not identified as having chronic conditions by the FACCT screener, approximately 895 (8%) reported having been diagnosed with a chronic condition such as down syndrome, sickle cell anemia, congenital heart problems or asthma. Examining these children gives us a rough idea of whether or not there are systematic differences among children that presumably should have been identified by the FACCT screener. To avoid small cell sizes, categories have been collapsed into broader groupings. Observing Table Two below, we can see that children significantly more likely to have a diagnosed chronic condition but not identified by the FACCT screener are living in households above the poverty line and in households where only one or neither parent is present. Differences by race/ethnicity and parental education are not statistically significant.

Table Two. Prevalence of Diagnosed Chronic Conditions Among Children Not Identified by the FACCT Screener by Race/Ethnicity and SES

Sociodemographic Characteristics	Has Diagnosed Chronic Condition?	
	No	*Yes*
Race/Ethnicity		
Non-Hispanic White	91.4%	8.6
Other	91.9%	8.2
Income to Poverty Ratio*		
Below poverty	92.1%	7.9
Above poverty	89.8%	10.2
Parental Education		
HS or less	92.2%	7.8
More than HS	91.4%	8.6
Family Structure*		
Two-parent family	93.0%	7.0
Other type of family	88.6%	11.4

*Differences are significant at p<0.05.
[1]Source: 2002 National Health Interview Survey Child Sample
[2]N = 10,713; N_{No} = 9,818; N_{Yes} = 895.

In Table Three below, we can see that children who have been diagnosed with a condition but not picked up by the FACCT screener are more likely to have a medical home, but also have poorer health outcomes. They are significantly more likely to have a functional limitation, be in fair or poor health, visit the doctor six times or ore, visit the emergency room at least once, and are nearly twice as likely to miss six or more school days because of illness or injury. As previous research has suggested, it appears that having better access to health care is related to probability of having a diagnosis.

Table Three. Prevalence of Diagnosed Chronic Conditions Among Children Not Identified by the FACCT Screener by Health Status and Access Indicators

Health Status and Access Indicators	Has Diagnosed Condition?	
	No	*Yes*
Has a Medical Home*	79.2%	81.5%
Insured	82.9%	82.1%
Has Functional Limitation*	3.9%	21.9%
Health is Fair/Poor*	0.6%	3.5%
Made 6+ Doctor Visits*	27.0%	37.1%
Made 1+ ER Visits*	19.5%	29.1%
Stayed 1+ Nights in Hospital	6.0%	4.7%
Missed 6+ School Days (Illness/Injury)*	12.4%	23.4%

*Differences are significant at p<0.05.
[1]Source: 2002 National Health Interview Survey Child Sample
[2]N = 10,713; N_{No} = 9,818; N_{Yes} = 895.

In the next two tables in this section, I examine the proportion of children positively identified by the FACCT screener within each demographic and socioeconomic subgroup. In the last table, I examine the proportion of children with each health-related characteristic within the non-chronic health conditions group and the chronic health conditions group.

Children older than age five, males, and either non-Hispanic Whites or Blacks are significantly more likely than other demographic subgroups to be identified as having a chronic condition. Far fewer children four years of age or younger are likely to be identified as having a chronic health condition than older children (6.5% versus about 18%). Approximately 5% more boys than girls are positively identified by the FACCT screener. Non-Hispanic White and Black children were about equally as likely to be identified as having a chronic health condition, where children in other racial or ethnic groups were about half as likely to be identified as having a chronic health condition (17% versus 9%). The percentages of each demographic subgroup by FACCT screener identification status is in Table Four below.

