



Approaches to Identifying Children and Adults with Special Health Care Needs

**A Resource Manual for
State Medicaid Agencies
and Managed Care Organizations**



*Prepared by CAHMI-
The Child and Adolescent Health Measurement Initiative
On behalf of the Centers for
Medicare and Medicaid Services*

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Background and Acknowledgements

This resource manual was developed with substantial input and guidance from the Special Health Care Needs Advisory Committee convened for this purpose. The advisory group met twice in-person and six times by teleconference to review and approve the outline of this manual as well as the design and testing of the adult special health care needs screening tool included here. In addition, the development of this manual benefited from input by State Medicaid members of CMS's Quality Technical Advisory Group and other Medicaid managed care organization representatives who participated in a national in-person meeting held in collaboration with the Health Services and Resources Administration.

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Please note: FACCT-The Foundation for Accountability closed in 2004. This manual and its authors are now with the CAHMI - The Child and Adolescent Health Measurement Initiative; previously based at FACCT and now with Oregon Health & Science University.

Introduction and Purpose

The goal of this manual is to provide State Medicaid Agencies and managed care organizations (MCOs) with information and resources regarding tested tools and methods for identifying children and/or adults with special health care needs. The Centers for Medicare and Medicaid Services of the U.S. Department of Health and Human Services has repeatedly highlighted the important need for such tools and methods:

- In 1999, CMS (then HCFA) first released in draft form criteria to be used in granting certain federal waivers to State Medicaid agencies planning to require children with special health care needs (CSHCN) to enroll in Medicaid managed care organizations. These waiver criteria articulated the need for such programs to have in place a process to identify these children and were issued in final form in a letter dated January 17, 2001 to all State Medicaid Directors.
- In January 2001, CMS released a report to Congress titled “Safeguards for Individuals with Special Health Care Needs Enrolled in Medicaid Managed Care.” This report contained a comprehensive set of recommendations to ensure that the needs of populations with special health care needs are being met and appropriate services provided under Medicaid managed care initiatives. Identification of enrollees with special health care needs is described as one of the essential ingredients or “first-tier priorities” for the successful implementation of these recommendations.
- Finally, in 1998 and 2001, CMS issued both proposed and final rules to implement the new managed care provisions of the Balanced Budget Act of 1997. While these regulations had not been finalized when this manual was written, regulatory issuances in January and August 2001 both called for State Medicaid agencies to implement methods to identify both children and adults with special health care needs.

This resource manual will assist States and managed organizations to identify child and adult Medicaid enrollees with special health care needs by:

- Outlining key questions to consider before selecting an identification method or tool, or to ask when evaluating an existing strategy;
- Describing approaches to define special health care needs populations and choices to operationalize a definition;
- Summarizing and comparing alternative methods and tools designed and/or tested for purposes of identifying special health care need populations;
- Noting special issues or considerations in selecting and implementing an identification method.

States which have already developed methods to identify children and/or adults with special health care needs may choose to continue using those methods. States without such methods in place or those wishing to assess and/or modify current practices may find the information presented in this manual to be valuable. All States should find the discussion of the currently available methods for finding people with special health care needs useful as they design strategies for ensuring high quality health care for Medicaid clients.

Section 1:

Who Are People With Special Health Care Needs?

Children and adults with special health care needs are a diverse group. They experience health conditions ranging from asthma or hypertension to severe mental and physical disorders. Their levels of disability may vary from speech disorders to quadriplegia. The type and intensity of services they need range from the regular use of prescription medicines to 24-hour nursing care. Added to this diversity is the fact that no absolute standard has been established for what constitutes a special health care need.

This absence of a definitive test or “gold standard” for determining the presence of a special health care need means that other criteria must be used. Most definitions of special health care needs incorporate, at a minimum, one or more of the following components:

- Functional limitations
- Need for health-related services
- Presence of a health condition
- Minimum expected duration of health condition (e.g., 12 months)

Definitions differ in the specific criteria used to characterize each of these components and how much emphasis each is given. As a result, prevalence estimates and descriptive profiles of special health care needs populations also vary widely according to the definition and criteria used.

For example, many definitions of special health care needs explicitly incorporate the concept of “disability” as one of their components. The United States government has generated over 40 different legislative definitions of disability (Mashaw and Reno, 1996). Depending upon which is used, the prevalence estimates of disability in the United States population range from seven to 21 percent. In the same way, estimates of special health care needs also vary according to the specific characterizations of disability and/or other elements included as part of any specific definition.

Continuum of options for defining special needs groups

When the components of an ongoing health condition, service use need, and functional limitations are considered simultaneously, options for determining whether a child or adult qualifies as having special health care needs become increasingly complex. The result is a continuum or range of possibilities for defining children and adults with special health care needs (Figure 1).

Figure 1: Continuum of Options for Defining Children and Adults With Special Health Care Needs

	Group A	Group B	Group C
	Most inclusive definitions, includes "at risk" groups (A + B + C)	Broader definitions, includes those with wide array of conditions, levels of severity and services needs (B + C)	Narrowest definitions, only includes those with very severe conditions or highly complex needs (C only)
No special health care needs	At risk for developing a special health care need	Ongoing health conditions; above average service use needs; few to moderate functional limitations	Ongoing health conditions high or complex services use needs; moderate to severe functional limitations
Range of prevalence estimates ¹		Children 0-12 yrs 15-20% Adol. 13 - 17 yrs 23-30% Adults <65 yrs 30-40% Adults >65 yrs 55-75%	3 - 5% 5 - 10% 10 - 15% 15 - 25%

¹ **Sources:** CSHCN Screener data: Bethell and Read, 2000; Bethell and Lansky, 2000, FACCT—The Foundation for Accountability; 3M CRG Data: John Muldoon, National Association of Children's Hospitals and Related Institutions (NACHRI), 2000; Estimates for people with functional impact: National Health Interview Survey (NHIS) results—1994, National Center for Health Statistics; Survey of Income and Program Participation (SIPP) results—1994-95, McNeil, J, 1997—US Department of Commerce, Bureau of the Census.

As shown in Figure 1, definitions of special health care needs can be more or less inclusive. Deciding where to draw the definitional line on the continuum has implications for the types of special needs and numbers of individuals identified. Therefore, it is important that decisions about who to include reflect the specific purpose(s) for identifying children or adults with special health care needs.

The narrowest definitions (Figure 1; Group C) include only those individuals having the most serious or debilitating types of conditions as well as significant disability or complex service use needs. Research indicates that three to five percent of children, five to 10 percent of adolescents and, depending upon age, 10 to 25 percent of adults have special health care needs that fall into this category. Examples might include:

- Children with spina bifida, muscular dystrophy, or severe mental retardation;
- Adults with serious or persistent mental illness, Alzheimer's disease, advanced heart disease, or in the terminal stages of cancer;
- Adults and children whose physical disabilities prevent or severely limit daily activities or self-care.

Broader definitions of special health care needs (Figure 1; Group B + Group C) include the diversity of diagnoses, levels of disability, and types and intensity of service use associated with a range of chronic health conditions – not simply those resulting in a serious loss of functioning. Such definitions are usually aimed at identifying a significant proportion of all those considered as having special health care needs. According to definitions of this type, 15 to 20 percent of children, 23 to 30 percent of adolescents, and 30 to 75 percent of adults have evidence of special health care needs (Figure 1).

In addition to identifying individuals who qualify under the narrowest definitions, broader definitions will include individuals such as:

- Children and adults with asthma or diabetes;

- Children and adolescents with ADHD and other emotional or developmental disabilities;
- Persons with heart disease, major depressive and other mental disorders, osteoarthritis, orthopedic impairments, or many other chronic conditions.

The last definitional category (Figure 1; Group A + Group B + Group C) includes not only the individuals described above but also those at risk for developing a special health care need. As with the term “special needs,” no definitional standard currently exists for determining “at-risk.” However, any discussion of special health care needs is incomplete without addressing this concept.

First, special health care needs populations are dynamic. Individuals with seemingly mild or moderate special needs are often at-risk of developing more serious or debilitating health problems. This transition can be rapid or occur over time. A case of well-managed Type II diabetes, for example, can quickly result in serious complications if an individual stops taking medication to control blood glucose level. On the other hand, the consequences of untreated high blood pressure or high cholesterol may take years to manifest.

Second, the definition of who is “at-risk” is also dynamic. Depending on where the definitional line is drawn on the special needs continuum, individuals whose needs are not included may become part of an “at-risk” group. For example, when a narrower definition is implemented (Group C), individuals normally included under a broader definition of special needs immediately become part of a group which is at heightened risk for developing more serious or debilitating health problems.

Approaches to defining special needs groups

Definitions also differ in the conceptual approach or starting point used to determine the criteria for who qualifies as having a special health care need. The most common conceptual approaches to specifying such needs are:

- Program-based approaches, which use eligibility in specific programs such as Supplemental Security Income (SSI), Title V children with medical handicap services, or foster care as the definitional criteria;
- Diagnosis-based approaches, which rely on clinically identified or self-reported health conditions as the starting point;
- Consequences-based approaches, which focus on the manifestations of functional limitations or service needs that may be the result of chronic health conditions.

Given the possibilities for defining individuals with special health care needs, State Medicaid Agencies and MCOs will encounter a series of choices and tradeoffs when determining where on the definitional continuum to focus and which conceptual approach to use. These decisions will be influenced as much by the purpose for identification as by currently available methodologies and the technical and data capacities for implementing them.

States and MCOs should find the key questions discussed in Section 3 helpful for addressing the considerations, choices, and challenges inherent to the process of identifying children and/or adults with special health care needs.

Section 2:

Why Identify People with Special Health Care Needs?

There are numerous reasons why identifying children and adults with special health care needs is a relevant activity for State Medicaid Agencies and MCOs:

- Individually and as a group, Medicaid enrollees with special health care needs typically require a greater diversity, intensity, and coordination of services than other Medicaid enrollees.

The type, scope, and frequency of health care service use that characterizes adults and children with special health care needs makes them a key group for early identification, follow-up, and potential case management.

- The diverse needs of Medicaid enrollees with special health care needs cannot adequately be served unless such individuals are identified.

Such Medicaid enrollees often have co-existing conditions that must be treated simultaneously, often by different service providers and with multiple funding streams. Access to services, continuity and coordination of care, and utilization of appropriate payment mechanisms cannot be ensured unless these individuals are identified. The ability to estimate the prevalence of people with special health care needs within a health plan means that resources and planning can potentially be targeted more effectively.

- People with special health care needs account for the majority of health care costs.

Chronic diseases such as heart disease, diabetes, and cancer are the leading causes of disability and mortality among adults in the United States. Conditions of this type account for 75 percent of the \$1 trillion spent on health care each year in the United States (CDC, 2002). Eighty to ninety percent of children's health care dollars are spent on

children with chronic conditions (Institute of Medicine, 1998; Neff and Anderson, 1995; Lewit and Monheit, 1992).

Improvements in care stimulated by measuring and improving quality for these population have the potential to reduce costs – both by helping avoid acute flare-ups, complications, hospitalizations, or emergency care for people with special health care needs, and also by identifying strategies to more efficiently organize and deliver care. Identifying these individuals can help assess the need for programs to manage and minimize avoidable health care expenses, and evaluate the success of such interventions.

- As a group, people with special health care needs can provide a more sensitive indication of health care quality.

Those with special health care needs often have increased exposure to all aspects, both good and bad, of health systems or providers. Because of the frequency, scope, and intensity of such contact, quality assessment based on the experience and outcomes for this population can provide a more comprehensive view and sensitive indicator of health care quality.

- Care quality for people with special health care needs is often inadequate.

Empirical research continually reveals deficits in the quality of care received by people with special health care needs (Bethell, 2000; NCQA, 2000). Measuring quality for this population can stimulate improvements in care with the potential to increase positive health outcomes through improving day-to-day functioning, increasing adherence to medical advice, and reducing emergency episodes.

Before the quality of their care can be examined and improved such individuals must first be identified. Quality assessment is particularly essential because MCO financial incentives, utilization management

review, and provider panels are likely to have greater implications for the care received by special health care needs populations.

An evolving field

The issue of identifying child and adult Medicaid enrollees with special health care needs has only emerged recently, along with current efforts by States to mandate enrollment of greater numbers of such beneficiaries into MCOs. Prior to this, identification of beneficiaries with such needs received little attention under fee-for-service Medicaid. As a result, Medicaid agencies typically do not employ mechanisms for designating a beneficiary as having special health care needs.

Evidence further suggests that MCOs rarely have mechanisms in place to uniformly identify all individuals with special health care needs among their enrollees. In fact, research shows that despite receiving higher rates for such enrollees, most MCOs are unlikely to know whether a new Medicaid enrollee has a chronic condition or a disability (Kaiser Commission, 1999).

The lack of routine or uniform identification of individuals with special health care needs is due to the newness of the perceived need for doing so and the methodological issues involved. Despite these challenges, a number of States and MCOs have begun to screen new enrollees to identify beneficiaries in need of case management services or specialized care. As such efforts increase so does the need for well-tested and validated screening tools that can be used to identify such individuals across a variety of purposes and settings.

As in all evolving fields, much is still to be learned about methods for identifying people with special health care needs and the challenges and benefits of doing so. Experience and knowledge in this area will increase as the practice of identifying special health care needs populations becomes more widespread. As methods are refined, evidence is expected to accumulate for the most efficient, feasible, and effective practices.

Section 3:

Selecting an Identification Strategy – Five Key Questions

There are five key questions for States and MCOs to consider when selecting and implementing an identification strategy. As Figure 2 illustrates, these questions are interrelated and will be revisited many times in the process.

1. **PURPOSE:** Why do you want to identify people with special health care needs?
2. **TARGET:** Who do you want to identify?
3. **DEFINITION:** How will you define special health care needs?
4. **CAPACITY:** What data and technical capacity do you have available?
5. **ATTRIBUTES:** What is important to consider when selecting methods and tools?

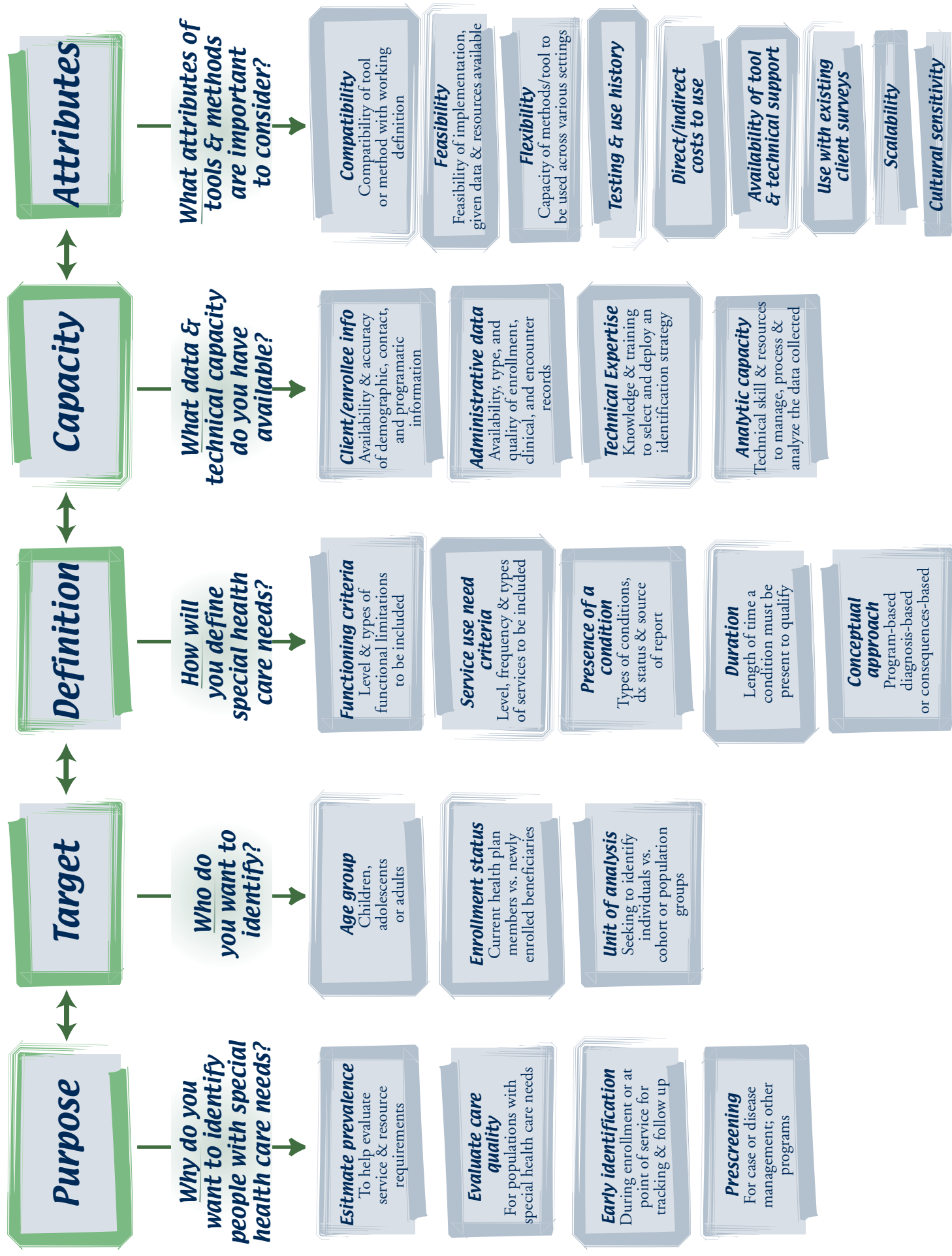
Figure 2: Key Questions for Selecting and Implementing Strategies to Identify People with Special Health Care Needs



The purposes that States or MCOs have for identifying children or adults with special health care needs directly influence the target populations and definitions chosen. In turn, the definition selected and populations to be targeted have implications for the methods or tools that can be considered. Each of these decisions are also influenced by the type and quality of available data, the technical capacity for collecting and analyzing them, and such attributes as the availability and cost of different methods or tools.

Figure 3 summarizes the specific considerations entailed in answering each of the five key questions. States and MCOs are encouraged to use these questions as a guide to help ensure relevant issues are adequately addressed when selecting and implementing identification strategies. Each of these key questions is examined in more detail on the following pages.

Figure 3: Selecting an Identification Strategy – 5 Key Questions



1. **PURPOSE: Why do you want to identify people with special health care needs?**

The purposes that States or MCOs have for identifying children and/or adults with special health care needs include:

ESTIMATING the prevalence of individuals with special health care needs either statewide or within a specific health plan or program to help evaluate service and resource requirements, and also to inform service planning, payment, and other activities.

EVALUATING the quality of care received by populations with special health care needs in order to ensure that these needs are being adequately met.

PROSPECTIVELY IDENTIFYING individuals with special health care needs at health plan enrollment or point of service for further assessment and follow-up or quality assurance activities.

PRE-SCREENING to identify individuals whose particular needs indicate they may benefit from case management, disease management, or similar programs.

Specifying the purpose(s) for identifying people with special health care needs is the first step in the selection and implementation of an identification strategy. All subsequent decisions will be guided by the explicit purpose(s) for identifying a particular population.

For example, suppose a State or MCO wishes to identify individuals with special health care needs from among Medicaid beneficiaries newly enrolled in managed care for the purpose of follow up assessment and potential case or disease management. Given such goals, they might want to consider:

- Broader definitions of special health care needs that cast a wider net and decrease the chances of missing potential cases.

- Tools and methods that are not dependent on clinical or administrative records since new enrollees will lack both.
- Methods and tools that provide person-level information and results that make it possible to identify individuals in order to track them for follow-up activities and evaluations.
- Methods and tools with the capacity to identify subgroups according to type of special need or level of service use in order to prioritize and tailor follow-up activities.
- Methods and tools with the flexibility to be used reliably in a variety of settings and across multiple administration modes. Administration modes include self-administration by pencil and paper, computer touch screen, and telephone or face-to-face interviews.

Alternatively, if the purpose for identifying people with special health care needs is to estimate population prevalence or assess care quality, a different set of priorities emerges. The capacity to track specific individuals is no longer an important factor as both purposes require random sampling techniques and rely on grouped, rather than person-level, data to generate results. Tools and methodologies which can be used with existing client surveys or permit survey data to be anonymously linked with clinical and administrative records can provide economies of scale and maximize the usefulness of data. The technical capacity available for data collection and analysis increases in importance when population-level identification is the goal.

2. TARGET: Who do you want to identify?

The purpose for identifying people with special health care needs helps determine the characteristics of the group targeted for identification. In turn, the characteristics of the population being targeted have direct implications for the types of definitions, methods, or tools considered and ultimately selected. These characteristics include:

- Age Group
- Enrollment Status
- Unit of Analysis

AGE GROUP: The age range of the population (adult, adolescent or children) being targeted has important implications for the definitions that will apply, the suitability of different methods and tools, the numbers identified, and types of special needs represented.

For example, the epidemiology of childhood special health care needs is quite different from that of adults. Relative to adults, the overall prevalence of childhood chronic disease is low, the number of potential conditions high, and few children experience any specific one. Children are also a “moving target” developmentally with differing abilities at different ages. Not being able to walk or get dressed alone is appropriate functioning for some age groups, but represents major disability in others.

Consequently, when children are the targeted population, the definition of special health care needs selected must take these factors into account. Tools or methods developed specifically for child populations will be necessary.

ENROLLMENT STATUS: The purposes for identifying people with special health care needs – and the tools or methods used – will vary depending on whether a State or MCO wishes to target newly enrolled health plan members or those who have been with the plan for some length of time.

For example, newly enrolled members are unlikely to have clinical or administrative records available to States and/or MCOs. Identification methods which rely on such data cannot be used. Self-report and/or interviewer-based methods may be the only viable options for screening.

When currently enrolled health plan members are the targeted population, length of continuous enrollment is a factor. Most diagnosis-based approaches using administrative records require at least six to 12 months of encounter data in order to be used with reasonable accuracy.

UNIT OF ANALYSIS: When selecting among tools and methods for identifying special health care needs, it is important to distinguish whether unique individuals or population groups are the targets. Not all methodologies are suitable for both.

If newly enrolled health plan members are being screened in order to conduct follow-up assessments or develop care plans for individuals having special health care needs, the tools and methods employed must be capable of generating unique, mutually exclusive results for each person screened. Information that allows individuals to be contacted later or be linked to their primary care physician is also necessary to implement follow-up activities.

If screening is conducted at the household level, the methods and tools selected must be capable of collecting individually identified screening results and other information for each child or adult in the household. It is also important to establish confidentiality protocols for handling and transmitting individual-level information containing screening results that comply with privacy standards.