Table Four. Demographic Characteristics of Children by FACCT Screener Identification Status

	Screener Identification Status	
Demographic Characteristics	*No*	*Yes*
Age*		
0-4 years	93.5%	6.5
5-11 years	82.8%	17.2
12-17 years	80.9%	19.1
Sex*		
Male	82.8%	17.3
Female	87.5%	12.5
Race/Ethnicity*		
Non-Hispanic White	83.0%	17.0
Hispanic	91.5%	8.5
Non-Hispanic Black	83.5%	16.5
Non-Hispanic Other	91.0%	9.0
Income to Poverty Ratio		
Below poverty	82.0%	18.0
Adequate	84.2%	15.8
Secure	84.7%	15.3
Family Structure*		
Neither parent in home	79.9%	20.2
One parent in home	81.0%	19.1
Both parents in home	86.7%	13.3
Parental Education*		
Less than HS	87.2%	12.8
HS graduate	84.2%	15.8
Some college	85.2%	14.8
College graduate	86.2%	13.8

*Differences are significant at p<0.05
[1]Source: 2002 National Health Interview Survey Child Sample
[2]N = 12,524; N$_{No}$ = 10,713; N$_{Yes}$ = 1,811.

Differences in the proportion of children positively identified by the FACCT screener by family structure and parental education are statistically significant, and differences by household income are not statistically significant. Children with both parents in the home were less likely to be identified by the screener than children with one or no parents in the home (13% versus approximately 20%). The relationship between parental education and screener identification is less clear cut. Children whose parents have less than a high school education are least likely to be identified as having a chronic health condition, and those with parents that are college graduates are the second least likely. Nearly 16% of children whose parents had a high school degree were identified as having a chronic health condition, making them the most likely to be identified by the FACCT screener.

Table Five. Health Access and Status Indicators by FACCT Screener Identification Status

Health Access and Status Indicators	Screener Identification Status	
	No	*Yes*
Has Medical Home*	79.4%	86.1%
Health Insurance*		
Uninsured	6.5%	6.1%
Privately insured	76.4	80.9
Publicly insured	17.1	13.0

*Differences are significant at p<0.05
[1]Source: 2002 National Health Interview Survey Child Sample
[2]N = 12,524; N_{No} = 10,713; N_{Yes} = 1,811.

Overall, children who were identified by the FACCT screener had better access to health care but worse health status levels. This pattern is similar to the one we observed for children with diagnosed chronic conditions who had not been identified by the FACCT screener, suggesting that those children are similar to children positively identified by the FACCT screener. Referring to table five above, positively identified children were nearly 7% more likely to have a medical home and less likely to be uninsured or publicly insured (19% versus 24%). However, when looking at table three, also note that they were also 7 times as likely to have a functional limitation, 8 times as likely to be in fair or poor health, nearly 3 times as likely to visit the doctor 6 times or more, twice as likely to have 2 or more visits to the emergency room, and four times as likely to miss 11 or more school days because of illness or injury.

Table Six. Health Status Indicators by FACCT Screener Identification Status

Health Status Indicators	Screener Identification Status	
	No	*Yes*
Has Functional Limitation*	5.4%	37.8%
Health Status*		
Excellent	58.8%	38.1%
Very good	27.7	29.4
Good	12.6	24.1
Fair/Poor	0.9	8.5
Doctor Visits*		
None	12.7%	3.7%
1 visit	22.9	8.8
2-3 visits	36.5	29.0
4-5 visits	15.7	23.6
6 or more visits	12.2	35.0
Emergency Room Visits*		
None	79.4%	67.0%
1 visit	14.4	18.5
2 or more visits	6.2	13.6
Nights Spent in Hospital		
None	94.1%	93.0%
1 or more nights	6.5	7.7
School Days Missed Due to Illness/Injury*		
0-5 days	86.6%	68.8%
6-10 days	9.6	16.9
11 or more days	3.9	14.3

*Differences are significant at p<0.05
[1]Source: 2002 National Health Interview Survey Child Sample
[2]N = 12,524; N_{No} = 10,713; N_{Yes} = 1,811.

The descriptive information above suggests that race, ethnicity, socioeconomic status, and access to health care all have a complex relationship with whether or not a child is positively identified by the FACCT screener. The information contained in table one indicates that the health dynamics of Hispanic and minority groups other than Black are different than health dynamics among White and Black children. Moreover, the prima facie differences between levels of household income do not appear to contribute to the likelihood that a child will be positively screened, despite the relationship of income to other potentially intervening factors such as access to health care. Analyses to be carried out will determine if these relationships will change when we control for other factors.