In contrast, it is not necessary to target unique individuals in order to estimate prevalence or assess the quality of care for groups having special health care needs. These goals rely instead on grouped or aggregate-level results to obtain a “big picture” snapshot of how many in a population have a special health care need or report specific aspects of care. Random sampling techniques can maximize efficiency and accuracy as well as minimize the cost of data collection

for population-level groups. When survey methods are used, data collection and handling protocols that ensure confidentiality are necessary to encourage responses and help minimize biases in reporting.

3. DEFINITION: How will you define special health care needs?

Developing a working definition of special health care needs is one of the most important and challenging aspects of selecting and implementing an identification strategy. The first step is to choose a conceptual definition aligned with the goals, purposes, and intents of the project. Depending on the specific goals and purposes for identification, such a definition will be more or less inclusive of the range of what are considered to be special needs. Narrower definitions of special needs may be appropriate if the goals of the project warrant identifying only those individuals with specific conditions, severe disabilities or the most complex service needs. On the other hand, broader definitions are necessary when the goal is to be as comprehensive as possible across the range and diversity of special health care needs.

Figure 4: Continuum of Special Health Care Needs



As Figure 4 shows, there is an array or continuum of special health care needs that potentially can be addressed. In the absence of an absolute standard for determining what constitutes a special health care need, decisions about where to intervene on this continuum are always somewhat arbitrary. “Gray”

or ambiguous areas regarding whether certain cases should or should not be included will always exist at the boundary lines of any chosen definition. States will want to consider such trade-offs when selecting a definition of special needs.

Developing a working definition

Limitations in functioning, the need for special services, and the presence of health conditions of different types or duration are commonly used either alone or in some combination when defining special health care needs. The process of developing a working definition includes specifying which of these are required to qualify an individual as having a special need. As discussed, the reasons for identifying people with special needs can vary. The combination of definitional elements and criteria selected for a working definition should, therefore, reflect the specific purposes and goals of the identification strategy being implemented.

Questions to guide the selection and specification of the definitional elements used in a working definition are presented below:

FUNCTIONING CRITERIA:

- Is having a current limitation in function a necessary criterion?
- Alternatively, if appropriate health care eliminates or reduces the frequency of limitations for people with certain chronic conditions (e.g., diabetes), should these individuals still be considered as having a special health care need?
- What types of functioning are important to include (e.g., physical, mental, emotional, and social role functioning)?
- Is there a threshold or level of limitation that must be present to qualify an individual as having a special need?

- What sources of information about level of functioning should be considered, are available, and/or are reliable (e.g., self-report by an individual or proxy, physician report, medical charts or records)?

SERVICE USE CRITERIA:

- Is the need for or use of health and related services a necessary criterion?
- Should individuals with diagnosed conditions that do not result in routine need or use of health or related services also be considered for having a special health care need?
- What types and level of service need or use are important?
- What source(s) should determine or confirm the need for or use of health and related services (e.g., self or proxy report, physician report, medical charts or records)?

PRESENCE OF A CONDITION:

- Is the presence of a health condition a necessary criterion?
- Should individuals with chronic functional limitations and/or service needs who are unable to name a specific condition or do not have a condition recorded in clinical records be considered for having a special health care need?
- What types of health conditions qualify (e.g., physical, mental, emotional)?
- What source(s) should determine or confirm the presence of a health condition (e.g., self or proxy report, physician report, medical charts or records)?

DURATION:

- Is a minimum period of duration a necessary criterion? If so, what specific length of time represents the qualifying minimum duration?
- Is it important that the functional limitation, need for services, and/or specific condition actually be present for a specific period of time – or is expected duration acceptable?
- What source(s) should determine or confirm the duration or expected duration of a current health condition, functional limitation, or need for services (e.g., self or proxy report, physician report, medical charts or records)?

Once the components of the working definition are clarified, the next step is to specify the criteria that will be used to operationalize each one. For example, the minimum amount of time that a health condition needs to be present for an individual to qualify must be explicitly stated in order to operationalize the durational component of a working definition. The source(s) that will be used to determine whether the minimum durational criteria are satisfied must also be identified.

CONCEPTUAL APPROACHES: The options available for specifying the criteria used in the components of a working definition are dependent, in part, on the conceptual approach(es) taken as the starting point.

The most common conceptual starting points for defining special health care needs rely on either programmatic eligibility, clinical diagnoses, or health-related consequences, such as limitations in functioning or need for services. While distinct, these approaches are not necessarily mutually exclusive, and under certain circumstances it may be appropriate to combine elements of each. Figure 5 summarizes issues to consider when evaluating the utility of each of these approaches for achieving the goals and purposes of a specific identification project.

Program-based approaches

Program-based approaches identify individuals based on their eligibility and/or enrollment in certain programs, such as Supplemental Security Income (SSI), Title V of the Social Security Act, foster care, etc. One of the strengths of such approaches is that people in these groups have already met a known set of criteria and usually can be identified in enrollment records. Generally speaking, however, such individuals represent a very specific or narrow range of special needs. Only a small minority of all those meeting more comprehensive definitions of special health care needs are likely to meet the eligibility criteria used by these types of programs.

Diagnosis-based approaches

Diagnosis-based approaches rely on the presence of a diagnosis for specific conditions in clinical/administrative records or individual self-report via checklists and other means. Depending on the number and types of diagnoses included and the reliability of the clinical, administrative, or self-report data used, such approaches can be more or less broad in terms of those identified.

These approaches are particularly suited when the goal is to identify individuals with specific conditions such as asthma or diabetes. However, several factors are important to consider. First, it is generally recognized that clinical and other types of administrative data are not always sufficient for identifying all individuals with certain health conditions due to unrecorded, unknown, and/or miscoded diagnoses. In addition, access barriers can keep eligible patients from receiving care or being diagnosed in the first place. Finally, diagnostic-based approaches often do not distinguish whether individuals with certain conditions experience limitations in functioning or have certain types or levels of service needs as a result.

Asking individuals to report their diagnoses directly is another option for diagnosis-based identification. In practice, however, this method may tend to over or under identify targeted groups. Reluctance to self report sensitive conditions such as AIDS, HIV, or mental health disorders can result in the under-identification of such diagnoses. Survey-based condition checklists may

also miss individuals who are unaware that they have a specific condition or are unable to recall a specific diagnosis (e.g., congestive heart failure, diabetes, depression).

Under-identification can also result from survey-based checklists being unable to cover every possible disorder. This limitation is especially an issue for children. In one study, over one-half of the chronic health conditions parents named as being experienced by their children were not included on the childhood condition checklist used in the National Health Interview Survey Child Health Supplement (Stein, 1997).

Variation in the reliability and validity of self-reported diagnoses can also lead to over or under identification. A 1998 review of asthma questionnaires reported a mean sensitivity of 68% (range: 48%–100%) and a mean specificity of 94% (range: 78%–100%) when self-reported asthma was compared with a clinical diagnosis of asthma (Toren, 1993).

Consequences-based approaches

Consequences-based approaches focus on the presence of limitations in functioning or need for services by individuals with on-going health conditions. Such approaches do not require that a specific diagnosis be recorded in a medical record or named through self-report. Rather, individuals qualify as having a special health care need if they experience one or more consequences attributable to a chronic health problem, whether or not that health problem can be identified by name or is coded in records. These approaches, therefore, may identify persons who do not have recorded diagnoses.

On the other hand, consequences-based approaches will not identify all persons who have formally recorded diagnoses, as many such individuals do not experience any marked functioning or service need consequences. Since the emphasis is on current level of functioning and service needs, approaches of this type tend to identify a broad range of special needs irrespective of the specific type of on-going health condition.

The focus on functioning and service needs, rather than specific conditions, helps reduce the under-identification of individuals reluctant to name sensitive diagnoses, such as AIDS and HIV, or those with conditions such as diabetes or depression that commonly go undiagnosed. Consequences-based approaches are also more likely to identify persons with special needs who are unable to access needed services because formally recorded diagnoses or service use are not required.

Figure 5: Defining Special Health Care Needs - Conceptual Starting Points

PROGRAM-BASED APPROACH

Requires established eligibility programs such as SSI, Title V or foster care

CONSIDERATIONS:

- Program eligibility status is used to identify individuals; additional identification methods/tools likely not needed.
- Definitional criteria such as levels of functioning & service need or types of diagnoses are pre-established by program eligibility rules.
- Eligibility criteria are not necessarily standardized & can vary state-to-state.
- Generally, only very specific or narrow ranges of special needs are captured as a only minority of all those with special needs meet the eligibility criteria used by programs of these types.
- Reliability of identification depends on the accuracy & availability of program records.
- MCOs may not have program eligibility status data on current and/or new enrollees.
- Program eligibility status information usually does not include details such as types & levels of functional limitations or service needs or specific diagnoses.

DIAGNOSIS-BASED APPROACH

Relies on diagnosed conditions recorded in patient records or reported via condition check lists

CONSIDERATIONS:

- Administrative records containing diagnosis & procedure codes are usually available and easily obtained.
- The quality, accuracy and completeness of encounter & other administrative records varies widely across MCOs and State Medicaid agencies.
- Range of special needs identified will depend on the types & number of diagnoses chosen for inclusion.
- Reliability of administrative data is often problematic due to un-recorded diagnoses, mis-codings, "rule-out" diagnoses & access barriers that keep patients from receiving care.
- A diagnosis in administrative records or named by a patient does not necessarily indicate a special need; additional information regarding functioning or service needs may be needed.
- Encounter data are not available for new enrollees; at least 6 - 12 mos. of continuous enrollment are needed for most administrative data-based methods.
- The time lag between service delivery & availability of data varies and is often significant.
- Survey-based chronic condition checklists are easy to administer. However, they have a tendency to over or under identify certain groups.
- Chronic condition checklists may systematically under identify important groups as people are often reluctant to report sensitive diagnoses such as HIV, AIDS or mental health disorders.

CONSEQUENCES-BASED APPROACH

Focuses on the functional limitations or service needs as a consequence of an on-going health condition

CONSIDERATIONS:

- Individuals must be experiencing one or more health consequences attributable to an on-going health condition, regardless of whether they have a formal diagnosis or known chronic condition.
- Self-report is usually the most accurate source for obtaining information about health consequences such as level of functioning and/or current service needs.
- Survey-based methods are often used to collect data on current consequences; ease of collection will depend on the length & format of the specific instrument used.
- Reliability of survey data is subject to the typical problems shared by all self-report methods including incomplete data & non-responders.
- The range of special needs included can be broad or narrow and depends on the specific types & levels of functioning and service needs chosen as qualifying criteria.
- The focus on current health consequences helps avoid under identification stemming from people's reluctance to report sensitive diagnoses or an inability to name their diagnoses.
- Length of enrollment is not a factor; same data can be collected for new & current enrollees.
- Greater likelihood of identifying individuals with special needs who are unable to access needed care and/or services because recorded diagnoses or service use is not required.

4. CAPACITY: What data & technical capacity do you have available?

The types and quality of data that can be accessed and the technical capacity available to collect, process and analyze it both have important implications when selecting and implementing an identification strategy. It is difficult to make generic statements about the nature of these implications because data and technical capacities vary widely and idiosyncratically across States, MCOs, and the settings in which identification may take place (e.g., clinic, enrollment office, health plan member services).

Most identification methods and tools also vary according to the type of information required, the level of technical skill necessary to implement, and the data collection burden represented. At a minimum, when comparing and selecting methods or tools States and MCOs will want to consider the following:

AVAILABILITY AND QUALITY OF BENEFICIARY OR ENROLLEE INFORMATION:

- How accurate, up to date, and complete is the address and telephone information available for Medicaid clients and/or health plan enrollees? This is important if survey methods are being considered or follow-up is desired for those identified through clinical or administrative data.
- Will it be necessary to merge Medicaid eligibility files and health plan membership records? If so, what is the feasibility of accomplishing this?
- Is additional demographic information such as household language or eligibility in other programs pertinent? If so, what is its availability and source?

AVAILABILITY AND QUALITY OF ADMINISTRATIVE DATA:

- Are the types of electronic patient encounter or clinical records required by the methods or tools under consideration available? How complete, accurate, and current are those records?

- Do the electronic data available meet the formatting parameters of the methods being considered?
- If current data formats must be modified to be compatible, what costs or other considerations are involved?
- Is it desirable and/or feasible to merge clinical or encounter records with survey results or other data? What technical and confidentiality issues must be considered or addressed?

TECHNICAL EXPERTISE AND ANALYTIC CAPACITY:

- What is the administration time for various survey-based tools, and level of training necessary to administer them?
- What is the type and complexity of the software and programming required to collect or process data, and the processing time necessary to obtain results?
- What type and level of database management and analytic skills are needed to analyze the data collected? Is the required level of expertise currently available or will additional training, staff, and/or other resources be required?

5. ATTRIBUTES: What attributes of methods and tools should be considered?

Once States and MCOs establish the purpose(s) for identification, specify a working definition, and assess data and resource capacities, the next step is to evaluate candidate methods and tools – or those already in use – according to their compatibility with the project’s goals and working definition. The following attributes should be kept in mind during this process:

TESTING AND USE HISTORY:

- Is the method or tool being considered explicitly designed to identify individuals or groups with special health care needs?
- Has the method or tool been used for identification purposes in settings that are the same or similar to those under consideration?
- Has the reliability and validity of the tool's use for identifying special health care needs been formally studied – and is that information available?
- How do results of a specific method or tool compare with others being considered in terms of the types and numbers of individuals identified?

DIRECT AND INDIRECT COSTS:

- Does use of the tool require payment to its developers or sponsors? If so, is this a one-time fee or is it required each time the tool is used?
- What is the cost of data collection and the analysis required to translate it into usable information?
- Is new software or upgraded computer capacity required – and at what cost? Will additional staff be required to implement the method or tool?
- Is there a cost associated with obtaining product support and technical assistance to implement the tool and interpret the results?

AVAILABILITY OF TOOL AND TECHNICAL SUPPORT:

- What is the availability of detailed information such as user's manuals, standardized protocols, software, and other supporting documents for the method or tool being considered? Where can they be obtained?
- What support is available to learn about the method or tool before purchasing or adopting it?

- What is the level and availability of technical support for troubleshooting should issues arise during its use?

USE WITH EXISTING CLIENT DATA COLLECTION:

- Is the method or tool compatible with existing data collection and/or analysis efforts, such as client quality surveys (e.g., CAHPS), enrollment surveys, or utilization reports?
- Would the method or tool increase efficiency overall by providing data for other purposes or by contributing to data collection efforts by other entities (e.g., cross agency collaboration on state or federal reporting requirements or program evaluation activities)?

SCALABILITY:

- Does the tool or method have the capacity to identify subgroups of people with special health care needs for the purposes of targeting or prioritizing follow up assessments and other activities?
- If not, can data for this purpose be easily collected in conjunction with the use of the method or tool?

CULTURAL SENSITIVITY:

- What is known about the appropriateness of the method or tool for use with culturally diverse populations and/or non-English speaking groups?
- Are non-English versions of survey-based tools available – and, if so, for which languages?

Section 4: ***What Methods and Tools are Available?***

The issue of identifying child and adult Medicaid enrollees with special health care needs has only recently emerged as a priority. In response, some States and MCOs have developed their own methods for identifying special health care needs populations. How accurate or generalizable these methods are to other States or settings has not been studied.

Currently, only a few formally tested and validated methods or tools for identifying persons with special health care needs are available. The tools and methods included in this section represent the state of science in this area. As the practice of identifying special health care needs populations becomes more widespread, the availability of tested and validated methodologies is expected to increase as well.

No single method or tool can meet all possible epidemiological, public health, case management, and program planning needs. Multiple, complementary strategies are required, given the range of settings and variety of purposes for identifying individuals with special health care needs. The tools and methods presented in this section have been tested and validated for one or more of the following applications:

- To ESTIMATE the overall prevalence of special health care need populations;
- To EVALUATE health care quality for populations with special health care needs;
- To SCREEN new enrollees to identify candidates for follow-up needs assessment and potential inclusion in case or disease management programs, or other care planning;

- To IDENTIFY current enrollees who may be candidates for case management or care coordination services;
- To TRACK individuals or populations with special health care needs prospectively to monitor quality and outcomes.

Selection Criteria

The following criteria were used in selecting the specific methods and tools¹ described in Table 1:

AVAILABILITY: The tool or method must be readily available and have the potential to be used with the systems or data available to States or MCOs. Detailed documentation and technical support must also be available, including information on administration and scoring. Tools and methods that are prohibitively expensive or burdensome to obtain do not meet the criteria of availability.

TESTING AND VALIDATION: The tool or method must be explicitly tested and validated for the purpose of identifying individuals with special health care needs. At a minimum, this testing should include the articulation of the theoretical framework and conceptual definition of special health care needs the tool or method is designed to operationalize. Also, comparison studies with other standards should establish the validity of its use as an identification method. Information about the development and testing of the method or tool must be readily available and extensive, including documentation in one or more peer-reviewed articles or presentations.

USE HISTORY: The tool or method must have a history of being used in some capacity by at least one State or MCO to identify children or adults with special health care needs in the Medicaid or SCHIP population.

¹ Methods and tools specifically designed to screen for “at-risk” populations, predict future utilization, conduct comprehensive need assessments or diagnostic workups, or set risk adjusted payment rates are intentionally not included here as these purposes fall outside the scope of this manual.

POTENTIAL FOR STANDARDIZATION: The tool or method must have the capacity to be used in standardized ways so that the results obtained across States, MCOs, and/or providers can be reasonably compared. Tools or methods dependent on data unlikely to be widely available to States and MCOs were not considered for inclusion.

Among those reviewed, four tools or methods met the above criteria:

1. The Questionnaire for Identifying Children with Chronic Conditions (QuICCC);
2. Children with Special Health Care Needs (CSHCN) Screener;
3. Adults with Special Health Care Needs (Adult SHCN) Screener;
4. 3M Clinical Risk Groups (CRGs) Classification of Chronically Ill Children and Adults.

These tools/methods are described and compared in Table 1. More comprehensive documentation, including technical summaries and sample copies, can be found in the Appendices.

Table 1: Comparison of Tools for Identifying Children

	QuICCC	CSHCN Screener
1) DESCRIPTION	<ul style="list-style-type: none"> ➤ Parent/caretaker survey ➤ 39 items in QuiCCC ➤ 16 item QuICCC-R uses a subset of the original QuICCC items ➤ Telephone or in-person administration ➤ Interviewer administered only ➤ <u>Administration time</u>: QuICCC – 7 to 8 minutes, on average, to screen all children in a household; QuICCC-R – less than 2 minutes for an individual child 	<ul style="list-style-type: none"> ➤ Parent/caretaker survey ➤ 5 items ➤ Mail, in-person or telephone administration ➤ Self-administered or by interviewer ➤ <u>Administration time</u>: 2 minutes, on average, to screen all children in a household; less than 1 minute for an individual child
2) PURPOSE	<ul style="list-style-type: none"> ➤ Originally developed for epidemiological purposes such as estimating prevalence of children with chronic conditions or disability 	<ul style="list-style-type: none"> ➤ Originally developed to identify a population of CSHCN for quality assessment; also used to estimate prevalence of CSHCN
3) TARGET POPULATION	<ul style="list-style-type: none"> ➤ Children under 18 yrs ➤ Able to identify individuals and population cohorts ➤ Generates unique, person-level screening profile when Individual Version is administered for a target child ➤ Household Version does not provide unique profile for each child 	<ul style="list-style-type: none"> ➤ Children under 18 yrs ➤ Able to identify individuals and population cohorts ➤ Generates unique, person-level results when self-administered for a target child ➤ Interviewer-based protocol can be used to collect individual screening profile for each child in household
4) DEFINITIONAL CRITERIA	<ul style="list-style-type: none"> ➤ Consequences-based approach ➤ Asks about consequences in the areas of functional limitations (16 items), dependency (12 items), and service use or needs (11 items) ➤ All health consequences must be due to a current physical, emotional, developmental, or behavioral condition that has lasted or is expected to last for at least 12 months ➤ To qualify as having special health care needs, a child must experience one or more functioning, dependency, or service use consequences resulting from a current health condition that is on-going for at least 12 months or more ➤ Formal diagnosis is not required ➤ Cost of care is not a criteria 	<ul style="list-style-type: none"> ➤ Consequences-based approach ➤ Asks about consequences in the areas of functional limitations (1 item) and service use or needs (4 items) ➤ All health consequences must be due to a current physical, emotional, developmental, or behavioral condition that has lasted or is expected to last for at least 12 months ➤ To qualify as having special health care needs, a child must experience one or more functioning, or service use/need consequences resulting from a current health condition that is on-going for 12 months or more ➤ Formal diagnosis is not required ➤ Cost of care is not a criteria

QuICCC: The Questionnaire for Identifying Children with Chronic Conditions. Stein, Westbrook, et al. 1997.

CSHCN Screener: Children with Special Health Care Needs Screener. Bethell, Read, et al. 2002.

and/or Adults with Special Health Care Needs

Adult SHCN Screener

- Self or proxy survey
- 5 items
- Mail, in-person or telephone administration
- Self-administered or by interviewer
- Administration time: Less than one minute for a single individual. Household screening time not available

3M/CRGs

- Categorical clinical classification system that can be used to classify individuals into mutually exclusive, clinically based categories
- Uses ICD-9 and procedures codes from claims data and encounter records to classify cases
- Requires proprietary computer software to implement

- Originally developed to identify a population for quality assessment; also used to estimate prevalence of adults with special health care needs

- Developed primarily to track chronic disease rates and set risk-adjusted payment based on future resource requirements as predicted by the diagnostic profile of a population.
- Also used to identify individuals for potential case management and other tracking

- Adults age 18 and over
- Able to identify individuals and population cohorts
- Generates unique, person-level screening results when self or interviewer administered, or when proxy respondent answers for targeted person

- All ages - child to adult
- Able to identify individuals and population cohorts
- Generates unique, person-level results by assigning individuals into mutually exclusive, clinically determined groups according to chronic, significant acute, or healthy status

- Consequences-based approach
- Asks about consequences in the areas of functional limitations (1 item) and services use or needs (4 items)
- All health consequences must be due to a current physical, mental health, emotional, or behavioral condition that has lasted or is expected to last for at least 12 months
- To qualify as having special health care needs, the adult must experience one or more functioning or service use/need consequences resulting from a current health condition that is on-going for 12 months or more
- Formal diagnosis is not required
- Cost of care is not a criteria

- Combines consequences-based and diagnosis-based approaches
- Requires at least 2 encounters with the same diagnosis of a physical, mental, emotional, behavioral or developmental disorder
- Diagnoses included in the algorithm were selected on the basis of consensus clinical judgment as likely to last 12 months or longer and require on-going treatment and monitoring
- Functional limitations are inferred from the ICD-9 and CPT codes used
- Type, combination, and frequency of service use codes found in encounter records are considered
- Cost of care is one of several criteria used to rate severity
- Severity algorithm takes into account type and number of diagnoses, recency, reoccurrence, comorbidities, number of acute incidences, costs, type, frequency, and combination of services used

Table 1: Comparison of Tools for Identifying Children

5) DATA & TECHNICAL CAPACITY

QuICCC

Data required to use tool:

- Age of child
- Telephone contact information for parent/family if not administered in-person
- Household language information is helpful if non-English language interviews are anticipated
- Tool collects child's birthdate, daycare or school enrollment status, and the relationship of respondent to child
- Other demographics for child and/or family are not required to use the QuICCC; however, additional information may need to be collected in order to stratify results or conduct other analyses

Technical skills required to use tool:

- Individuals trained to administer the QuICCC to parents or other caregivers
- If administered by telephone, interviewers trained in data collection and entry methods
- Sampling design expertise if stratification or other sampling strategies are used- especially if seeking a representative population-based prevalence estimate
- Data entry, database management, and programming skills to score the results (SPSS, SAS, ACCESS, etc.)
- Data analysis and presentation skills to process and communicate results

CSHCN Screener

Data required to use tool:

- Age of child
- Telephone or address contact information for parent/family required if telephone or mail administration is planned
- Household language information is helpful if non-English language interviews are anticipated
- Other demographics for child and/or family are not required to use the CSHCN Screener; however, additional information may need to be collected in order to stratify results or conduct other analyses

Technical skills required to use tool:

- Survey project management skills if the CSHCN Screener is used in a mailed survey
- Survey design expertise if the CSHCN Screener is integrated into another survey
- If administered by telephone, interviewers trained in data collection and entry methods
- Sampling design expertise if stratification or other sampling strategies are used- especially if seeking a representative population-based prevalence estimate
- Data entry, database management, and programming skills to score the results (SPSS, SAS, ACCESS, etc.)
- Data analysis and presentation skills to process and communicate results

6) ATTRIBUTES

Testing and use history:

(see Appendix #1)

Direct and indirect cost to use:

- The QuICCC is available at no cost
- Cost of data collection involves training and payment of in-person or telephone interviewers, and may include additional expenses for programming or data entry
- Analysis cost will include writing of scoring program as a standard scoring program is not currently available

QuICCC: The Questionnaire for Identifying Children with Chronic Conditions. Stein, Westbrook, et al. 1997.

Testing and use history:

(see Appendix #2)

Direct and indirect cost to use:

- The CSHCN Screener is available at no cost
- Cost of data collection depends on survey mode: mailed survey includes printing, mailing and data entry expenses; telephone survey costs include programming expenses and the training and payment of interviewers
- SPSS scoring program available at no cost; includes test dataset for checking other code (see Appendix #2)

CSHCN Screener: Children with Special Health Care Needs Screener. Bethell, Read, et al. 2002.

and/or Adults with Special Health Care Needs

Adult SHCN Screener

Data required to use tool:

- Age of targeted individual
- Telephone or address contact information required if telephone or mail administration is planned
- Household language information is helpful if non-English language interviews are anticipated
- Other respondent demographics are not required to use the Adult SHCN Screener; however, additional information may need to be collected in order to stratify results or conduct other analyses

Technical skills required to use tool:

- Survey project management skills if the Adult SHCN Screener is used in a mailed survey
- Survey design expertise if the Adult SHCN Screener is integrated into another survey
- If administered by telephone, interviewers trained in data collection and entry methods
- Proxy-respondent protocol for administering survey when targeted individual is not able to respond unaided
- Sampling design expertise if stratification or other sampling strategies are used - especially if seeking a representative population-based prevalence estimate
- Data entry, database management, and programming skills to score the results (SPSS, SAS, ACCESS, etc.)
- Data analysis and presentation skills to process and communicate results

Testing and use history:

(see Appendix #3)

Direct and indirect cost to use:

- The Adult SHCN Screener is available at no cost
- Cost of data collection depends on survey mode: mailed survey includes printing, mailing and data entry expenses; telephone survey costs include programming expenses, and the training and payment of interviewers
- SPSS scoring program available at no cost - includes test dataset for checking other code (see Appendix #3)

Adult SHCN Screener: Adult Special Health Care Needs Screener. Bethell, Read, et al. 2002 (under development).

3M/CRGs

Data required to use tool:

- Optimally, at least six months of medical claims or encounter records (HCFA 1500 data elements) for each adult or child
- Birth date and sex

Technical skills required to use tool:

- CRG software available for Window NT or HP-UX
- Large database management and analysis capabilities including:
 - a) Data cleaning, recoding and reformatting encounter files into CRG specified formats
 - b) Ability to transfer data across software platforms
 - c) Ability to link Medicaid eligibility records with health plan or other encounter data files
- Database manipulation and file disaggregation expertise to create meaningful results from CRG output
- Data analysis and presentation skills to process and communicate results

Testing and use history:

(see Appendix #4)

Direct and indirect cost to use:

- CRG software is purchased directly from 3M HIS. Cost not advertised.
- Cost to use will include analyst time to learn software and reformat encounter records to CRG specified formats

3M/CRGs: 3M Clinical Risk Group Classification System. 3M Health Information Systems, 2000.

Table 1: Comparison of Tools for Identifying Children

**5) ATTRIBUTES
(continued)**

QuICCC

CSHCN Screener

Availability of tool and technical support:

- The QuICCC is a copyrighted instrument; it may not be reproduced without written permission of the authors
- User's guide available for nominal fee
- See Appendix #1 for contact information

Availability of tool and technical support:

- Written permission is not required to use CSHCN Screener; users are asked to fill out User's Form
- Go to the Child and Adolescent Health Measurement Initiative (CAHMI) web site at www.facct.org/cahmi/html to fill out a User's Form and download a copy of the CSHCN Screener
- SPSS scoring program, test dataset, supporting documents, and information are available upon request at no charge.
- See Appendix #2 for contact information.

Use with other surveys:

- The QuICCC is designed to be a stand-alone tool; however, it has been used in the context of other telephone surveys
- Interviewer-only format limits compatibility with mail and other self-administered survey modes

Use with other surveys:

- The CSHCN Screener is specifically designed to be used in conjunction with other mail or telephone surveys, especially the Consumer Assessment of Health Plan Survey (CAHPS)
- The screener can be used as a stand-alone instrument; however, additional questions to collect basic child and parent demographics are necessary

Scalability:

- The QuICCC was not originally designed to classify individual children according to type or level of service use needs or severity of illness/special need; however, recent research indicates it may be a valid method for some of these purposes
- See Appendix #1 for details

Scalability:

- The CSHCN Screener was not originally designed to classify individual children according to type or level of service use needs or severity of illness/special need
- Preliminary analyses suggest children qualifying on certain questions and/or combinations of questions may have significantly higher service use need and/or functional impairment. This information may useful for prioritizing or tailoring follow up activities.
- See Appendix #2 for more information

Cultural sensitivity:

- English language version is currently available
- The QuICCC was tested in Spanish, as well
- The QuICCC has been used with culturally diverse populations - primarily inner city Latino and African-American families
- The reliability and validity of QuICCC for culturally diverse populations has not been formally tested

Cultural sensitivity:

- English and Spanish language versions are available
- Spanish language translation was tested with native Spanish speakers
- The CSHCN Screener has been used with culturally diverse populations- including Spanish-speaking Medicaid recipients and other low income groups
- The reliability and validity of CSHCN Screener for culturally diverse populations has not been formally tested

QuICCC: The Questionnaire for Identifying Children with Chronic Conditions. Stein, Westbrook, et al. 1997.

CSHCN Screener: Children with Special Health Care Needs Screener. Bethell, Read, et al. 2002.

and/or Adults with Special Health Care Needs

Adult SHCN Screener

Availability of tool and technical support:

- Written permission is not required to use Adult SHCN Screener; users are asked to fill out User's Form
- SPSS scoring program, test dataset, supporting documents and information are available upon request at no charge.
- See Appendix #3 for contact information

3M/CRGs

Availability of tool and technical support:

- Software can be purchased directly from 3M Health Information Systems (HIS)
- Go to the 3M HIS web site for sales assistance: www.3mhis.com/us/products/crg
- Detailed user's manual provided with software
- Ongoing technical support available from 3M HIS

Use with other surveys:

- The Adults SHCN Screener is specifically designed to be used in conjunction with other mail or telephone surveys, especially the Consumer Assessment of Health Plan Survey (CAHPS)
- The screener can be used as a stand-alone instrument; however, additional questions to collect basic respondent demographics are necessary

Use with other surveys:

- Linking CRG clinical classifications with survey-based screening tool or patient survey results may provide information useful for case management, quality monitoring, or other applications (See Appendix #4)
- Encounter or episode of care systems such as Diagnosis Related Groups (DRGs) or Ambulatory Patient Groups (APGs), which classify visits or services, can be used to describe inpatient and outpatient services received by individuals as categorized by the CRG classification system

Scalability:

- The Adult SHCN Screener was not originally designed to classify individuals according to type or level of service use needs or severity of illness/special need
- Preliminary analyses suggest individuals qualifying on certain questions and/or combinations of questions may have significantly higher service use need and/or functional impairment. This information may be useful for prioritizing or tailoring follow up activities.
- See Appendix #3 for more information

Scalability:

- CRGs provide four levels of categorical classification and aggregation for each individual. These range from the full set of 1,981 categories to the Core Health Status Groups and Severity (37 cells)
- Severity ratings are provided for all persons designated as having a chronic condition

Cultural sensitivity:

- English language version is currently available
- Spanish language version of screener is under development
- The Adult SHCN Screener has been used with inner city African-American populations and other low income groups
- The reliability and validity of Adult SHCN Screener for culturally diverse populations has not been formally tested

Cultural sensitivity:

- Studies have shown that individuals from different cultural backgrounds vary in their propensity to seek or successfully access health care services. These factors may have an impact on the probability of identification when recorded diagnoses or service use are used as criteria for identification

Table 1: Comparison of Tools for Identifying Children

**6) OTHER
CONSIDERATIONS**

QuICCC

Limitations:

- It is uncertain how parent responses might vary if the QuICCC is not administered through an interviewer
- The QuICCC is subject to the limitations shared by all survey-based methods, including insufficient contact information, missing data (although this tends to be less of an issue when interviewer-administration is used), and non-responders

QuICCC: The Questionnaire for Identifying Children with Chronic Conditions. Stein, Westbrook, et al. 1997.

CSHCN Screener

Limitations:

- To date, all formal testing of the CSHCN Screener is in the context of confidential mail and telephone surveys
- How parent responses might vary if the CSHCN Screener is administered in a non-confidential manner is currently under study
- Despite the lack of formal testing, many users are currently administering the CSHCN Screener to identify children prospectively from among new enrollees or at point of service such as during a physician visit (see Appendix #2)
- The CSHCN Screener is subject to the limitations shared by all survey-based methods, including insufficient contact information, missing data (although this tends to be less of an issue when interviewer-administration is used), and non-responders

CSHCN Screener: Children with Special Health Care Needs Screener. Bethell, Read, et al. 2002.

and/or Adults with Special Health Care Needs

Adult SHCN Screener

Limitations:

- To-date, the Adult SHCN Screener has only been studied in the context of confidential mail and telephone surveys
- How responses might vary if the screener is administered in a non-confidential manner such as during health plan enrollment or during a physician visit is not yet known and will be a topic addressed by future studies
- The Adult SHCN Screener is subject to the limitations shared by all survey-based methods, including insufficient contact information, missing data (although this tends to be less of an issue when interviewer-administration is used), and non-responders

3M/CRGs

Limitations:

- CRGs share the same limitations typical of methods that rely upon claims, encounter, or other types of administrative data to identify and classify individuals with chronic illness and disability.
- These include:
 - a) Under-identification of individuals with conditions which do not require frequent interaction with the health system or are rarely the primary purpose of a medical visit (e.g., mental retardation, learning disorders, developmental disabilities)
 - b) Under-identification of individuals with conditions not reimbursable under a certain benefit structure - such as when behavior health care is "carved out" or delivered through separate programs
 - c) Reliability of identification depends upon the accuracy and availability of comprehensive claims or encounter records; individuals without records for whatever reasons, including access barriers, are not eligible for identification

*Section 5:
Next Steps*

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Appendix #1

***Questionnaire for
Identifying Children
with Chronic
Conditions (QuICCC)***

Questionnaire for Identifying Children with Chronic Conditions (QuICCC) †

Technical Summary

DESCRIPTION

The Questionnaire for Identifying Children with Chronic Conditions (QuICCC) is an interviewer-administered instrument for identifying children with a chronic or disabling condition. It consists of 39 question sequences administered either by telephone or in-person interview to the parents or guardians of children under age 18. The QuICCC was originally developed for epidemiological purposes such as prevalence estimation.¹ More recently, it has been validated as a screening tool for individual child identification.²

The Household Version of the QuICCC collects data for all children in a family. It takes seven to eight minutes on average to screen all children in a household. The Household Version does not provide person-level results. If a detailed profile for each child is desired, then the Individual Version of the QuICCC must be used.

A brief form of the QuICCC has recently been developed. The Questionnaire for Identifying Children with Chronic Conditions–Revised (QuICCC-R) is a 16-item subset of the original 39 QuICCC items. In testing, the QuICCC-R demonstrated greater than 98 percent agreement with the longer QuICCC instrument.³ The Individual Version of the QuICCC-R takes less than two minutes to administer per child.

The QuICCC and the QuICCC-R are available in English or Spanish. Self-administered versions are not currently available.

† The QuICCC is a copyrighted instrument. It may not be reproduced without the written permission of the authors.

Conceptual approach

The QuICCC was specifically designed to operationalize the conceptual definition of children with chronic conditions and disability developed through the National Child Health Assessment Planning Project (NCHAPP) that was funded by the federal Maternal and Child Health Bureau (MCHB). The definition focuses on health-related consequences present as the result of having a childhood chronic condition, rather than diagnostic labels and etiology. A set of three definitional elements described by Stein et al.⁴ are used to determine the presence of a chronic health condition or disability: 1) the disorder is biological, psychological, or cognitive in origin; 2) the expected or actual duration is at least 12 months; and 3) the disorder produces some type of functioning, service use, or dependency consequence.

The definition of children with special health care needs put forth by the federal MCHB⁵ and the CSHCN Screener⁶ designed to operationalize it both draw closely on the theoretical framework used first by the QuICCC.

Definitional criteria

The QuICCC uses consequences-based criteria to identify children with chronic health conditions or disability. The following must all be present to qualify:

- The child currently experiences a specific consequence;
- The consequence is due to a medical, behavioral, or other health condition;
- The duration or expected duration of the condition is 12 months or longer.

The QuICCC measures consequences in three domains:

1. Functional limitations (16 questions);
2. Dependence on compensatory mechanisms and assistance (12 questions);
3. Above routine service use for age (11 questions).

The first part of each question asks about a specific consequence. If the respondent reports that a child experiences the consequence, the interviewer moves to the second part of the question, which asks whether it is the result of a medical, behavioral, or other health condition. If the response is “yes,” the interviewer then proceeds to the final part of the question, which asks if the duration or expected duration of the condition is one year or more. To classify as having a chronic health condition or disability, a child must have a “yes” response to all parts of at least one question sequence.

BACKGROUND

The National Child Health Assessment Planning Project (NCHAPP) was charged with the task of developing a national survey of children with chronic conditions. The QuICCC instrument was developed in response. The theoretical underpinning of the instrument draws upon research indicating that childhood chronic conditions often share similar consequences in terms of functioning and service use.^{7,8,9} As a result, the QuICCC uses consequences-based criteria, not diagnoses, to accomplish its goal of comprehensively identifying children across the range and diversity of chronic disease and disability. The QuICCC’s developers judged such an approach to be more suited to this goal than traditional diagnosis-lists because:

- Not every condition known to be experienced by children can be included on such lists;
- Diagnoses may be applied inconsistently by clinician, and across settings;
- It is not uncommon for symptoms and consequences to be present for a period of time before diagnosis occurs;
- Diagnostic labels alone do not convey the extent of disease burden or disability experienced; and

- Diagnosis-based methods are biased towards identifying individuals with access to medical care.⁴

The development QuICCC was accomplished in several phases which included literature review, expert input, interviews with families of children with chronic conditions or disabilities, and pilot testing in three hospital-based samples drawn from inpatient and outpatient settings. A national advisory committee, formed by the NCHAPP, guided this process.

TESTING AND USE HISTORY

Testing

The final version of the QuICCC instrument was field-tested in a national study (712 households, representing 1,388 children) and an inner city population (657 households, representing 1,275 children).¹ In these studies, results from the QuICCC were compared to parents' descriptions of their children's health conditions, a checklist of childhood health conditions from the National Health Interview Survey (NHIS), and functional status scores on the Functional Status-II(R) Measure.

Compared to the NHIS diagnostic checklist, the QuICCC identified a wider range of disorders. Use of the checklist alone would have resulted in missing about one-quarter of the children identified by the QuICCC because the specific conditions named by their parents were not included on the list. On the other hand, the QuICCC excluded those children identified by the checklist who were not currently experiencing significant health-related consequences, who had single or recurrent episodes of acute conditions, and who had past conditions that resolved. These findings helped confirm the validity of the consequences-based approach used by the QuICCC.

Proportion identified

In the national and inner city studies summarized above, the QuICCC identified approximately 19 percent of children age 0 to 17 as having a chronic condition

or disability.¹ In the national sample, the QuICCC identified all of the children whose parents reported that they were receiving Supplemental Security Income (SSI).

A 2001 study using the 16-item QuICCC-R identified about 24 percent of children age 0 to 17 as having special health care needs in a national sample of households with children (n = 2,420).¹⁰ A similar proportion were identified by the QuICCC-R in a random sample (n = 497) of children age 0 -14 enrolled for six months or longer in a mixed model health plan covering a four county region in the State of Washington.¹⁰

No published results using the QuICCC or QuICCC-R in a Medicaid managed care population are available. However, when administered in a sample of families with children enrolled in the Healthy Kids Program, the largest component of Florida's Title XXI State Children's Health Insurance Program initiative, approximately 32 percent of children age 5 to 19 were identified by the QuICCC as having a special health care need.¹¹

Use History

In addition to describing the epidemiology of pediatric populations, the QuICCC and the QuICCC-R have been also used in published research to examine racial and ethnic variations among children with special health care needs,¹¹ and to compare screening results from other survey-based and administrative data-based methods.^{10, 11, 12}

AVAILABILITY and COST

The QuICCC is available at no cost; however, it is a copyrighted instrument and may not be reproduced without written permission from its developers. To obtain a copy of the QuICCC and permission to use it, contact:

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TECHNICAL SUPPORT

A user's manual with detailed scoring instructions and resource materials is available for a nominal fee from the developers of the QuICCC. It can be obtained at the address above.

OTHER CONSIDERATIONS

The QuICCC was originally developed for epidemiological purposes to identify children with chronic conditions or disability. The majority of its testing and use history reflect this application. The utility and validity of the QuICCC for accurately identifying individual children for further assessment, program eligibility, or reimbursement is just beginning to be studied. The findings from a recent study support its usage as a screening tool for individual child identification; however, the authors note that no screening method is 100 percent accurate.² Potential sources of error must be taken into consideration and follow-up practices established with this in mind.

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Appendix #2

***Children with
Special Health Care
Needs (CSHCN)
Screener***

Children with Special Health Care Needs (CSHCN) Screener †

Technical Summary

DESCRIPTION

The Children with Special Health Care Needs (CSHCN) Screener is a set of five questions used to identify children with chronic or special health care needs. The questions are designed to be self-administered or telephone administered as part of a parent/caretaker survey. It was originally developed to identify a population for quality assessment and, with appropriate sampling, to estimate the prevalence of CSHCN.

The screener takes approximately one minute to administer for a single child and an average of two minutes to complete when screening all children in a household (range: 1 to 4½ minutes). English and Spanish language versions of the screening tool are available.

Conceptual approach

The CSHCN Screener was specifically designed to operationalize the children with special health care needs definition endorsed by the federal Maternal and Child Health Bureau (MCHB). This definition states that a child with a special health care need 1) has or is at risk for having a physical, developmental, behavioral, or emotional condition and 2) requires health or related services of a type or amount beyond that required by children.¹ Like the MCHB definition, the CSHCN Screener focuses on the health consequences a child experiences as a result of having an on-going health condition rather than on the presence of a specific diagnosis or type of disability.

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Definitional criteria

The screening tool uses consequences-based criteria to identify children with special health care needs. All of following must be present to qualify:

- The child currently experiences a specific consequence;
- The consequence is due to a medical, behavioral, or other health condition;
- The duration or expected duration of the condition is 12 months or longer.

The first part of each CSHCN Screener question asks whether a child experiences one of five different health consequences:

1. Use or need of prescription medication;
2. Above average use or need of medical, mental health or educational services;
3. Functional limitations compared with others of the same age;
4. Use or need of specialized therapies (e.g., OT, PT, speech);
5. Treatment or counseling for emotional, behavioral, or developmental problems.

The second and third parts of each screening question[‡] ask those responding “yes” to the first part of the question whether the consequence is due to any kind of health condition and, if so, whether that condition has lasted or is expected to last for at least 12 months.

All three parts of at least one screener question (or, in the case of question 5, both parts) must be answered “yes” in order for a child to meet the CSHCN Screener criteria.

[‡] Question 5 of the screener is a two-part question; both are answered “yes” to qualify.

BACKGROUND

The CSHCN Screener was developed in response to the need for an efficient, standardized method of identifying CSHCN for the purposes of quality assessment and other population-based applications.

The theoretical framework used by the CSHCN screener is based on that of a longer tool, the Questionnaire for Identifying Children with Chronic Conditions (QuICCC).² Like the QuICCC, the criteria used by the CSHCN screener to determine if a child has a chronic condition or special health care need are independent of specific diagnostic labels or formally recorded diagnoses.

The relatively low prevalence of any single childhood chronic condition and the large number of applicable diagnoses, many of which are very rare, makes condition-specific checklists and/or diagnosis-based case finding inadequate for capturing the full range of pediatric chronic disease. In addition, diagnoses-based approaches are known to miss many children due to coding errors, misdiagnoses, lack of access to care, and the global or developmental nature of some childhood problems.

In contrast, a non-condition specific approach identifies children across the range and diversity of childhood chronic conditions and special needs. The inclusion of a wide range of childhood chronic conditions allows a more comprehensive assessment of health care system performance than is attainable by focusing on any single diagnosis or type of special need. In addition, the low prevalence of most childhood chronic conditions makes it problematic to find adequate numbers with a specific diagnosis or type of special need. A non-condition specific approach such as that used by the CSHCN Screener makes it possible in many cases to identify enough children with special health care needs to allow statistically robust quality comparisons across health care systems and/or providers.

The CSHCN Screener was developed through the Child and Adolescent Health Measurement Initiative (CAHMI), a national effort focused on measuring and

improving the quality of health care for children and adolescents. The CAHMI is led by FACCT–The Foundation for Accountability.

TESTING AND USE HISTORY

Testing

Over 36,000 cases of CSHCN Screener data were collected during its development. Testing included administration in commercial and Medicaid managed care, Medicaid Fee-for-Service, and primary care case management populations. The screening tool was also fielded in two national samples of households with children during pre-testing for the SLAITS National CSHCN Survey sponsored by the federal Maternal and Child Health Bureau.

Results from the CSHCN Screener have been compared with the QuICCC-R (a reduced version of the QuICCC), the 3M/CRG clinical classification system, medical chart reviews, and parental reports of their children's specific health conditions, service needs, and utilization levels. Overall, the CSHCN Screener identified numbers of children commensurate with other epidemiological studies of special health care needs. The screener did not systematically exclude categories of children according to the type and/or severity of their health conditions, and exhibited a high level of agreement with other methods.³ For an in-depth description of the development and testing of the CSHCN Screener, refer to the two *Ambulatory Pediatrics* journal articles included in this appendix.

Proportion identified

In a general population sample of households with children age 0 to 17 years, the CSHCN Screener identified 15-16 percent of children as having special health care needs.⁴ In a statewide sample of families with children enrolled in Medicaid managed care through Temporary Aid to Needy Families (TANF), 21 percent of children age 0 to 13 years were identified.⁴ In the same study, nearly 95 percent of children receiving Supplemental Security Income (SSI) benefits met the CSHCN Screener criteria. When administered in a sample of families with children enrolled in the Florida Healthy Kids Program, the

CSHCN Screener identified approximately 24 percent of children age 5 to 19 years as having a special health care need.⁵

As in other studies of children with special health care needs^{6,7} the proportions identified by the CSHCN Screener vary according to the age (higher for older children), gender (higher for males), and race/ethnicity of the child. In particular, children of Hispanic origin are less likely to be identified as having a special health care need. Other researchers also report lower rates among Hispanic children; these differences are not fully understood and deserve further study.^{5,8}

Use History

The CSHCN Screener is currently being used in several national and statewide surveys, including the National Survey of Children with Special Health Care Need, and as part of the CAHPS[®] survey items in the Medical Expenditure Panel Survey (MEPS). The Agency for Healthcare Research and Quality (AHRQ) has included the screener as an integral part of the new CAHPS 2.0 Child Survey. The screener is also formally integrated into the CAHPS 2.0H Child Survey to identify the Children with Chronic Conditions Measurement Set, a component of the National Committee for Quality Assurance's Health Plan Employer Data and Information Set (HEDIS[®]).

The CSHCN Screener is answered by parents of adolescents in several of these surveys. There is some concern, however, whether parents or the adolescents themselves are more reliable responders to these types of questions. The screener has also been administered directly to adolescents in several large samples. The question of adolescent self-report versus parent proxy-report will be evaluated in future studies.

The Spanish language translation of the CSHCN Screener is being used in both national and statewide survey applications. As with all survey-based measures, continued study is necessary to ensure the cultural competency of such methods.

AVAILABILITY and COST

The CSHCN Screener is available at no cost from FACCT–The Foundation for Accountability. To fill out a User’s Form and download a copy of the CSHCN Screener, go to www.facct.org/cahmi.

TECHNICAL SUPPORT

Technical support for administering, scoring, and interpreting results of the CSHCN Screener can be obtained by e-mailing childs@facct.org. Scoring programs, test data sets, and supporting materials are also available upon request.

OTHER CONSIDERATIONS

The CSHCN Screener was originally developed to identify a population for quality assessment and monitoring. All formal testing of the screener to date has occurred in the context of confidential, point in time (cross-sectional) surveys of parents or other caretakers. More study is needed to understand its use in non-confidential settings such as patient assessment during a physician office visit or as a component of a health plan enrollment interview.

The pressing need for a self-administered, standardized method has led many State Medicaid agencies and MCOs to adopt the CSHCN Screener as a method for screening new Medicaid or health plan enrollees to identify CSHCN for the purposes of further follow up and evaluation. The use of the screening tool to identify individual CSHCN for case management and other types of assessments or tracking is just beginning to be studied on a formal basis.

The CSHCN Screener has not been evaluated for use as a risk adjustment method, nor has it been fielded across the full range of clinical and community settings. Both self-administration and telephone interview administration of the instrument are well tested but further study is needed to assess in-person interview and online methods.

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***CSHCN
Screener***

Children with Special Health Care Needs (CSHCN) Screener[®]

(mail or telephone)

1. Does your child currently need or use **medicine prescribed by a doctor** (other than vitamins)?
 - Yes → Go to Question 1a
 - No → Go to Question 2
 - 1a. Is this because of ANY medical, behavioral or other health condition?
 - Yes → Go to Question 1b
 - No → Go to Question 2
 - 1b. Is this a condition that has lasted or is expected to last for at least 12 months?
 - Yes
 - No

2. Does your child need or use more **medical care, mental health or educational services** than is usual for most children of the same age?
 - Yes → Go to Question 2a
 - No → Go to Question 3
 - 2a. Is this because of ANY medical, behavioral or other health condition?
 - Yes → Go to Question 2b
 - No → Go to Question 3
 - 2b. Is this a condition that has lasted or is expected to last for at least 12 months?
 - Yes
 - No

3. Is your child **limited or prevented** in any way in his or her ability to do the things most children of the same age can do?
 - Yes → Go to Question 3a
 - No → Go to Question 4
 - 3a. Is this because of ANY medical, behavioral or other health condition?
 - Yes → Go to Question 3b
 - No → Go to Question 4
 - 3b. Is this a condition that has lasted or is expected to last for at least 12 months?
 - Yes
 - No

4. Does your child need or get **special therapy**, such as physical, occupational or speech therapy?
 - Yes → Go to Question 4a
 - No → Go to Question 5
 - 4a. Is this because of ANY medical, behavioral or other health condition?
 - Yes → Go to Question 4b
 - No → Go to Question 5
 - 4b. Is this a condition that has lasted or is expected to last for at least 12 months?
 - Yes
 - No

5. Does your child have any kind of emotional, developmental or behavioral problem for which he or she needs or gets **treatment or counseling**?
 - Yes → Go to Question 5a
 - No
 - 5a. Has this problem lasted or is it expected to last for at least 12 months?
 - Yes
 - No

Scoring the Children with Special Health Care Needs (CSHCN) Screener[®]

The CSHCN Screener[®] uses consequences-based criteria to screen for children with chronic or special health care needs. To qualify as having chronic or special health care needs, the following criteria must be met:

- a) The child currently experiences a specific consequence.
- b) The consequence is due to a medical or other health condition.
- c) The duration or expected duration of the condition is 12 months or longer.

The first part of each screener question asks whether a child experiences one of five different health consequences:

- 1) Use or need of prescription medication.
- 2) Above average use or need of medical, mental health or educational services.
- 3) Functional limitations compared with others of same age.
- 4) Use or need of specialized therapies (OT, PT, speech, etc.).
- 5) Treatment or counseling for emotional or developmental problems.

The second and third parts* of each screener question ask those responding “yes” to the first part of the question whether the consequence is due to any kind of health condition and if so, whether that condition has lasted or is expected to last for at least 12 months.

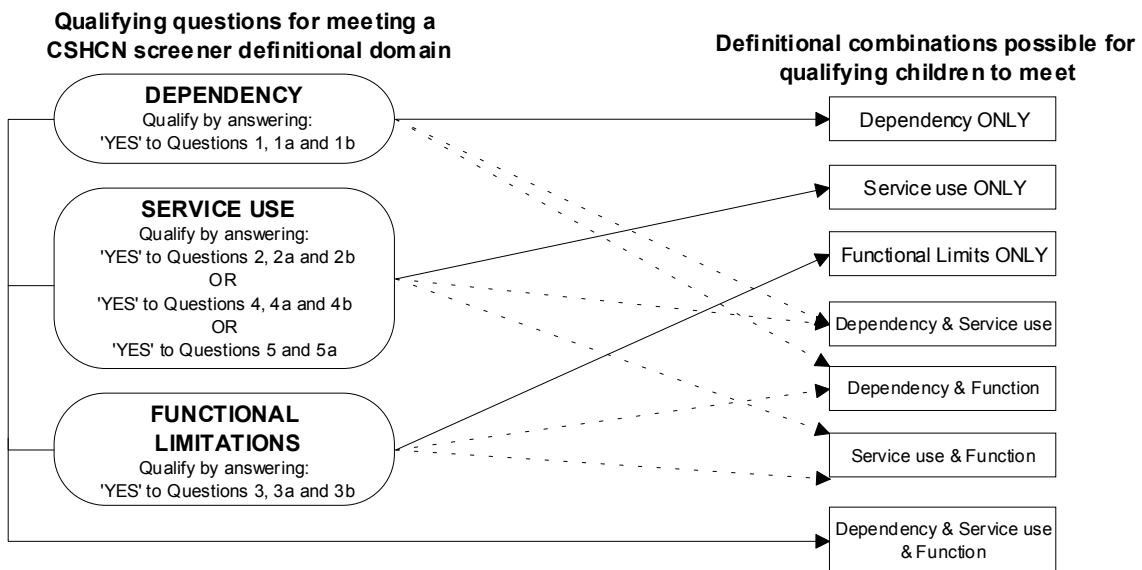
**NOTE: CSHCN screener question 5 is a two-part question. Both parts must be answered “yes” to qualify.*

All three parts of at least one screener question (or in the case of question 5, the two parts) must be answered “yes” in order for a child to meet CSHCN Screener[®] criteria for having a chronic condition or special health care need.

The CSHCN Screener[®] has three “definitional domains:”

- 1) Dependency on prescription medications.
- 2) Service use above that considered usual or routine.
- 3) Functional limitations.

The definitional domains are not mutually exclusive categories. A child identified by the CSHCN Screener[®] can qualify on one or more definitional domains (*see diagram*).





***Journal
Articles***

***CSHCN
Screeners***

Identifying Children With Special Health Care Needs: Development and Evaluation of a Short Screening Instrument

Christina D. Bethell, PhD, MBA, MPH; Debra Read, MPH; Ruth E. K. Stein, MD;
Stephen J. Blumberg, PhD; Nora Wells, MEd; Paul W. Newacheck, DrPH

Background.—Public agencies, health care plans, providers, and consumer organizations share the need to monitor the health care needs and quality of care for children with special health care needs (CSHCN). Doing so requires a definition of CSHCN and a precise methodology for operationalizing that definition.

Research Objectives.—The purpose of this study was to develop an efficient and flexible consequence-based screening instrument that identifies CSHCN across populations with rates commensurate with other studies of CSHCN.

Methods.—The CSHCN Screener was developed using the federal Maternal and Child Health Bureau (MCHB) definition of CSHCN and building on the conceptual and empirical properties of the Questionnaire for Identifying Children with Chronic Conditions (QuICCC) and other consequence-based models for identifying CSHCN. The CSHCN Screener was administered to 3 samples: a national sample of households with children ($n = 17985$), children enrolled in Medicaid managed care health plans ($n = 3894$), and children receiving Supplemental Security Income (SSI) benefits in Washington State ($n = 1550$). The efficiency, impact of further item reduction, and flexibility of administration mode were evaluated. Rates and expected variation in rates across demographic groups of children positively identified by one or more of the 5 CSHCN Screener item sequences in each sample were examined and multinomial logistic regression analysis were conducted to evaluate the effect of child characteristics in predicting positive identification.

Results.—The CSHCN Screener took approximately 1 minute per child to administer by telephone and 2.1 minutes per household. During self-administration, over 98% of respondents completed each of the 5 CSHCN Screener item sequences, and respondents accurately followed each of the item skip patterns 94% of the time. Mailed surveys and telephone-administered surveys led to similar rates of positive identification in the same sample. Two Screener items would have identified 80%–90% of children positively identified as CSHCN across the study samples, although using only 2 items eliminates some children with more complex health needs. Rates of children identified by the CSHCN Screener varied according to age, sex, race/ethnicity, health status, and utilization of health services.

Conclusions.—Results of this study indicate that the CSHCN Screener requires minimal time to administer, is acceptable for use as both an interview-based and self-administered survey, and that rates of children positively identified by the CSHCN Screener vary according to child demographic, health, and health care–need characteristics. The CSHCN Screener provides a comprehensive yet parsimonious and flexible method for identifying CSHCN, making it more feasible than existing measures for standardized use across public agencies, health care plans, and other users.

KEY WORDS: children; chronic conditions; identification; quality; screening; special health care needs

Ambulatory Pediatrics 2002;2:38–48

Public agencies, health care plans and providers, and consumer organizations share the need to identify and monitor the health care needs and quality of care for children with special health care needs (CSHCN).^{1–5} Not only do CSHCN consume the majority of health care dollars spent on children, their requirements for health services make them particularly vulnerable to access, cost, quality, and coverage weaknesses in the health care system.^{6–8} Recent guidelines for state Medicaid programs to identify and monitor care for CSHCN reflect concerns about whether CSHCN are receiving needed and high-quality health care services.⁴

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With regard to CSHCN, monitoring their health care needs, quality of care, and the impact of changes in the organization and delivery of health care requires that we first identify those CSHCN. Doing so requires a definition of CSHCN and a precise methodology for operationalizing that definition. Such a methodology should be as efficient as possible and flexible for use in a variety of health care and community settings, should be based on a definition of CSHCN that is acceptable to a broad range of users, and should yield results that are commensurate with epidemiological studies of CSHCN.

Recent years have seen significant progress in establishing a common definition of CSHCN to guide program planning, service delivery, and monitoring efforts.⁹ Specifically, the federal Maternal and Child Health Bureau (MCHB) spearheaded the development of a widely adopted definition that states that a child with a special health care need 1) has or is at risk for having a physical, developmental, behavioral, or emotional condition and 2) requires health or related services of a type or amount beyond that required by children generally.⁹ With its focus on the full range of health conditions, the MCHB definition moves beyond conceptualizations of this population

of children that are based primarily on physical health problems. It also requires that a health condition have a service need or consequence for the child to be considered to have a special health care need. Finally, because it includes the concept of being “at risk” for a condition, the MCHB definition implies that a child may have a special health care need even if a health care provider has not yet formally diagnosed a condition.

The MCHB definition of CSHCN was built on a foundation of work by several influential researchers whose empirical studies indicated that childhood chronic conditions often share similar consequences in terms of function and service use.^{10–14} This recognition led to the development of 2 consequence-based definitional frameworks that also served as underpinnings for the MCHB definition.^{15,16} Common to all of these definitional efforts is an emphasis on identifying the functioning and service need consequences children experience rather than simply identifying the presence of a chronic condition. In contrast to approaches that identify children only if parents and/or administrative records name a specific diagnosed health condition, these consequence-based approaches increase the probability of identifying children with ongoing health conditions that are either 1) not yet formally diagnosed even though they yield significant health and service need consequences or 2) less likely to be recalled or acknowledged by name by parents. In addition, consequence-based approaches that rely upon parent report and not on administrative data may identify children whose health conditions are less likely to appear in clinical or administrative records because of recording oversights, absence of payment incentives, lack of access to care, or poor continuity of care for children.

While it is not the case for adults, a large number of conditions, most with relatively low prevalence, characterize the epidemiology of childhood chronic conditions.^{14,17,18} These rates make condition-specific monitoring unfeasible in most cases. Childhood diabetes, for example, has a prevalence of 1.8 per 1000 children.^{17,19,20} An average-sized health plan comprising 90 000 covered lives and 30 000 children will have only 54 children with diabetes. Many other diagnoses, such as cystic fibrosis or juvenile arthritis, affect even fewer children. Consequently, monitoring any single childhood condition will not allow statistically robust assessments unless very large populations of children are included. Finally, single-condition monitoring provides an inadequate view of the overall quality and outcomes of care for children with chronic conditions.

The Questionnaire for Identifying Children with Chronic Conditions (QuICCC) represents one way to operationalize a broad, consequence-based approach such as that embodied in the MCHB definition. The interviewer-administered QuICCC asks a parent if his or her child experiences one of 39 specific health-related consequences.^{16,18} For most questions, if a parent answers “yes,” the QuICCC next asks the parent 2 follow-up questions regarding the presence and duration of an ongoing condition. To qualify as having a special health care need, the

child must have at least one of the 39 consequences, and, for most of these consequences, each must be attributable to a medical, behavioral, or other condition lasting or expected to last at least 12 months.

The QuICCC is suitable for many applications. However, its use across public agencies or health plans creates several problems. The QuICCC and the related QuICCC-Revised (QuICCC-R) include 39 and 16 item sequences, respectively, which represents an administration burden that is greater than that which is generally desirable for large-scale survey efforts.²¹ In addition, both versions of the QuICCC are validated only for interviewer administration and are not compatible for use with the self-administered surveys commonly used by states and health care plans. Finally, because the QuICCC is designed to identify children falling into “the gray area or boundary area . . . where there is uncertainty over whether a particular child has a chronic condition,” it is less appropriate for users who seek to avoid the identification of children falling into this uncertain area.²²

This article reports on the development and testing of a new parent survey-based screening instrument to identify CSHCN, referred to here as the CSHCN Screener. The CSHCN Screener is designed to fill a gap in currently available methods by providing an instrument that is efficient, flexible for use across different modes of administration, and that yields rates of CSHCN across populations of children that are commensurate with epidemiological studies of CSHCN. We report on 5 specific objectives. First, we assess the efficiency of the CSHCN Screener in terms of the time required for telephone administration. Next, recognizing the desire of many potential users of the CSHCN Screener to use the most parsimonious identification method possible, we evaluate the impact of further item reduction of the CSHCN Screener. Third, we evaluate the feasibility of using the CSHCN Screener as either a self- or interviewer-administered instrument. Fourth, we assess both the proportion and characteristics of children identified by the CSHCN Screener in each of the study samples and determine whether these rates of CSHCN vary by demographic characteristics, health status, and health care utilization, as has been observed in other studies of CSHCN.^{14,17,23,24} Specifically, we examine whether rates of identification are higher for male children and for older children.

METHODS

Development of the CSHCN Screener

The CSHCN Screener was developed through a national collaborative process as part of the Child and Adolescent Health Measurement Initiative (CAHMI), the activities of which are coordinated by the Foundation for Accountability (FACCT). The collaborative effort included task force participation on the part of over 30 individuals representing federal and state program directors and policy makers, health care provider organizations, the health services research community, and consumer organizations. Members of the task force met 6 times in person

and more than a dozen times by teleconference, beginning in June 1998 (task force member list available from the authors). Developing the CSHCN Screener involved 4 major milestones:

- 1) Selection of the MCHB definition and a broad, consequence-based framework for defining and identifying CSHCN;
- 2) Review of existing parent survey items and instruments that may align with the federal MCHB definition and consequence-based model of identification;
- 3) Drafting, pilot testing, and revision of the CSHCN Screener; and
- 4) Field testing in a national sample of households with children and in statewide Medicaid managed care and Supplemental Security Income (SSI) samples.

The established consensus among public agencies as well as the merits of the MCHB definition and consequence-based framework reviewed earlier led to their use in the development of the CSHCN Screener. We identified a wide range of functioning and health service-related consequences for incorporation into the CSHCN Screener. A parent survey approach was necessary to allow the integration of the CSHCN Screener into current efforts to monitor and assess health care quality for children, many of whom utilize client surveys such as the self-administered Consumer Assessment of Health Plans Study (CAHPS) survey.²⁵ This integration was important because an explicit goal for the CSHCN Screener is its usefulness for standardized assessment of health care quality for CSHCN enrolled in managed health care plans. As such, the Screener needed to be acceptable to organizations vested with accreditation and assessment of health plan performance as well as to state Medicaid agencies, through which many children are enrolled in managed care health plans.

Items from existing surveys were reviewed, including the QuICCC and questions on limitation of activity and functional status included in the National Health Interview Survey (NHIS), both of which use consequence-based criteria.^{17,18} Items and instruments reviewed varied as to the type, scope, and intensity of health and health service need consequences addressed and in the specific types and duration of conditions required (eg, medical, mental, behavioral, or developmental conditions; duration of 3 vs 12 months) to qualify a child as having a special health care need. The items and instruments also varied in the number, wording, content, and formatting of survey items used.

A pilot version of the CSHCN Screener consisted of 3 items related to a child's functioning, need for health care services, and/or dependence on devices or prescription medicines. These items were selected, in part, based on information about which QuICCC items had the highest frequency of positive responses. Drawing on the QuICCC format, each question included one follow-up item asking whether a specific functional limitation, service need, or dependency on devices or medication was due to a medical, behavioral, or other health condition that has lasted

or is expected to last for at least 12 months. One item included a checklist of 7 health care service use or need consequences often experienced by CSHCN. The pilot version of the CSHCN Screener was evaluated through 18 cognitive interviews with parents of children with and without special health care needs. The draft version was then tested by mail and telephone in 4 health plan samples (n = 1995).

The draft version of the CSHCN Screener was modified based on findings from the pilot that raised concerns about the reliability of the checklist format and the readability of the single follow-up item to establish the presence of an underlying chronic condition. To improve the reliability and readability of the CSHCN Screener, 2 service use or need items replaced the checklist format. As with the QuICCC, the single follow-up item was divided into 2 items. Final wording edits ensured the compatibility of the CSHCN Screener with the CAHPS survey.²⁵

The CSHCN Screener

The final version of the CSHCN Screener consists of 5 question sequences, each of which asks about a specific health consequence. Parents who respond "yes" to any of the 5 consequence questions are then asked up to 2 follow-up questions to determine if the consequence is attributable to a medical, behavioral, or other health condition lasting or expected to last at least 12 months. The 5 health consequences queried include whether the child 1) is limited or prevented in any way in his or her ability to do things most children of the same age can do; 2) needs or uses medications prescribed by a doctor (other than vitamins); 3) needs or uses specialized therapies such as physical, occupational, or speech therapy; 4) has above-routine need or use of medical, mental health, or educational services; or 5) needs or receives treatment or counseling for an emotional, behavioral, or developmental problem. Only children with positive responses to one or more items and each of the associated follow-up questions qualify as having a special health care need.

As was the case with the QuICCC and the NHIS, we selected a 12-month period rather than a shorter duration of condition requirement in order to minimize the probability that the CSHCN Screener identifies children with acute rather than chronic health needs. Also, as with the QuICCC and the NHIS, the CSHCN Screener not only attempts to identify CSHCN who currently use health services and who require devices and medicines but also those who may need but are not receiving these things. See the Appendix for a copy of the CSHCN Screener.

Field Testing the CSHCN Screener

To address study objectives, we fielded the final version of the CSHCN Screener in one national sample of households with children, a sample of children enrolled in Medicaid managed care through the Temporary Aid to Needy Families (TANF) program, and a sample of children receiving SSI benefits in Washington State. These samples provide information for a range of children with different health insurance and socioeconomic characteristics.

National Sample

The national sample was obtained through the second round of pretesting for the National Survey of CSHCN, which included the CSHCN Screener.²⁶ MCHB sponsored this pretest, which was conducted in the fall of 2000 and used the State and Local Area Integrated Telephone Survey (SLAITS) mechanism. The National Center for Health Statistics (NCHS) conducts the SLAITS and utilizes the large random-digit-dial sampling frame from the National Immunization Survey (NIS).²⁷ From the NIS sampling frame, 141 391 telephone numbers were randomly generated and selected using the area codes and telephone exchanges for each of the 50 states. The sample sizes of numbers randomly generated for each state and for each of 28 metropolitan areas were roughly equal. When households with children were successfully contacted, all children under the age of 18 years were screened for special health care needs using the CSHCN Screener. The respondent was the parent or guardian who the initial household contact determined to be most knowledgeable about the health and health care of the children living in the household. Abt Associates, Inc, under contract to NCHS, collected the data for the National CSHCN Survey pretest. Using survey items included in the National Survey of CSHCN, demographic data such as age, race/ethnicity, and sex of the child were collected for all children, including those who were not positively identified by the CSHCN Screener. A more in-depth interview was then conducted for a subset of households with children positively identified by the CSHCN Screener. In households with more than one CSHCN, this in-depth interview was conducted for one randomly selected child. Using survey items that were eventually included in the National Survey of CSHCN, the in-depth interviews asked about the child's health and functional status, presence and adequacy of health insurance, utilization and access to health care, care coordination, satisfaction and experience of care, and the impact of the child's health on the family.²⁶

Medicaid Managed Care Sample

A statewide sample of children enrolled across 9 managed care health plans through the TANF program was obtained through the administration of the CAHPS survey in the state of Washington. The CSHCN Screener was incorporated into the CAHPS survey and was administered by mail with a telephone follow-up administration for those not responding to the mailed survey.²⁸ DataStat, Inc conducted the survey under contract to PROWest, Inc, on behalf of the Washington State Medical Assistance Administration.

The sampling frame included all child Medicaid clients under the age of 13 years who were continuously enrolled in a managed care health plan for at least 6 months as of March 2000. Up to a 1-month break in enrollment was allowed. Separate samples of 1050 children were randomly selected from the eligible population in each of the 9 participating health plans, yielding an overall starting

sample size of 9450 children. A target child was randomly selected for households with more than one eligible child. Households flagged in the Medicaid enrollment files as having Spanish as the primary language were given a choice of responding in English or Spanish. CSHCN Screener responses were obtained for each child, as was information about child health status, utilization of and access to care, and experience of care. Children are eligible for Medicaid under TANF in the state of Washington if their family income is less than or equal to 200% of the federal poverty level and if the child is under the age of 19 years.

SSI Sample

Like the Medicaid managed care sample, the SSI sample was obtained through the administration of the CAHPS survey to a statewide sample of families with children under the age of 13 years who were currently receiving SSI benefits in the state of Washington as of March 2000. A sample of 2500 children was randomly selected from all children currently receiving SSI benefits. The majority of the children in the sample received health care through Medicaid fee-for-service programs; however, a few also had additional third-party payer coverage. All surveys were collected in English only using the same survey instrument and administration protocol described for the statewide Medicaid managed care sample.

Analytical Methods

The assessment of the efficiency of the CSHCN Screener is limited to an estimate of the time required to administer by telephone in the National CSHCN Survey, as reported to the NCHS by Abt Associates, Inc. The impact of further reducing the number of items in the Screener was partially assessed by examining differences in the proportion of children identified as CSHCN and the characteristics of children who would not be identified if lower frequency Screener items were removed. The feasibility of administering the CSHCN Screener as a self-administered instrument was evaluated by examining the proportion of parents in the Medicaid managed care sample who fully answered Screener items and who appropriately followed the CSHCN Screener item skip patterns. The proportions of children positively identified when the instrument was administered by mail or through the telephone follow-up in the Medicaid managed care sample were compared to assess the different administration modes.

Positive identification on the CSHCN Screener was determined for each child based on responses to the screening questions and the scoring algorithm described earlier. The proportions of children positively identified were calculated separately for the national, Medicaid managed care, and SSI samples as well as for subgroups of children within each sample according to child's age, sex, and race/ethnicity. The statistical significance of observed variation in rates of identification across subgroups of children was evaluated for each sample using standard chi-square tests of statistical significance. The effect of child characteristics in predicting the likelihood of positive identification

TABLE 1. Summary of Characteristics of Child Respondents and Survey Administration Mode

	National Sample	Statewide Medicaid Managed Care Sample	Statewide SSI Sample
Mode	Telephone	Mail with telephone follow-up	Mail with telephone follow-up
Response rate	60.0%*	57.7%†	62.8%†
Number of cases	n = 17 985‡	n = 3894§	n = 1550
Age range	0–17 y	0–13 y	0–13 y
Mean age	8.7 y	6.9 y	8.7 y
% Male	51.2	51.2	62.7
% Hispanic	10.7	13.8	7.0
% White/non-Hispanic	66.1	72.8	79.6
% Black/non-Hispanic	18.5	7.8	7.7
% Other/non-Hispanic	4.6	5.7	5.7

SSI, Supplemental Security Income.

*American Association for Public Opinion Research (AAPOR) response rate for random-digit–dialing surveys with screening for eligible subpopulations.²⁴

†Adjusted response rate = complete surveys/total eligible sample.

‡This is the final sample after removing Spanish-language surveys. All results reported are based on this sample.

§This is the final sample after removing Spanish-language surveys and surveys in which a parent mistakenly responded for more than one child. All results reported are based on this sample.

on the CSHCN Screener was determined separately for each sample using multivariate logistic regression methods. Each model included age, sex, and race as covariates. In addition, multivariate models for the Medicaid managed care and SSI samples included parent ratings of child health status and the number of child outpatient visits to a doctor's office or clinic in the past 6 months. These variables were not available for all children in the national sample. All analyses were conducted using SPSS version 9.0 software.

Only data from surveys completed in English are used in these analyses. This decision was made to allow for comparable analysis across all 3 samples, not all of which used the same version of the Spanish translation of the CSHCN Screener. Also, the survey administered to the SSI sample did not include a Spanish version. All comparisons presented in the results are significant at a level of .05 or less.

RESULTS

Survey Respondents

The 3 study samples represent a total of 26 062 cases. Of these, 23 429 cases were used for the analyses reported in this paper. Table 1 summarizes the survey and response rates for each of the 3 samples as well as the age, sex, and racial/ethnic characteristics of the children included.

For the national sample, CSHCN Screener data were collected for 19 507 children from 10 178 telephone households in all 50 states and 28 metropolitan areas. Household interviews were conducted in both English (n = 9421 households and 17 985 children) and Spanish (n = 695 households and 1522 children). Data for the 17 985 children whose interviews were completed in English were used in this analysis. In addition, 2274 in-depth CSHCN interviews were completed from among the 2753 children positively identified by the CSHCN Screener. Using the American Association for Public Opinion Research standard definitions for response rates, the overall

survey response rate was 60.0%, which includes the rates for resolving whether generated telephone numbers are residential or nonresidential (87.4%), for screening contacted households for the presence of children (91.1%), for screening households with children for the presence of CSHCN (76.6%), and for completing detailed interviews in households with CSHCN (98.3%).²⁹

In the statewide Medicaid managed care sample, the overall response rate, adjusted for cases lacking valid addresses or phone numbers, was 57.7%, or 4972 usable surveys. A total of 3894 cases were used in this analysis, after removing surveys completed in Spanish and cases in which it appeared that respondents may have mistakenly answered for more than one child. The final response rate for the SSI sample was 62.8%, or 1583 usable surveys, after adjusting for cases lacking valid addresses or telephone numbers. After removing surveys in which it appeared that respondents may have mistakenly answered for more than one child, a total of 1550 SSI cases were used in this analysis. Respondents in the Medicaid managed care and SSI samples completed the mail version of the survey 80% and 83% of the time, respectively, with the remainder of responses obtained by telephone interview during follow-up phone calls.

Time to Administer the CSHCN Screener

As reported by the survey vendor for the National CSHCN Survey, the CSHCN Screener took an average of 2.1 minutes to administer by telephone when all children in the household were included (range = 1.1–4.5 minutes). When administered by telephone for a single target child in a household, administration time averaged 1 minute.

Impact of Item Reduction of the CSHCN Screener

In the national and Medicaid managed care samples, respectively, 89.0% and 80.0% of children positively identified by the CSHCN Screener had positive responses

to either or both of the prescription medicine (Q1) or above routine service use (Q2) item sequences. Of these children, 40.5% and 54.0% also had positive responses to one or more of the remaining 3 Screener items in the national and Medicaid managed care samples, respectively. In the SSI sample, 90.5% of children positively identified by the CSHCN Screener had positive responses to either or both of the prescription medicine (Q1) or above routine service use (Q2) item sequences. Over 96.5% of these children also had positive responses to one or more of the remaining 3 Screener items.

Among the 11% of children in the national sample who were positively identified by the CSHCN Screener on the basis of questions other than the 2 highest frequency items, one third reported functional limitations and 57.0% had some type of ongoing emotional, developmental, or behavioral condition requiring treatment. This is a not an unexpected finding, particularly given that many functional disabilities and developmental or emotional problems do not necessarily require traditional medical services or medication. Such conditions might include mental retardation, learning disabilities, speech and other communication difficulties, blindness, deafness, autism, or post-traumatic stress syndromes. Children in this group would not be identified if the CSHCN Screener were further reduced to include only the 2 items on which children in this study were most often positively identified by the CSHCN Screener.

Reducing the CSHCN Screener to just the 2 highest frequency items may also limit the ability to identify subgroups of CSHCN based on their answers to one or more of the other 3 Screener items. For example, when compared to children with positive answers to one or both of the high-frequency items only, children qualifying on the functional limitations survey item in combination with one or both of these 2 survey items were significantly more likely to have visited the doctor 10 or more times during the time period previous to the survey (39% vs 16.9%), to have experienced health conditions that limited their ability to function significantly more often (91.1% vs 21.9%), and to have experienced health conditions that were more likely to be rated as being severe/very severe in nature by parents (31.9% vs 6.7%). Identification of other subgroups may be possible. However, an examination of the characteristics of all possible subgroups is beyond the scope of this article.

Feasibility of Self-Administration of the CSHCN Screener

In the Medicaid managed care sample, over 98% of individuals who self-administered the CSHCN Screener completed each of the 5 items, and 94% appropriately followed the 7 skip patterns. These item completion rates and appropriate skip pattern completion rates are commensurate with or higher than those observed for other items included in the Survey of CAHPS. Finally, in both the statewide Medicaid managed care and SSI samples, rates of children positively identified by the CSHCN Screener did not differ according to whether the screening

instrument was administered by mail or telephone ($P = .50$).

Rates of Positive Identification by the CSHCN Screener

In the national sample, the CSHCN Screener positively identified 15.3% of children under the age of 18 years. This rate is not adjusted for noncoverage of households without telephone numbers and for other potential sampling, selection, and response biases. In the Medicaid managed care and the SSI samples, the CSHCN Screener positively identified 20.7% and 94.6% of children under the age of 13 years, respectively (Table 2).

As noted earlier, in the national sample and the Medicaid managed care sample, need or use of prescription medication for an ongoing condition was the CSHCN Screener criterion most frequently met by children (11.4% and 14.4%, respectively), followed by above-routine use of health or related services (6.5% and 9.7%, respectively). The proportion of children in these samples qualifying on the functional limitations criterion was low relative to other CSHCN Screener items (3.8% and 6.4%, respectively). However, among children in the statewide SSI sample, the CSHCN Screener item addressing functional limitations had the greatest frequency of positive responses (83.4%), and the prescription medication item had the lowest frequency of positive responses (54.4%) (Table 3).

In the national and Medicaid managed care samples, approximately one half of the children positively identified by the CSHCN Screener qualified on only one screening question. Just over 20% of the positively identified children in these 2 samples qualified on 2 out of the 5 screening questions, with the remaining positively identified children qualifying on the basis of 3 or more of the 5 questions. In contrast, in the SSI sample, over 85% of children positively identified by the CSHCN Screener qualified on 3 or more of the 5 CSHCN Screener items (Table 3).

Variation in Positive Identification by the CSHCN Screener According to Child Characteristics

As summarized in Table 2, variations in rates of positive identification on the CSHCN Screener were observed according to a child's demographic characteristics for all 3 samples. As shown in Table 4, the adjusted odds were 1.48 times greater that male children were positively identified in both the national and Medicaid managed care samples. The adjusted odds were 2.25 to 5.83 times greater (across the 3 samples) that older children were positively identified by the CSHCN Screener (Table 4). The adjusted odds were .61 to .84 times less that Hispanic children were positively identified in the national and Medicaid managed care samples, respectively, compared to White, non-Hispanic children. However, the Hispanic sample includes only children from households responding in English and therefore cannot be generalized to all Hispanic families. In the national sample, for example, just over half (55.2%) of all Hispanic children were from

TABLE 2. Percentage of Children Identified by Children With Special Health Care Needs (CSHCN) Screener Overall and By Age, and Sex, Race/Ethnicity By Study Sample

	National Sample (n = 17 985)*	Statewide Medicaid Managed Care Sample (n = 3894)†	Statewide SSI Sample (n = 1550)
% Meeting CSHCN Screener criteria	15.3	20.7	94.6
% Meeting CSHCN Screener criteria by sex, age, and race/ethnicity			
Female	12.8	18.4	94.6
Male	17.7 (<i>P</i> < 0.001)	25.6 (<i>P</i> < 0.001)	94.5 (NS)
Under 1 y to 4 y old	8.0	12.5	93.6
5–9 y old	17.2	22.6	95.7
10–14 y old	17.9	31.1 (<i>P</i> < 0.001)	94.0 (NS)
15 y old and over	18.4 (<i>P</i> < 0.001)	n/a	n/a
Mean age			
CSHCN	10.0 y	8.3 y	8.7 y
Non-CHSCN	8.5 y (<i>P</i> < 0.001)	6.5 y (<i>P</i> < 0.001)	8.8 y (NS)
Race/ethnicity–specific rates among children 0–13 y old‡			
	CSHCN rate	CSHCN rate	CSHCN rate
Hispanic child	12.8	16.3	94.2
White/non-Hispanic child	15.1	23.3	95.7
Black/non-Hispanic child	14.6	24.1	91.3
Other/non-Hispanic child	9.7 (<i>P</i> < 0.001)	14.4 (<i>P</i> < 0.001)	87.1 (<i>P</i> < 0.001)

SSI, Supplemental Security Income.

*Data from surveys collected in English only.

†Data from surveys collected in English only; non–multi-child responders only.

‡To allow comparability across samples, race/ethnicity–specific rates include only children from 0 to 13 years of age.

households responding in English and 44.2% were from households responding in Spanish.

We also investigated the effect of parent-reported utilization of care and child health status on the probability of positive identification in the Medicaid managed care and SSI samples. As expected, children with more outpatient visits to a health care provider in the past 6 months and children whose parents rate their child's health as less than excellent or very good were significantly more likely to be positively identified by the CSHCN Screener (Table 4).

DISCUSSION

The CSHCN Screener was developed to be an instrument for the comprehensive, efficient, and flexible identification of CSHCN. Because of its brevity and flexible administration, the CSHCN Screener is more viable than existing screening instruments for standardized use in identifying CSHCN for a variety of purposes, including public health monitoring, health care quality assessment, and program planning and evaluation. In addition, the consensus-based process used to develop this instrument contributes to its acceptability across the range of potential users.

The results presented above indicate that the CSHCN Screener requires minimal time to administer and is acceptable for use as both an interviewer- and self-administered survey. Findings also indicate that limiting the CSHCN Screener to the 2 items with the highest frequency of positive responses would eliminate many children with current health problems and health care needs, especially those with problems of an emotional, mental, or

developmental nature. Hence, we do not recommend further item reduction at this time. The interest in parsimonious screening instruments is high, given the costs of survey administration. Further evaluation regarding the impact of item reduction is underway.

The variation observed in the proportions of children positively identified by the CSHCN Screener across the 3 study samples was expected given the different age, socioeconomic, and health status characteristics of children represented in each sample. The overall rates in the national and Medicaid managed care samples and observed variation in the proportion of children positively identified by the CSHCN Screener in these samples are consistent with the findings from other research on CSHCN. In particular, higher rates for male children, older children, and children who regularly utilize health services are consistent with findings from other studies on the epidemiology of CSHCN.^{23,24,30,31} In addition, the CSHCN Screener identified nearly all children in the SSI sample, a group whose special health care needs are presumably well-verified. Taken together, these findings support the face validity of this instrument. Additional findings on the validity of the CSHCN Screener are reported on in Bethell et al.³³ Studies are also underway to assess the use of the CSHCN Screener for a wider range of settings and purposes than are reported here.

The lower CSHCN screening rates observed among Hispanic children in the national and Medicaid managed care samples were anticipated based on prior studies of CSHCN, however, these differences are not fully understood and merit further investigation. Caution is necessary in interpreting these findings as the Hispanic sample in-

TABLE 3. Percentage of Children Positively Identified By Children With Special Health Care Needs (CSHCN) Screener, By Screener Question and According to the Type and Number of CSHCN Screener Questions

	National Sample (n = 17 985)*	Statewide Medicaid Managed Care Sample (n = 3894)†	Statewide SSI Sample (n = 1550)
A) Percentage of children overall positively identified by each CSHCN Screener question			
Q1: Need/use of prescription medicines	11.4	14.4	54.5
Q2: Above-average need/use of services	6.5	9.7	80.5
Q3: Functional limitations	3.8	6.4	83.4
Q4: Need/use of specialized therapies	2.7	3.4	75.9
Q5: Need/use of emotional, behavioral, or developmental treatment/counseling	4.2	9.7	65.4
B) Percentage of children positively identified by CSHCN Screener according to type or number of screening questions			
Number of children in sample positively identified by CSHCN Screener	n = 2753	n = 808	n = 1466
Highest yield questions;			
% of CSHCN who qualified on prescription, medication and/or above-routine service use, alone or in combination with other questions	89.4%	80.0%	90.5%
% CSHCN qualifying on 1, 2, or 3+ questions:			
On 1 screening question (%)	53.3	46.4	5.5
On 2 screening questions (%)	21.2	23.5	8.9
On 3 or more screening questions (%)	25.5	30.1	85.6

SSI, Supplemental Security Income.

*Data from surveys collected in English only.

†Data from surveys collected in English only; non-multi-child responders only.

TABLE 4. Odds Ratios from Multivariate Logistic Regression Models Assessing the Impact of Child Characteristics on the Probability of Positive Identification on the Children With Special Health Care Needs (CSHCN) Screener*

Characteristic	National Sample (n = 17 985)†		Statewide Medicaid Managed Care Sample (n = 3894)		Statewide SSI Sample (n = 1550)	
	Odds ratio	P value	Odds ratio	P value	Odds ratio	P value
Age of child						
0–3 y	1.00	—	1.00	—	1.00	—
4–7 y	2.25	<0.001	2.50	<0.001	5.17	<0.001
8–11 y	2.75	<0.001	4.56	<0.001	5.83	<0.001
12–13 y	3.03	<0.001	5.19	<0.001	3.56	<0.001
14–17 y	2.84	<0.001	n/a	n/a	n/a	n/a
Sex of child						
Male	1.48	<0.001	1.48	<0.001	1.23	<0.001
Race/ethnicity of child						
Hispanic	0.84	<0.05	0.61	<0.001	0.61	(NS)
White/non-Hispanic	1.00	—	1.00	—	1.00	—
Black/non-Hispanic	0.92	(NS)	1.12	(NS)	0.66	(NS)
Other/non-Hispanic	0.67	<0.001	0.48	0.001	0.29	0.001
Doctor’s office or clinic visits, past 6 mo						
No visits			1.00	—	1.00	—
1–2 visits		n/a	2.73	<0.001	1.64	(<0.10)
3–4 visits			4.38	<0.001	3.69	0.001
5 or more visits			6.69	<0.001	17.35	<0.001
Parent rating of child’s health						
Excellent, very good			1.00	—	1.00	—
Good		n/a	3.12	<0.001	1.76	<0.05
Fair, poor			6.85	<0.001	2.34	0.05

SSI, Supplemental Security Income.

*Odds ratios and P values are for the sample indicated compared to the children in the sample who were not identified by the CSHCN Screener.

†Number of doctor’s office/clinic visits was only obtained for children identified by CSHCN Screener. Parent rating of child’s health was not included in this study.

— = Reference category.

cludes only children from households responding in English and therefore cannot be generalized to all Hispanic families. The observed differences in rates of positive identification by the CSHCN Screener by race/ethnicity are also not attributable to artifacts of language or translation as only data from cases where the CSHCN Screener was administered in English were included in the analysis.

The CSHCN Screener was fielded in a national sample that sought to be representative of all 50 states and 28 metropolitan areas. Still, results may not be generalizable to subpopulations of children not included in this sample, such as homeless and migrant children or children in institutional settings. The rate of CSHCN identified in the national sample should be interpreted cautiously. Roughly equivalent-sized samples were drawn from each state and each of the 28 metropolitan areas, and no sampling weights were used to adjust for potential selection biases. Caution is also necessary in interpreting the rate of identification of CSHCN for the Medicaid managed care sample, as this sample included only children under the age of 13 years with at least 6 months' continuous enrollment in a Medicaid health plan. The proportion of children positively identified by the CSHCN Screener would likely be different in a random sample that included all Medicaid-enrolled children under the age of 18 years, regardless of health plan enrollment, because older children are more likely to be identified by the CSHCN Screener and because those continuously enrolled in a health plan may be different from those with less-stable coverage. In addition, incomplete response rates to the CAHPS survey may affect results in unknown ways.

Findings regarding differences in rates of positive identification by the CSHCN Screener for mail versus telephone survey administration should not be taken as conclusive until a more careful study examining the effect of survey administration mode is conducted. In addition, we did not test face-to-face interview administration nor did we administer the screening instrument across a variety of health care or community settings. Work is underway to evaluate the use of the CSHCN Screener in alternate settings.

All data used in this study were collected with assurances of confidentiality; consequently, we do not have information on how parent responses to the CSHCN Screener may vary under circumstances where this is not the case. In the national sample, the CSHCN Screener was administered to the parents of adolescents. There are concerns about whether parents or adolescents themselves are the more reliable responders to these types of questions, especially regarding mental health and substance abuse problems. The question related to parents serving as proxy respondents for adolescents will be evaluated in future studies. Finally, this study did not attempt to fully examine the concurrent or convergent validity of the CSHCN Screener. Results of a study further evaluating the validity of the CSHCN Screener can be found in a separate article in this issue of *Ambulatory Pediatrics*.

The CSHCN Screener is the product of a broad collaborative process that built upon a quarter century of pro-

gress toward developing a shared understanding of how best to define and identify CSHCN. The CSHCN Screener is currently being used in the National Medical Expenditures Panel Survey to develop national estimates of the prevalence of CSHCN.³³ In addition, the Screener has been incorporated into the National Survey of CSHCN to allow both national- and state-level prevalence estimates.²⁶ Moreover, it has been formally integrated in the CAHPS Child Survey 2.0H, which is a part of the National Committee for Quality Assurance's Health Plan Employer Data and Information Set. This application allows for the identification and measurement of basic aspects of health care quality for CSHCN enrolled in managed care health plans and is expected to be used in many states' Medicaid quality assessment initiatives during the coming years. The use of the CSHCN Screener in these and other applications will contribute to the creation of a common understanding of the health, health care needs, and health care quality provided to this important population of children.

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Appendix. Children With Special Health Care Needs (CSHCN) Screener

All 3 Parts of at Least One Screener Question (or, in the case of question 5, the 2 parts) Must Be Answered “Yes” In Order for a Child to Meet CSHCN Screener Criteria for Having a Special Health Care Need.

1. Does your child currently need or use **medicine prescribed by a doctor** (other than vitamins)?
 - Yes → Go to Question 1a
 - No → Go to Question 2
 - 1a. Is this because of ANY medical, behavioral, or other health condition?
 - Yes → Go to Question 1b
 - No → Go to Question 2
 - 1b. Is this a condition that has lasted or is expected to last for at least 12 months?
 - Yes
 - No
 2. Does your child need or use more **medical care, mental health, or educational services** than is usual for most children of the same age?
 - Yes → Go to Question 2a
 - No → Go to Question 3
 - 2a. Is this because of ANY medical, behavioral, or other health condition?
 - Yes → Go to Question 2b
 - No → Go to Question 3
 - 2b. Is this a condition that has lasted or is expected to last for at least 12 months?
 - Yes
 - No
 3. Is your child **limited or prevented** in any way in his or her ability to do the things most children of the same age can do?
 - Yes → Go to Question 3a
 - No → Go to Question 4
 - 3a. Is this because of ANY medical, behavioral, or other health condition?
 - Yes → Go to Question 3b
 - No → Go to Question 4
 - 3b. Is this a condition that has lasted or is expected to last for at least 12 months?
 - Yes
 - No
 4. Does your child need or receive **special therapy**, such as physical, occupational, or speech therapy?
 - Yes → Go to Question 4a
 - No → Go to Question 5
 - 4a. Is this because of ANY medical, behavioral, or other health condition?
 - Yes → Go to Question 4b
 - No → Go to Question 5
 - 4b. Is this a condition that has lasted or is expected to last for at least 12 months?
 - Yes
 - No
 5. Does your child have any kind of emotional, developmental, or behavioral problem for which he or she needs or receives **treatment or counseling**?
 - Yes → Go to Question 5a
 - No
 - 5a. Has this problem lasted or is it expected to last for at least 12 months?
 - Yes
 - No
-

Comparison of the Children With Special Health Care Needs Screener to the Questionnaire for Identifying Children With Chronic Conditions—Revised

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Background.—The Children with Special Health Care Needs (CSHCN) Screener is an instrument to identify CSHCN, one that is based on parent-reported consequences experienced by children with ongoing health conditions. Information about how this instrument compares to other methods for identifying CSHCN is important for current and future uses of the CSHCN Screener.

Research Objectives.—The goal of this study was to assess the level of agreement between the CSHCN Screener and the Questionnaire for Identifying Children With Chronic Conditions—Revised (QuICCC-R) and to describe the characteristics of children in whom these methods do not agree.

Methods.—The CSHCN Screener and the QuICCC-R were administered to 2 samples: a random sample of parents of children under age 18 years through the first pretest of the National CSHCN Survey (n = 2420) and a random sample of children under age 14 years enrolled in a managed care health plan (n = 497). Information on specific conditions and needs for health services were collected for children identified by one or both instruments in the national sample. Data from the administrative data-based Clinical Risk Groups (CRGs) were collected for all children in the health plan sample. The proportions of children identified with the CSHCN Screener and the QuICCC-R were compared, the level of agreement between these 2 methods was assessed, and the health service needs of children identified by the QuICCC-R but not the CSHCN Screener were evaluated.

Results.—In both study samples, the CSHCN Screener agreed with the QuICCC-R approximately 9 out of 10 times on whether or not a child was identified as having a special health care need. Compared to the CSHCN Screener, the QuICCC-R identified an additional 7.6% and 8.5% of children as having special health care needs in the national and health plan samples, respectively. Compared to children identified by the QuICCC-R only, the odds were 12 times greater that children identified by both the CSHCN Screener and the QuICCC-R needed health care services, 6 times greater that parents named a specific chronic health condition, and 9 times greater that children were identified with a chronic condition using the CRG algorithm. Study design and purposeful differences in question design or content account for most cases in which children are not identified by the CSHCN Screener but are identified using the QuICCC-R.

Conclusions.—The brief CSHCN Screener exhibits a high level of agreement with the longer QuICCC-R instrument. Whereas nearly all children identified by the CSHCN Screener are also identified by the QuICCC-R, the QuICCC-R classifies a higher proportion of children as having special health care needs.

KEY WORDS: children; chronic conditions; identification; quality; screening; special health care needs

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Interest in monitoring the health, health care needs, and quality of health care for children with special health care needs (CSHCN) has grown in recent years.^{1–5} Yet neither national nor state efforts to monitor these variables have used a common method to define and identify CSHCN. Use of a common method is key to developing a shared understanding among policy makers, health care

providers, and consumers regarding priorities and approaches for addressing the health care needs of CSHCN.⁶

The CSHCN Screener is a 5-item survey-based measure for identifying CSHCN based on parent-reported consequences experienced by children with ongoing health conditions. This measure is based on the federal Maternal and Child Health Bureau definition of CSHCN⁴ and is the product of a broad collaborative process that built upon a quarter century of progress toward developing a shared understanding of how to define and identify CSHCN. The conceptual framework, technical properties, and development process leading to the CSHCN Screener as well as results for the screening instrument in different populations of children are reported in Bethell et al⁷ in this issue of *Ambulatory Pediatrics*.

Although a gold-standard method for identifying CSHCN does not exist, potential users of the CSHCN Screener should understand how this instrument compares to other recognized methods for identifying CSHCN, such as the Questionnaire for Identifying Children with Chronic Conditions (QuICCC) and the Questionnaire for Identifying Children with Special Health Care Needs (QICSHCN).

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tifying Children with Chronic Conditions–Revised (QuICCC-R).^{8–11} As explained in Bethell et al, the CSHCN Screener uses a consequences-based framework for identifying CSHCN, a framework similar to that of the QuICCC and QuICCC-R.⁷ The 39-item QuICCC and the shorter 16-item QuICCC-R have been validated for use in identifying a broad range of CSHCN with current health and/or health service needs or consequences, regardless of the specific underlying health condition.^{9–11} These instruments identify children with common childhood chronic conditions as well as comparatively rare health conditions not typically included in condition checklists. Because the QuICCC-R has a shorter administration time and because it has demonstrated greater than 95% agreement with the longer QuICCC,¹¹ the QuICCC-R may supersede the QuICCC as an instrument for identifying children with chronic conditions for some purposes. Consequently, we have restricted our analysis to comparisons of the CSHCN Screener and QuICCC-R.

The CSHCN Screener and the QuICCC-R are similar in that each asks parents whether their child experiences one of several health or health care consequences CSHCN may experience. Also, with some exception for several QuICCC-R items, both instruments ask parents whether each consequence is attributable to a medical, behavioral, or other health condition lasting or expected to last at least 12 months. There are some differences in the objectives of the QuICCC and QuICCC-R and the CSHCN Screener. The QuICCC and the QuICCC-R intended to include children falling into “the gray area or boundary area. . . . where there is uncertainty over whether a particular child has a chronic condition.”¹⁰ This was not an explicit goal of the CSHCN Screener. There are 5 other important features that distinguish the CSHCN Screener from the QuICCC-R. First, the CSHCN Screener does not directly inquire about all the specific health and health care service need consequences included in the QuICCC-R. In some cases, the CSHCN Screener items ask about broader categories of functioning problems and/or health care service needs rather than asking about specific needs or health consequences in separate questions. Based on results from a comparison of a pilot version of the CSHCN Screener and the QuICCC, we expected that children identified by the specific items included in the QuICCC-R and not in the CSHCN Screener may be likely to have positive responses to these broader questions. In other cases, QuICCC-R consequences are purposely not reflected in the CSHCN Screener questions. However, since most children with positive responses to QuICCC-R items about these consequences also have positive responses to items that are explicitly reflected in the CSHCN Screener, we expected that the CSHCN Screener would still identify many of these children.

Second, the CSHCN Screener requires that parents indicate the presence of a health condition for their child that has lasted or is expected to last at least 12 months, whereas several items in the QuICCC-R do not have such a requirement. In these cases, we may expect to see discrepancies in children identified by the 2 screening in-

struments. Third, the CSHCN Screener attempts to identify not only CSHCN who currently use health services but also CSHCN who may need services they are not receiving by asking whether a child gets *or needs* a certain type of health service for an ongoing condition as a part of each question. In contrast, the QuICCC-R includes a single question about unmet need rather than incorporating this concept into all questions about consequences children may experience. Fourth, the CSHCN Screener is shorter than the QuICCC-R. It includes 5 question sequences, each comprised of one stem question and one or two follow-up items for parents with positive responses to the stem question (totaling 14 component questions). The QuICCC-R includes 16 question sequences totaling 41 component questions once follow-up items are included. Finally, the CSHCN Screener can be self-administered or administered by an interviewer by phone or in person, whereas the QuICCC-R has been validated for interviewer administration only.

Despite these differences, we expected to find a high level of agreement between the CSHCN Screener and the QuICCC-R because of their conceptual and content similarities. The purpose of this study was to examine this hypothesis by formally assessing the level of agreement between the CSHCN Screener and the QuICCC-R. A second objective was to assess differences in the demographic, health status, and health care use characteristics of children for whom these methods did not agree. By doing so, we sought to determine whether the shorter CSHCN Screener might systematically miss certain groups of children with special health care needs according to the child’s type of health condition, health care needs, or demographic characteristics.

In this study, we first assessed the proportion of children in which the CSHCN Screener and the QuICCC-R agree on the presence of a special health care need. Then, among discrepant cases, we assessed differences between cases identified on one screener and not the other by 1) age, sex, and race/ethnicity; 2) the type and number of health issues parents report for children; 3) the proportion of parents who name a specific chronic condition for children; 4) the proportion of children for whom a diagnosis for a chronic condition is recorded in administrative records and/or the child’s medical chart; and 5) parent-reported need for health services. We also present an evaluation of study design and question construction effects in explaining discrepant cases. Finally, we present an assessment of the degree to which discrepant cases are represented by children falling into “the gray area or boundary area. . . in which there is uncertainty over whether a particular child has a chronic condition.”¹¹

METHODS

Two samples were used in this study. First, the CSHCN Screener and the QuICCC-R were administered to a random sample of parents of children aged 17 years and under through the first pretest of the National CSHCN Survey. Second, data on the CSHCN Screener, the QuICCC-R, and the diagnosis-based Clinical Risk Groups (CRGs)

were collected for each child in a random sample of children under the age of 14 years who were enrolled in a mixed-model managed health care plan in the State of Washington.

National Sample

Data for the national sample were collected during the first of 2 rounds of pretesting for the National CSHCN Survey.¹² The federal Maternal and Child Health Bureau (MCHB) sponsored this pretest, which was conducted in the spring of 2000 and used the State and Local Area Integrated Telephone Survey (SLAITS) mechanism. The National Center for Health Statistics of the Centers for Disease Control and Prevention conducts SLAITS, and Abt Associates, Inc, administers the surveys under contract to the National Center for Health Statistics. The survey utilizes the large random-digit-dial sampling frame from the National Immunization Survey.¹³ From the NIS sampling frame, 20711 telephone numbers were randomly generated and selected using the area codes and telephone exchanges in 6 states and 5 metropolitan areas across the United States, leading to roughly equal sample sizes for each state and metropolitan area. After removing identifiable nonworking and nonresidential numbers, remaining numbers were dialed. With successful contact, the person answering the phone gave verbal consent and provided the birth dates for any children 17 years of age or younger living or staying in the household. The respondent was the parent or guardian identified by the initial phone respondent to be most knowledgeable about the health and health care of the children living in the household.

Measures Used

We used the CSHCN Screener and the QuICCC-R to screen all sample children. Both screeners were administered for each sample child, and the order of administration was randomized. A more in-depth interview was then conducted for 75% of children positively identified by either or both the CSHCN Screener and the QuICCC-R. All children in households with only one CSHCN and a randomly selected CSHCN in households with more than one CSHCN were chosen as the target children for the interviews. Parents were asked about the presence of a condition and were asked to name the condition. In addition, parents were asked a series of questions about their child's need or use of different types of health and related services during the past 12 months. Finally, information on age, sex, and race/ethnicity were collected for children identified with special health care needs by either of the instruments.

The data from this national sample are limited because neither demographic nor health-related data were collected for the group of children not identified as having special health care needs by either screener. Also, verbatim answers naming children's specific health conditions were only collected for children positively identified by one or more of the screening instruments and were collected at the household level only. Therefore, in those households

having multiple children with positive screening results, the conditions named by the respondent could not be linked specifically to the child randomly selected for the longer interview. Consequently, analyses of verbatim responses included children in single-child households or in multiple-child households in which only one child had positive screening results, representing 75% of households with one or more children who were positively identified by the CSHCN Screener and/or the QuICCC-R and who received the in-depth interview.

Health Plan Sample

Data for the health plan sample were collected in the fall of 1999. The sampling frame for the health plan sample included all children under the age of 14 years who had been continuously enrolled in the health plan for at least 12 months with no more than one gap of up to 45 days. In 1999, the health plan insured 46 600 children, ages 0–17 years, representing about 45% of the under age 18 population in a 4-county region in the state of Washington. Enrolled children were covered through Medicaid capitated managed care (37%), Medicaid fee-for-service (0.9%), non-Medicaid capitated managed care (17%), and non-Medicaid fee-for-service (45%). A random sample of 890 children was selected. Where more than one child in a single household appeared in the sample, a target child from that household was randomly chosen for the survey. An independent research firm, Matteson and Sutherland, Inc, administered the survey under contract to the health plan on behalf of FACCT—The Foundation for Accountability.

Measures Used

The CSHCN Screener and the QuICCC-R instruments were administered by telephone to the parent/caretakers of children in the sample, as in the national sample. Administrative encounter records were also analyzed for all children using the CRG software as an alternative method of identifying a chronic condition. The CRG algorithm is a categorical clinical system that uses a minimum of 6 months of administrative data to classify individuals into mutually exclusive categories indicative of chronic, acute, or no health conditions. A detailed description of the CRG system can be found in Neff et al¹⁴ in this issue of *Ambulatory Pediatrics*.

Medical chart reviews (n = 86) were conducted for all cases in which the CSHCN Screener did not positively identify a child but in which the QuICCC-R did as well as in some of the few cases in which the CSHCN Screener identified a child but the QuICCC-R did not. Chart reviews were conducted by an independent registered nurse consultant using a standardized computer-prompted data-collection protocol.

Analytic Methods

Using both samples, the proportion of cases where the CSHCN Screener and QuICCC-R agreed was calculated. Each child positively identified by one or both screening measures was further classified according to whether he

was positively identified by both instruments or by only one of the 2 screening methods. Then we compared children identified by both instruments to those positively identified by the QuICCC-R only. Smaller numbers of children positively identified by the CSHCN Screener only prevent comparisons of these children with those identified by other methods. To further understand agreement between screening methods, we examined the positive predictive value of each method against the other. The predictive value of a positive test (PPV) is the probability that a child identified by one screening method will be positively identified by the comparison method. The predictive value of a negative test (NPV) is the probability that a child not identified by one screening method will not be positively selected by the comparison method.¹⁵

The demographic characteristics of children positively identified by both screeners and those positively identified by the QuICCC-R only were compared in both samples. In the national sample, these groups were also compared on parent reports of the type and number of health issues children experience, the presence of a health condition for their child, and the child's need for health services. In the health plan sample, whether a child has an indication of a chronic condition according to the CRG algorithm was assessed for children identified by both the CSHCN Screener and the QuICCC-R and for children positively identified by the QuICCC-R only. Whether or not a chronic health condition diagnosis is explicitly noted or could be inferred through a review of the child's medical chart based on symptoms, use of services, medications, or other variables was summarized for the subset of children identified by the QuICCC-R only.

We then compared the proportion of children positively identified by each screening instrument on the "use of prescription medicine" question to determine whether study design might affect the performance of each instrument. This question identifies the largest proportion of children as having a special health care need in both instruments and has nearly identical wording in each instrument. Therefore, differences in parent responses to each question are more likely attributable to study design than to differences between the instruments.

Next, the proportion of children positively identified by the QuICCC-R only due to positive responses to QuICCC-R items that do not require parental report of the current presence of an ongoing condition was calculated to assess the degree to which discrepant cases may be accounted for by purposeful differences in question design between the 2 screening methods. Finally, the proportion of children positively identified only by the QuICCC-R and only on items that identify children representative of those falling into the aforementioned "gray area" was calculated. The 3 QuICCC-R items selected for this illustration inquire about whether children experience life-threatening allergic reactions, require a special diet, or have a vision problem that is not completely corrected by glasses.

This study uses a 5% level of significance. Unless otherwise specified, all comparisons presented in the text are significant at this level. Chi-square tests were used in

TABLE 1. Characteristics of Study Samples*

	National Sample	Health Plan Sample
Mode	Telephone	Telephone
Response rate (%)	68.0	70.0
Number of cases	n = 2420	n = 497
Age range	0–17 y old	0–14 y old
Mean age	n/a	7.3 y
% Male	n/a	53.2
% Identified by CSHCN Screener	16.0	16.7
% Identified by QuICCC-R	23.6	25.2

*n/a Indicates data not available to calculate; CSHCN, Children With Special Health Care Needs; QuICCC-R, Questionnaire for Identifying Children With Chronic Conditions–Revised.

comparing distributions. SPSS version 9.0 software was used to conduct all data analyses.

RESULTS

Survey Respondents

The 2 study samples included a total of 2917 cases. Table 1 summarizes the survey and response rates for each sample as well as the age and sex characteristics of children included for each sample. The national sample included 2420 children from 1284 English-speaking households. Using the American Association for Public Opinion Research standard definition for response rates in telephone surveys that screen for eligible subpopulations, the overall survey response rate was 68.0%, which includes the rates for resolving whether generated telephone numbers are residential or nonresidential, screening contacted households for the presence of children, screening households with children for the presence of CSHCN, and completing detailed interviews in households with CSHCN.¹⁶ Using the same American Association for Public Opinion Research definition, the overall response rate was 70% in the health plan sample, generating 497 usable surveys.

Agreement Between the CSHCN Screener and the QuICCC-R

In both samples, the CSHCN Screener and the QuICCC-R agreed approximately 9 out of 10 times with regard to whether a child had a special health care need. The QuICCC-R positively identified an additional 7.6% and 8.5% of the children in the national and health plan samples, respectively (see Table 2). Specifically, the CSHCN Screener positively identified 16% of children and the QuICCC-R 23.6% of children in the national sample. The CSHCN Screener identified 16.7% and the QuICCC-R 25.2% of children in the health plan sample. Overall, 14.9% and 15.5% of children were classified as having a special health care need by both survey instruments and 73.6% and 75.3% were classified as not having a special health care need in the national and health plan samples, respectively.

Whereas level of agreement between the CSHCN Screener and the QuICCC-R was high, these methods are not interchangeable. In other words, even though these

TABLE 2. Agreement Between the CSHCN Screener and the QuICCC-R*

Type of Agreement or Disagreement	National Sample (n = 2420)	Health Plan Sample (n = 497)
% Both CSHCN Screener and QuICCC-R classify child as having a special health need	14.9	15.5
% Both CSHCN Screener and QuICCC-R classify child as NOT having a special health need	75.3	73.6
% Only QuICCC-R classifies child as having a special health need	8.7	9.7
% Only CSHCN Screener classifies child as having a special health need	1.1	1.2
% Overall agreement between CSHCN Screener and QuICCC-R	90.2	89.1
Positive predictive value (PPV)		
CSHCN Screener as “test”	.93	.93
QuICCC-R as “test”	.63	.62
Negative predictive value (NPV)		
CSHCN Screener as “test”	.89	.88
QuICCC-R as “test”	.98	.98

*CSHCN indicates Children With Special Health Care Needs; QuICCC-R, Questionnaire for Identifying Children With Chronic Conditions–Revised.

instruments agree 90% of the time, this does not mean that the same children will be identified 90% of the time. As displayed in Table 2, in both study samples, if the CSHCN Screener positively identified a child, there was a 93% probability of identification by the QuICCC-R as well. However, a child identified by the QuICCC-R had a 62% and 63% probability of identification by the CSHCN Screener in the health plan and national samples, respec-

tively. If the CSHCN Screener did not identify a child, there was an 88% and 89% probability that the child was also not identified by the QuICCC-R in the health plan and national samples, respectively. If a child was not identified by the QuICCC-R, there was a 98% probability that the child was also not identified by the CSHCN Screener in both study samples (Table 2).

Assessment of Discrepancies Between the CSHCN Screener and the QuICCC-R

Age, Sex, and Race/Ethnicity Distribution

In the national sample, the age, sex, and race/ethnicity distributions did not differ significantly between the group of children positively identified by both the CSHCN Screener and the QuICCC-R and those identified by the QuICCC-R only. In the health plan sample, children in each group did not differ in terms of sex. However, children identified in the health plan sample by the QuICCC-R only were significantly more likely to be under the age of 4 years compared to children identified by both screening instruments (Table 3).

Parent-Reported Type and Number of Health Issues

In both samples, compared to children identified by both screeners, children positively identified by the QuICCC-R only differed significantly in the type and number of health issues parents indicated that their children experienced. The QuICCC-R instrument asks about 16 different health consequences, and children can qualify on single or multiple items. In the national sample, parents of children who qualified on the QuICCC-R only were twice as likely as children identified by both screeners to report that their children experienced only one rather than

TABLE 3. Demographic Characteristics of Children Positively Identified by Both Screening Methods Versus by the QuICCC-R Only*

Child Characteristic	National Sample		Health Plan Sample	
	Positively identified on the CSHCN Screener and the QuICCC-R (n = 275) (%)	Positively identified on the QuICCC-R only (n = 149) (%)	Positively identified on the CSHCN Screener and the QuICCC-R (n = 77) (%)	Positively identified on the QuICCC-R only (n = 48) (%)
Age				
0–4 y	11.5	14.4	19.5	38.3
5–9 y	24.8	28.8	27.3	34.0
10–14 y	39.7	29.5	53.2	27.7
15–17 y	24.0	27.3	—	—
	(P = .24)		(P < .05)	
Sex				
Male	51.3	58.7	62.3	51.1
	(P = .18)		(P = .30)	
Race				
White	74.8	66.9		
Black/African American	19.2	24.3		n/a
Other	6.0	8.8		
	(P = .23)			

* CSHCN indicates Children With Special Health Care Needs; QuICCC-R, Questionnaire for Identifying Children With Chronic Conditions–Revised.

TABLE 4. Comparing the CSHCN Screener and the QuICCC-R

Characteristic	Cases Qualifying on Both CSHCN Screener and QuICCC-R		Cases Qualifying on QuICCC-R Only	
	National Sample (n = 361)	Health Plan Sample (n = 77)	National Sample (n = 210)	Health Plan Sample (n = 48)
Parent reported child experienced 2 or more of 16 health consequences asked about by the QuICCC-R*	73.7% (n = 266)	80.5% (n = 62)	33.3% (n = 70)	33.3% (n = 16)
Parent named verbatim a specific chronic or likely chronic condition*	68.2% (142/208)†	n/a	32.1% (n = 35/109)†	n/a
Parent answered “NONE” when asked to name any acute or chronic health condition*	13.0% (n = 27/208)†	n/a	47.7% (n = 52/109)†	n/a
Classified as having a chronic condition by the administrative data-based CRG system*	n/a	72.7% (n = 56)	n/a	22.9% (n = 11)
Parent reported child needed or used one or more health and related services during the past 12 months*	92% (n = 332)	n/a	49% (n = 103)	n/a
Met QuICCC-R by qualifying on only one of the 4 QuICCC-R items that use a different definitional framework than the CSHCN Screener (no presence or duration of condition requirement)	1.1% (n = 4)	1.3% (n = 1)	18.1% (n = 38)	31.3% (n = 15)
Met QuICCC-R by qualifying only on one of 3 QuICCC-R items likely to identify children falling into the gray area for having a special health care need (allergic reactions, special diet, vision difficulties)	0.8% (n = 29)	0.0%	13.8% (n = 29)	14.6% (n = 7)
Cases accounted for by potential order effects due to study design (cases qualifying on QuICCC-R prescription medication item only)	n/a	n/a	9.0% (n = 19)	6.3% (n = 3)

*Within sample odds ratios for the national sample comparing agreement versus QuICCC-R only cases are presented in the text. CSHCN indicates Children With Special Health Care Needs; QuICCC-R, Questionnaire for Identifying Children With Chronic Conditions–Revised; CRG, Clinical Risk Groups.

†Drawn from subgroup asked to name health conditions (see Methods).

2 or more of the 16 types of health consequences queried by the QuICCC-R (66.7% vs 33.3%). In contrast, children identified by both the QuICCC-R and the CSHCN Screener were 2.8 times more likely than children identified by the QuICCC-R only to have qualified on multiple items (73.7% vs 26.3%; odds ratio [OR] = 5.6; 95% confidence interval [CI] = 3.9–8.1). Similar results were found for the health plan sample (Table 4).

Parent-Reported Health Conditions

In the national sample, parents of children identified by both the CSHCN Screener and the QuICCC-R named a specific chronic condition about twice as often as did parents of children qualifying on the QuICCC-R only (68.2% vs 32.1%). In addition, parents of children identified by both instruments named some type of health condition almost 7.0 times more often than they replied “NONE” (87.0% vs 13.0%; OR = 6.1; 95% CI: 3.5–10.6). In contrast, parents of children in the QuICCC-R–only group were nearly equally likely to name any type of health condition, chronic or acute, as they were to say ‘none’ (52.3% vs 47.7%) (Table 4).

Overall, asthma and ADHD/ADD were the most frequent chronic conditions named by parents, accounting for 40% of cases in which the CSHCN Screener and the QuICCC-R agreed that a child had a special health care

need and 19% of cases positively identified as having a special health care need by the QuICCC-R only. In both groups, asthma and ADHD/ADD represented approximately 60% of children for whom a specific chronic condition (vs acute or no condition) was named by parents. Despite this similarity, children described as having asthma or ADHD/ADD in the 2 groups differed with respect to service needs. When identified by both instruments, parents of children with asthma or ADHD/ADD reported that their children required any health services during the past year at about twice the rate of parents of children with asthma or ADHD/ADD who were identified by the QuICCC-R only (96.5% vs 54.4%).

Diagnostic Code Recorded in Administrative Data

In the health plan sample, the odds were nearly 9 times greater that children positively identified by both screeners were classified as having a chronic condition using the CRG algorithm compared to children positively identified as having a special health care need by the QuICCC-R only (OR = 8.9, 95% CI = 3.9–20.8). Specifically, 72.7% of children positively identified by the CSHCN Screener were classified as having a chronic condition using the CRG administrative data-based algorithm compared to 22.9% in the group qualifying on the basis of the QuICCC-R only (Table 4). Most of these children (n = 7)

TABLE 5. Parent-Reported Child Need for Health Services During the Past 12 Months—National Sample*

Type of Service Needed	Qualified on CSHCN Screener and the QuICCC-R (n = 275) (%)	Qualified on the QuICCC-R Only (n = 149) (%)
Prescription medicine due to condition	77.5	12.7
Special education services (>2 y old)	25.4	17.1
Mental health counseling	24.5	9.0
Medical supplies	22.7	7.6
Special therapies	20.1	12.5
Medical equipment	17.2	2.8
Hearing care	4.4	2.8
Home health care	5.4	1.4
Assistive devices	5.8	2.8
Substance abuse treatment	2.2	0.7

*All differences between results for cases where screeners agree versus QuICCC-R only cases are statistically significant, $P < .05$. CSHCN indicates Children With Special Health Care Needs; QuICCC-R, Questionnaire for Identifying Children With Chronic Conditions—Revised.

had recorded diagnoses of asthma, ADHD, or eye disorders (eg, amblyopia or strabismus).

Need for Health Services

In the national sample, the odds that a child who is positively identified by both the CSHCN Screener and the QuICCC-R used, versus did not use, one or more health and related services during the past 12 months were 12 times greater than those odds associated with children qualifying on the QuICCC-R only (OR = 12.0; 95% CI: 6.9–20.6). Specifically, 92% of children qualifying on both screeners used health and related services during the past 12 months compared to 49% of children qualifying on the QuICCC-R only.

For children positively identified by both the CSHCN Screener and the QuICCC-R, need for services ranged from a low of 2.2% for substance abuse treatment/counseling to a high of 77.5% for prescription medication for an ongoing condition. The next most frequently needed services for this group were special education services (25.4%), mental health counseling (24.5%), medical supplies (22.7%), special therapies (20.1%), and medical equipment (17.2%). For children identified by the QuICCC-R only, need for services ranged from a low of 0.7% for substance abuse treatment/counseling to a high of 17.1% for special education services (eg, an individual education plan). The next most frequently needed services for this group included prescription medicines for a chronic condition (12.7%), special therapies (12.5%), mental health counseling (9.0%), and medical supplies (7.6%) (Table 5).

Study Design Effects

Although the majority of children qualifying on the prescription medication screening criteria did so on both instruments, a small number of children in the QuICCC-R-only group qualified on the prescription medication criteria alone. The discrepant responses to the prescription medicine questions may be attributable to question order effects. Among the children whose parents reported prescription medicine on the QuICCC-R but not the CSHCN Screener, 61% received the QuICCC-R measure as the second screener in the national sample. The prescription

medicine question is the first item that is asked on both screening instruments. A negative response the first time the question was asked and a positive response the second time the question was asked may have occurred if parents did not “hear” or “tune in” to the first screener question asked. An estimated 9.0% and 6.3% of children identified by the QuICCC-R only are accounted for by this probable study design effect in the national and health plan samples, respectively (Table 4).

Differences in Question Design

Some of the discrepant cases may be attributable to intentional differences in questionnaire construction. In the national sample, 18.0% of children positively identified by the QuICCC-R only had positive answers to just one of the 4 QuICCC-R items that differed from the CSHCN Screener by having no presence or duration of condition follow-up questions. This estimate was 31% for the health plan sample. These 4 items ask (a) whether the child has difficulty understanding simple instructions (over 24 months), (b) whether others outside the family who speak the same language have trouble understanding the child (over 36 months), and (c) whether a health care provider has ever indicated that the child had a serious delay in his/her physical growth or (d) in his/her mental or emotional development. These QuICCC-R items do not have the presence or duration of condition requirement intentionally as such consequences were explicitly assumed to be indicative of an ongoing special health care need by developers of the QuICCC-R.

Gray-Area Cases

As noted earlier, about two thirds of children identified by the QuICCC-R only qualified on only one of the 16 QuICCC-R criteria. Overall, these cases appear to represent children who are more likely to fall into a gray area between children who are at-risk for a special health care need and those who have a more established or readily identifiable ongoing special need. This gray area, in which people may reasonably disagree about the presence of a special health care need, has been described by Stein et al as reflecting “the problem that the construct, *chronic condition*, is a social notion and that health and illness

occur on a spectrum... (with) no absolute cutoff or threshold.”¹⁰ Here, these gray-area cases are illustrated by children qualifying on one of 3 QuICCC-R items related to special diet, vision problems not completely corrected by glasses, or the presence of a life-threatening allergic reaction. Overall, 13.8% and 14.6% of children identified by the QuICCC-R only qualified on only one of these 3 items in the national and health plan samples, respectively.

In these cases, the child’s medical chart did not indicate the presence of a chronic health condition when reviewed for the presence of a chronic medical, behavioral, or other condition diagnosis or symptoms, use of services, medication or devices that may indicate a chronic medical, or behavioral or other health condition in the absence of a diagnosis. Yet, in most cases, there was an indication of a special diet, vision problem, or allergy-related health issue in the child’s medical chart. For example, for children qualifying only on the QuICCC-R item related to life-threatening allergic reactions, a mention of a food or environmental allergy was almost always found in the chart (eg, soy or chocolate allergy, or an allergy to dust mites). Indications were also present for children qualifying only on items related to special diet and vision problems (eg, advised to limit consumption of juices, lactose intolerance, amblyopia, color blindness, astigmatism, or nearsightedness). The likely lower severity and impact of these health conditions indicates that these children may fall into a gray area such that researchers with different perspectives may disagree about the inclusion of these children into the category of CSHCN.

DISCUSSION

This study contributes to an understanding of how the CSHCN Screener compares to the QuICCC-R, a conceptually similar but longer instrument that has been previously validated as a method for identifying a broad range of CSHCN. The CSHCN Screener exhibited 90% agreement with the longer QuICCC-R instrument. The QuICCC-R classifies a higher proportion of children as having special health care needs. In part, purposeful differences in the question design and content of the CSHCN Screener compared to the QuICCC-R account for these differences. In particular, the QuICCC-R intends to include children falling into the “gray area” described earlier and therefore is more likely to also identify children whose special health care need status is less certain. On the contrary, the CSHCN Screener attempts to minimize uncertainty that children identified do have a special health care need. Also, study design effects account for some of these cases, such that that the differences in rates of CSHCN observed in this study may be overstated.

Based on results from this study, when compared to those obtained with the QuICCC-R, the CSHCN Screener does not appear to systematically miss or leave out children with specific types of medical, behavioral, or other health conditions, nor does it appear to fail to identify children with more serious diagnoses or conditions requiring extensive use of health care services. In the health plan sample, the CSHCN Screener was less likely to iden-

tify children under the age of 4 years. However, this finding was not replicated in the broader and larger national sample.

The children identified by both screeners were more likely to have a chronic health condition named by parents and/or recorded in medical charts or administrative data and have greater reported health consequences and health care needs compared to children positively identified by the QuICCC-R only. These findings indicate that, compared to children not identified by the CSHCN Screener, children identified by the QuICCC-R only 1) have health conditions that are less likely to be understood by parents to be ongoing health conditions; 2) have health conditions less likely to have a diagnosis, symptoms and service use requirements recorded in clinically oriented administrative data and medical charts; 3) have health conditions that are less likely to result in a use of health and related services; and 4) are more likely to fall into the gray area such that people may reasonably disagree about whether a child has a special health care need. It is important to note that although children identified by the QuICCC-R only were much less likely to have chronic health conditions named by parents or recorded in medical charts or administrative data compared to children identified by both instruments, because of the high level of agreement, the overall difference between the 2 instruments is much smaller.

Conclusions from this study are limited by the lack of a clear and accepted gold standard for identifying CSHCN. Also, the limited demographic, health status, and health services utilization data for children not identified by either the CSHCN Screener or the QuICCC-R prevent us from drawing clear conclusions about whether children identified by either one of these methods differ from those not identified as having a special health care need by either instrument. Whereas findings from the national sample comparing the CSHCN Screener and the QuICCC-R are more generalizable, those from the health plan sample are limited, as this analysis was based on data from one health plan only. Specifically, results analyzing discrepant results between the 2 screeners using the CRG algorithm require further study because of the small number of cases in which the screening methods did not agree. Also, other questions about the reliability of administrative data and how to interpret the presence or absence of a recorded diagnosis when identifying CSHCN are not addressed here. Finally, all data used are from surveys completed in English only, preventing generalizability of findings to non-English-speaking populations.

The CSHCN Screener operationalizes the definition of CSHCN endorsed by the federal MCHB. In spite of momentum toward a common understanding of CSHCN, a single gold standard for defining and identifying CSHCN is not expected. In particular, because the federal MCHB definition of CSHCN does not specify clearly the precise types of health conditions, duration of conditions, level of service need, and level or type of limitations in functioning or sources of data to use to identify CSHCN, even results from instruments designed to reflect the MCHB definition, such as the CSHCN Screener and the QuICCC-

R, will vary. Similarly, differences are likely to continue to exist among health care providers, policy makers, and patient/consumers in the conceptualization of what constitutes an ongoing health condition and when that health condition has consequences for the functioning or health care needs of a child. This study has shown that although available measures to identify CSHCN share many conceptual and technical characteristics, differences exist among available methods.

The CSHCN Screener has been incorporated in the National Medical Expenditures Panel Survey as a parent self-administered questionnaire.¹⁷ In addition, the screener has been adopted by the National CSHCN Survey, which is administered by telephone.¹² Together, these surveys will provide both national and state-level prevalence estimates as well as a wealth of other pertinent information on the health and health care experiences of CSHCN. Moreover, the CSHCN Screener has been formally integrated in the CAHPS Child Questionnaire 2.0H, which is a part of the National Committee for Quality Assurance's Health Plan Employer Data and Information Set.^{18,19} This application allows for the identification and measurement of basic aspects of health care quality for CSHCN enrolled in managed care health plans, and it is expected to be used in many states' Medicaid quality assessment initiatives during the coming years. The use of the CSHCN Screener in these and other applications will help build a common understanding of the health, health care needs, and health care quality provided to this important population of children.

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Appendix #3

***Adults with Special
Health Care Needs
(Adult SHCN)
Screener***

Adults with Special Health Care Needs (Adult SHCN) Screener

Technical Summary

DESCRIPTION

The Adult Special Health Care Needs (Adult SHCN) Screener is a set of five questions used to identify individuals with chronic disease or disability. These questions are designed to be self or telephone-administered. The Adult SHCN Screener was originally developed to identify a population with chronic conditions or disability for the purpose of quality assessment.

The screener takes approximately one minute to administer by telephone for a single respondent. It takes a similar amount of time to complete when self-administrated. The Adult SHCN Screener is currently available only in English; however, a Spanish-language version is under development.

Conceptual approach

The Adult SHCN Screener uses a consequences-based approach to define special health care needs and disability. The screener criteria are independent of diagnostic label or etiology. They focus on limitations in functioning and type and amount of services needed as a result of having an on-going health condition rather than the presence of a specific diagnosis or type of disability.

Definitional criteria

The screening tool uses consequences-based criteria to identify adults with chronic or special health care needs. All of the following must be present to qualify:

- The individual currently experiences a specific consequence;
- The consequence is due to a medical, behavioral, or other health condition;

- The duration or expected duration of the condition is 12 months or longer.

The first part of each Adult SHCN Screener question asks whether the respondent experiences one of five different health consequences:

1. Use or need of prescription medication;
2. Above average use or need of medical care, mental health, or other health services;
3. Functional limitations;
4. Use or need of specialized therapies (e.g., OT, PT, speech);
5. Treatment or counseling for mental health, substance abuse, or emotional problems.

The second and third parts of each screening question[†] ask those responding “yes” to the first part of the question whether the specific consequence is due to any kind of health condition and, if so, whether that condition has lasted or is expected to last for at least 12 months.

All three parts of at least one screener question (or, in the case of question 5, both parts) must be answered “yes” in order for a person to meet the Adult SHCN Screener criteria.

BACKGROUND

The Adult SHCN Screener was developed in response to the need for an efficient, standardized method of identifying adults with chronic or special health care needs for the purposes of quality assessment, potential care management, and other follow-up activities.

[†] Question 5 of the screener is a two-part question; both are answered “yes” to qualify.

The Adult SHCN screener uses a theoretical framework originally developed to identify children with special health care needs for epidemiological purposes.¹ This framework draws upon research indicating that childhood chronic conditions often produce similar consequences in terms of functioning and service use.^{2,3,4} Extensive research supports the validity of non-condition specific criteria to comprehensively identify children across the range and diversity of chronic disease and disability.^{5,6}

Under the impetus of the new managed care provisions of the Balanced Budget Act of 1997, the Centers for Medicare and Medicaid Services (CMS) recognized the need for research to address gaps among available methods for identifying adults with chronic disease or disability. As a result, CMS (then HCFA) contracted with FACCT–The Foundation for Accountability to develop and test a short, survey-based screening tool for adults using the consequences-based, non-condition specific approach first developed to identify children. The goal was an instrument with the flexibility to be used in a variety of settings to identify adults with a broad range of special health care needs for which assessment for care management and quality monitoring might be appropriate.

The development of non-condition specific methodology for identifying adults is important for several reasons:

- The utility and accuracy of methods that rely upon administrative data is constrained by the availability, reliability, and inconsistencies of claims and encounter records;
- New health plan enrollees do not have administrative records available. Consequently, other methods are needed if they are to be screened for special health care needs at the point of enrollment;
- Diagnosis-based approaches miss people whose special health needs or chronic conditions are not yet diagnosed, are more difficult to diagnose, or are of the type commonly under-diagnosed (e.g., diabetes, depression,

lupus). It is not unusual for symptoms and consequences to be present for a period of time before formal diagnosis occurs;

- Diagnostic labels alone do not convey the extent of disease burden or disability experienced;
- Diagnosis-based methods are biased towards identifying individuals with access to medical care.

Researchers at FACCT built on their previous work to develop an adult version of the Children with Special Health Care Screener. The process leading to the Adult SHCN Screener described here included expert input and review from a specially convened national advisory committee, cognitive testing with adults with chronic illness or disability, and refinements based on pilot testing of earlier versions.

TESTING AND USE HISTORY

Testing

During Spring 2001, the Adult SHCN Screener and other survey questions were administered by telephone to 2,500 adult Ohio Medicaid clients eligible through Temporary Aid to Needy Families (TANF) and 900 adult clients enrolled in Ohio Medicaid through the Supplemental Security Income (SSI) eligibility. A total of 3,400 telephone survey interviews were collected. The SSI sample included Medicaid clients under 65 years old (n = 650) and over 65 years old (n = 250). The majority of clients in the TANF sample (n = 2,100) were enrolled in one of three Ohio Medicaid managed care organizations. The remainder of the TANF sample were covered by the Medicaid Fee-for-Service program (n= 400).

In addition to the Adult SHCN Screener, the telephone interview included disability questions from the National Health Interview Survey, good health days questions developed by the Centers for Disease Control, the SF-12 health status

instrument, as well as other questions on utilization of services, and social and behavioral characteristics of respondents.

The study design included obtaining encounter or claims data for all survey respondents in order to compare survey-based findings with administrative data-based methods of identifying people with special health care needs. Researchers used software from the 3M Clinical Risk Groups (CRGs) administrative data-based clinical classification system to assign each respondent into a category of chronic, significant acute or healthy.

Proportion identified

In the study summarized above, the five-item Adult SHCN Screener identified approximately 36 percent of the TANF sample, which was predominately females (92%) between age 18 and 45, as having a chronic condition or special health care need.⁷ In the same study, the screening tool identified approximately 93 percent of the SSI sample.⁷

Individuals identified by the Adult SHCN Screener differed dramatically and significantly from those not identified in terms of overall health status, level of disability and functional limitations, and in their need for or use of services. In the TANF sample:

- About half of the individuals identified as having special health care needs (SHCN) reported “fair or poor” health compared to only 1 in 10 of those not identified.
- One in 4 with SHCN reported experiencing two or more limitations in activities of daily living (ADLs) compared to 1 in 100 of the group not identified.
- Over 40 percent of the SHCN group reported 10 or more outpatient visits during the past year compared to 16 percent of those without SHCN.

- Individuals with SHCN needed or used specialized services, such as medical equipment or special therapies, 6 to 7 times more frequently than did individuals who did not screen positively for having chronic or special health care needs.
- One in 4 with SHCN needed or used treatment or counseling during the past year for emotional, mental health, or substance abuse problems compared to less than 1 in 20 in the group not identified by the screener.

Several articles reporting findings from this study, including comparisons of survey-based and administrative-based identification methods, are under development. A poster presentation of Adult SHCN Screening results accepted for display during the 2001 annual meeting of the Academy for Health Services Research is included in this appendix.⁷

Use History

The Adult SHCN Screener is a fairly new instrument. Although experience with its use is limited, some early examples are available. The State of Ohio included the Adult SHCN Screener in the 2002 Consumer Assessment of Health Plans Survey (CAHPS) administered in a statewide sample of clients enrolled in the Ohio Fee-for-Service Medicaid program.⁸ For two consecutive years (2001 and 2002), the State of Iowa has used the Adult SHCN Screener in several general population and Medicaid studies.⁹ Neighborhood Health Plan, a Medicaid managed care organization in Massachusetts, is administering a version of the Adult SHCN Screener to new health plan enrollees to identify special health care needs.¹⁰ The Adult SHCN Screener was recently administered in a national online survey to adolescents age 13 to 18.

AVAILABILITY and COST

The Adult SHCN Screener is available at no cost from FACCT–The Foundation for Accountability. A copy can be obtained by emailing dread@facct.org or by calling (503) 546-9391.

TECHNICAL SUPPORT

Technical support for administering, scoring, and interpreting results of the Adult SHCN Screener can be obtained by e-mailing dread@facct.org . Scoring programs, test data sets, and supporting materials are also available upon request.

OTHER CONSIDERATIONS

Preliminary analyses of Adult SHCN Screener data suggest that the type and number of screening criteria on which an individual qualifies may be useful for prioritizing follow-up. The use of the Adult SHCN Screener to identify individuals for case management and other types of assessments or tracking is just beginning to be studied on a formal basis.

When screening adults, it is important to ensure that individuals unable to respond for themselves because of health or cognitive limitations are not excluded from the process. One way to accomplish this is to include an option for response by a proxy familiar with the targeted individual's health issues. In the Ohio Adult Medicaid study summarized in the *Testing and Use History* section above, the telephone interview protocol included queries to identify situations in which it might be necessary for another person to answer as a proxy for the targeted respondent. In the TANF sample, less than 2 percent of the interviews were obtained via a proxy responder. However, approximately 1 in 4 interviews in the SSI sample were collected through proxy responders.

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- ⁸ For more information, contact Rosemary Chaudry of the Ohio Department of Jobs and Family Services at chaudr@odjfs.state.oh.us .
- ⁹ For more information, contact Peter C. Damiano at peter-damiano@uiowa.edu .
- ¹⁰ For more information, contact Pamela Gossman at Pamela_Gossman@nhp.org .



***Adult SHCN
Screenener***

Adults with Special Health Care Needs (Adult SHCN) Screener (mail or telephone)

1. Do you currently need or take **prescription medicine** (*other than vitamins or birth control pills*)?
 - Yes → Go to Question 1a
 - No → Go to Question 2
 - 1a. Is this because of ANY medical, mental health or other health condition?
 - Yes → Go to Question 1b
 - No → Go to Question 2
 - 1b. Is this a condition that has lasted or is expected to last for at least 12 months?
 - Yes
 - No
2. Do you need or use **medical care, mental health or other health services** on a regular basis?
 - Yes → Go to Question 2a
 - No → Go to Question 3
 - 2a. Is this because of ANY medical, mental health or other health condition?
 - Yes → Go to Question 2b
 - No → Go to Question 3
 - 2b. Is this a condition that has lasted or is expected to last for at least 12 months?
 - Yes
 - No
3. Do you have difficulty doing or need assistance to do **day-to-day activities**? (*for example: work, go to school, do housework, socialize, cook, do paperwork*)
 - Yes → Go to Question 3a
 - No → Go to Question 4
 - 3a. Is this because of ANY medical, mental health or other health condition?
 - Yes → Go to Question 3b
 - No → Go to Question 4
 - 3b. Is this a condition that has lasted or is expected to last for at least 12 months?
 - Yes
 - No
4. Do you need or get **special therapy**? (*for example: physical, occupational, speech or respiratory therapy*)
 - Yes → Go to Question 4a
 - No → Go to Question 5
 - 4a. Is this because of ANY medical, mental health or other health condition?
 - Yes → Go to Question 4b
 - No → Go to Question 5
 - 4b. Is this a condition that has lasted or is expected to last for at least 12 months?
 - Yes
 - No
5. Do you need or get **treatment or counseling** for any kind of mental health, substance abuse or emotional problem?
 - Yes → Go to Question 5a
 - No
 - 5a. Has this problem lasted or is it expected to last for at least 12 months?
 - Yes
 - No

Scoring the Adult with Special Health Care Needs (Adult SHCN) Screening Tool

The Adult SHCN screener uses consequences-based criteria to screen for persons with chronic or special health needs. To qualify as having chronic or special health needs, the following set of conditions must be met:

- a) The person currently experiences a specific service use or functioning consequence.
- b) The consequence is due to a medical, mental or other health condition.
- c) The duration or expected duration of the condition is 12 months or longer.

The first part of each screener question asks whether a person experiences one of five different health consequences:

- 1) Use or need of prescription medication (except vitamins or birth control pills)
- 2) Above average use or need of medical, mental health or other health services
- 3) Functional limitations
- 4) Use or need of specialized therapies (OT, PT, speech, etc.)
- 5) Treatment or counseling for mental health, substance abuse or emotional problems

The second and third parts* of each screener question ask those responding “yes” to the first part of the question whether the consequence is due to any kind of health condition and if so, whether that condition has lasted or is expected to last for at least 12 months.

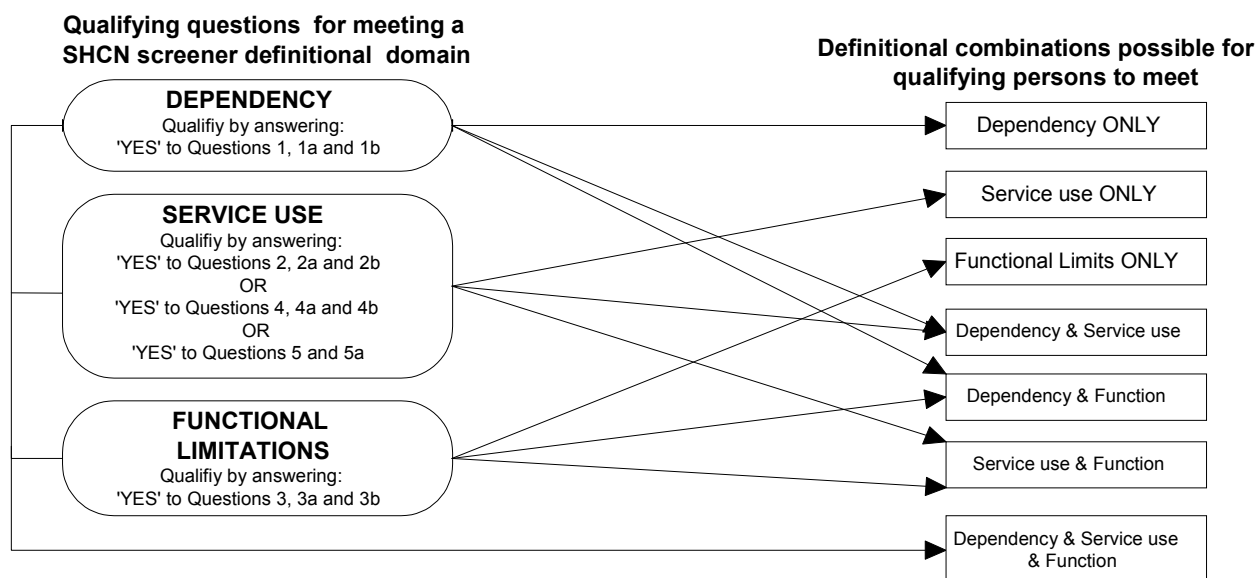
**NOTE: Screener question 5 is a two-part question. Both parts must be answered “yes” to qualify.*

All three parts of at least one screener question (or in the case of question 5, the two parts) must be answered “yes” in order for an adult to meet any one of the five SHCN screener criteria for having a chronic condition or special health care need. The five criteria are not mutually exclusive and a person may qualify only a single criterion or any combination of the five.

The Adult SHCN screener has three “definitional domains”. These are:

- 1) Dependency on prescription medications
- 2) Service use above that considered usual or routine
- 3) Functional limitations

The definitional domains are not mutually exclusive categories. A person meeting the screener criteria for having a chronic condition may qualify for one or more definitional domains (see diagram below). In addition to the proposed scoring of meeting at least one qualifying criterion, the field trial study will test additional scoring options using type and number of qualifying criteria and definitional domain combinations.



***Identifying Adults
with Chronic or
Special Health Care
Needs: Evaluation
of a Short
Screening Tool***

***Poster presentation
Academy for
Health Services Research
Annual Meeting***

June 2001

Identifying Adults with Chronic or Special Health Care Needs: Evaluation of a Short Screening Tool

Christina Bethell, PhD, MPH, Debra Read, MPH

Background

Identification of adults with chronic or special health care needs for the purposes of assessing and improving their health and health care quality is a need shared by Federal, State and local health agencies, health plans, providers and consumer organizations alike. An efficient, standardized survey-based method to identify adults with special health care needs (SHCN) is not currently available.

Study Objective

The goal of this study is to specify an accurate, efficient, and flexible approach to identifying adults with special health care needs with the potential for standardized use in Medicaid populations.

The Adult SHCN Screener tested for this purpose includes five survey items asking whether specific health consequences are experienced. To qualify as having a special health care need, an individual must indicate that he or she experiences at least one of these five consequences and that the specific consequence is due to a medical, mental health or other health condition lasting or expected to last at least 12 months. The screening tool uses consequences-based, rather than condition-based criteria to identify adults with special health care needs. That is, a formally diagnosed condition is not required in order for an individual to qualify. Likewise, individuals who are not currently experiencing consequences from a diagnosed condition may not be identified by the screener criteria. See **Exhibit 1** for a copy of the screening tool evaluated in this study.

Research Questions

1. Population Identified: Does the proportion of adults identified by the Adult SHCN Screener have face validity and vary as expected across population subgroups?
2. Expected Associations: Does the Adult SHCN Screener exhibit predictive and concurrent validity as demonstrated by expected associations observed among study variables indicative of chronic or special health care needs, functional status and the level of health and health service needs?

Methods

The Adult SHCN Screener was administered by telephone in a sample of Medicaid clients enrolled in managed care or fee for service health systems (n = 3,222). Individuals eligible for Medicaid through the Temporary Aid to Needy Families (TANF) and Supplemental Security Income (SSI) were included. See **Table 1**.

The proportion and type of adults identified were evaluated and compared to respondents' verbatim reports of current health conditions, health and functional statuses, and use or need for health services.

EXHIBIT 1: Adult SHCN Screener

1. Do you currently need or take **prescription medicine** (*other than vitamins or birth control pills*)?
 - 1a. Is this because of ANY medical, mental health or other health condition?
 - 1b. Is this a condition that has lasted or is expected to last for at least 12 months?
 2. Do you need or use **medical care, mental health or other health services** on a regular basis?
 - 2a. Is this because of ANY medical, mental health or other health condition?
 - 2b. Is this a condition that has lasted or is expected to last for at least 12 months?
 3. Do you have difficulty doing or need assistance to do **day-to-day activities**? (*for example: work, go to school, do housework, socialize, cook, do paperwork*)
 - 3a. Is this because of ANY medical, mental health or other health condition?
 - 3b. Is this a condition that has lasted or is expected to last for at least 12 months?
 4. Do you need or get **special therapy**? (*for example: physical, occupational, speech or respiratory therapy*)
 - 4a. Is this because of ANY medical, mental health or other health condition?
 - 4b. Is this a condition that has lasted or is expected to last for at least 12 months?
 5. Do you need or get **treatment or counseling** for any kind of mental health, substance abuse or emotional problem?
 - 5a. Has this problem lasted or is it expected to last for at least 12 months?
-
-

Results

Proportion of adults identified: The five-item Adult SHCN Screener identified approximately 36% of adult TANF Medicaid clients age 18 – 65 as having a chronic condition or special health care need. Approximately 93% of adults enrolled in Medicaid through SSI eligibility were identified. See **Table 2**.

Expected Associations:

- As expected, the proportion of adults identified by the Adult SCHN Screener varied significantly by age ($p = .000$), however, significant differences in screening rates by gender were not observed among adults in the TANF and SSI samples (**Figure 1**).
- Individuals meeting the screening criteria reported significantly poorer health status ($p = .000$); 50% of the group identified by the screener described their health as “fair or poor” compared to 11% of the group not identified by screening tool (**Figure 2**).
- Individuals identified by the Adult SHCN Screener criteria in each of the samples experienced significantly more limitations in daily function, days of poor physical health or mental health than individuals in the groups not identified (**Table 3**).
- Individuals identified by the Adult SHCN Screener criteria in each of the samples needed or used significantly more health care services during the past 12 months than those not meeting the screening criteria (**Table 4**).
- Each individual meeting the screening criteria was asked to name up to 3 health conditions they had in mind when responding to the screener questions. In the TANF sample, 43% of the 875 individuals identified by the screening tool named one condition, and over half (57%) named at least two health conditions. Almost all of the health conditions respondents named verbatim are generally considered chronic or ongoing in nature according to the standard list of chronic conditions used in the National Health Interview Survey (**Table 5**).

TABLE 1: OHIO Adult Medicaid Study: Summary of Sample Characteristics

Study populations	TANF / Managed care	TANF / Fee- for-service	SSI / under 65 yrs old	SSI / over 65 yrs old
Mode	Telephone	Telephone	Telephone	Telephone
Number of cases	n = 2,058	n = 394	n = 493	n = 180
Female	(%) 91.8	(%) 80.2	(%) 68.8	(%) 86.7
18 – 24 yrs	(%) 23.4	(%) 17.8	(%) 4.5	(%) *
25 – 34 yrs	44.3	44.7	11.6	*
35 – 44 yrs	25.1	28.7	27.0	*
45 – 54 yrs	6.4	7.6	23.7	*
55 – 64 yrs	0.8	0.8	32.7	*
65 yrs & over	0.1	0.5	0.6	100.0
% Hispanic	(%) 4.2	(%) 1.8	(%) 1.8	(%) 0.0
% White/non-Hispanic	33.6	91.9	93.2	88.9
% Black/non-Hispanic	60.6	6.1	3.7	10.0
% Other/non-Hispanic	1.6	0.3	1.2	1.1

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TABLE 2: OHIO Adult Medicaid Study: Percentage Identified by Adult Special Health Care Needs Screener

Study populations	TANF / Managed care	TANF / Fee- for-service	SSI / under 65 yrs old	SSI / over 65 yrs old
Number of cases	n = 2,058	n = 394	n = 493	n = 180
% identified by Adult Screener as having chronic or special health care needs	(%) 35.2	(%) 38.3	(%) 91.0	(%) 93.3
% with qualifying responses to each of the Adult Special Health Care Needs Screener questions				
	(%)	(%)	(%)	(%)
Q1: Need/use of prescription medicines	29.3	35.3	85.8	91.1
Q2: Above average need/use of services	22.6	25.9	78.1	79.4
Q3: Functional limitations	9.3	10.9	51.5	56.1
Q4: Need/use of specialized therapies	6.5	3.8	15.6	6.7
Q5: Tx or counseling for emotional or mental health problem	8.2	9.6	24.7	1.7

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Figure 1: Age & gender-specific rates for meeting Adult Screener criteria for having chronic or specific health care needs
 (OHIO Adult Study: TANF and SSI over 65 yrs old samples combined)
 n = 2,632

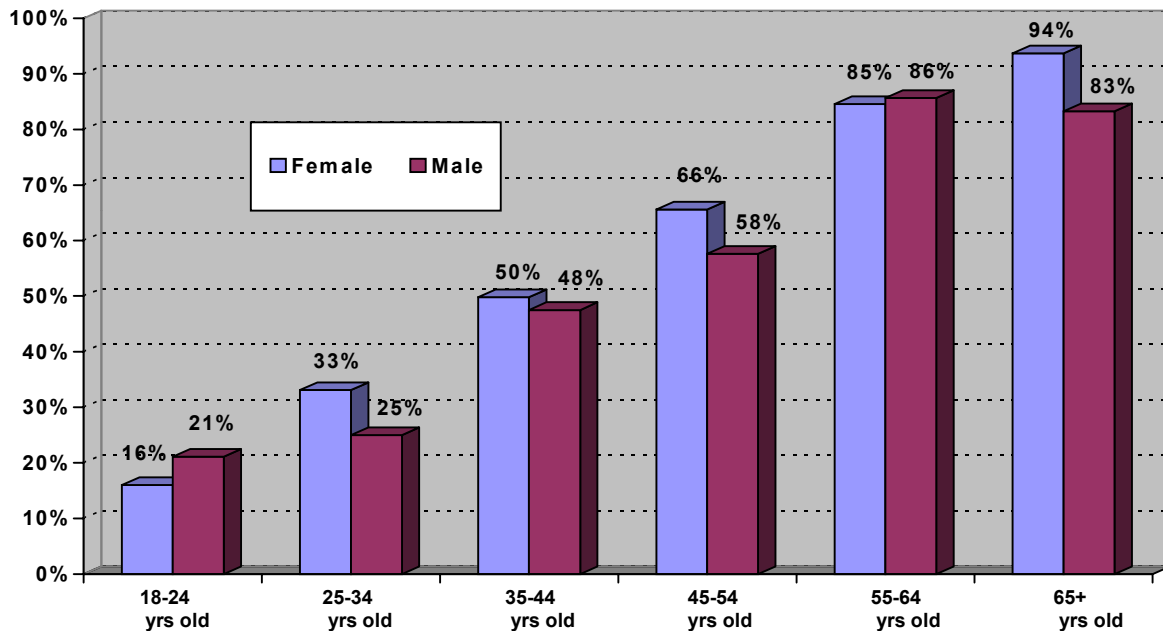
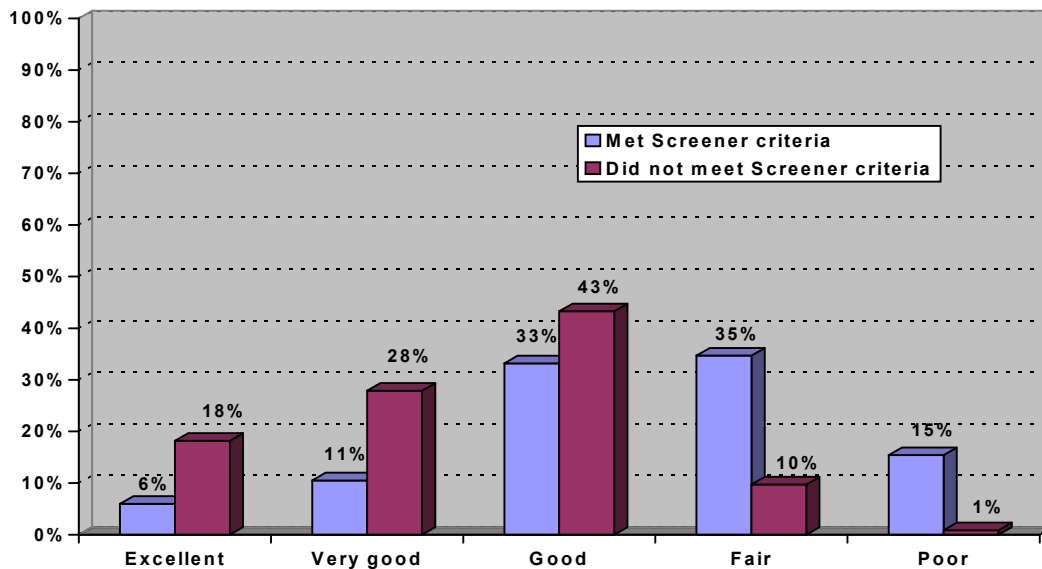


Figure 2: Self-reported health status by Adult Screener results
 (OHIO Adult Study: TANF and SSI over 65 yrs old samples combined)
 n = 2,632



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**TABLE 3: OHIO Adult Medicaid Study: Functional limitations and health status
by Adult Special Health Care Needs Screener status**

Study populations	TANF / Managed care & fee-for- service samples combined		SSI / under 65 yrs old		SSI / over 65 yrs old	
	Did not meet screener	Met screener	Did not meet screener	Met screener	Did not meet screener	Met screener
Number of cases	n = 1,577	n = 875	n = 46	n = 447	n = 12	n = 168
Functional limitations in Activities of Daily Living (ADL list from NHIS)	(%)	(%)	(%)	(%)	(%)	(%)
No limitations	95.0	64.1	87.0	34.5	91.7	42.9
1 ADL limitation	3.3	12.0	8.7	17.2	8.3	9.5
2 – 3 ADL limitations	1.1	13.0	0.0	23.0	0.0	17.3
4 – 7 ADL limitations	0.7	11.0	4.3	25.2	0.0	30.4
	(P = .000)		(P = .000)		(P = .02)	
Currently uses special equipment such as wheelchair, cane, special bed or special telephone, etc.	(%)	(%)	(%)	(%)	(%)	(%)
	0.8	10.4	8.7	30.7	0.0	54.8
	(P = .000)		(P = .003)		(P = .001)	
Mean number of “poor physical health days” during past 30 days	2.4 days	9.9 days	3.3 days	17.5 days	1.5 days	16.5 days
	(P = .000)		(P = .000)		(P = .000)	
Mean number of “poor mental health days” during past 30 days	4.4 days	12.0 days	5.2 days	14.4 days	2.8 days	4.8 days
	(P = .000)		(P = .000)		(P = .45)	

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TABLE 4: OHIO Adult Medicaid Study: Level of health services use past 12 months by Adult Special Health Care Needs Screener status

Study populations	TANF / Managed care & fee-for- service samples combined		SSI / under 65 yrs old		SSI / over 65 yrs old	
	Did not meet screener n = 1,577	Met screener n = 875	Did not meet screener n = 46	Met screener n = 447	Did not meet screener n = 12	Met screener n = 168
Number of cases	(%)	(%)	(%)	(%)	(%)	(%)
Dr office or clinic visits during past 12 months						
No visits	16.6	3.8	17.4	3.6	50.0	1.2
1 –2 visits	35.1	13.3	45.7	8.8	16.7	10.7
10 or more visits	16.0 (P = .000)	43.0	8.7 (P = .000)	44.7	8.3 (P = .000)	40.0
Emergency room visits during past 12 months	(%)	(%)	(%)	(%)	(%)	(%)
No ER visits	56.6	41.8	54.3	44.0	83.3	50.6
1 ER visit	21.8	21.0	21.7	20.0	8.3	22.6
2 or more ER visits	21.3 (P = .000)	37.2	24.0 (P = .19)	36.1	8.3 (P = .17)	26.8
Overnight hospitalizations during past 12 months	(%)	(%)	(%)	(%)	(%)	(%)
1 or more overnight hospitalizations	18.1 (P = .001)	23.9	6.5 (P = .001)	30.7	8.3 (P = .07)	33.3

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Table 5: Type and frequency of health conditions named verbatim by group qualifying on the Adult Screener criteria

(OHIO Adult Medicaid Study: TANF managed care & fee-for-service)

Type & frequency of health conditions named verbatim by individuals identified by the Adult Screener as having a chronic or special health need (n = 875)*			
Low prevalence chronic conditions	26.7%	Refused	1.7%
Depression	24.6%	COPD/Emphysema	1.6%
High Blood Pressure	16.2%	High Cholesterol	1.6%
Chronic Back Problems	13.9%	Cancer	1.4%
Mental Health (COD, schizophrenia, anxiety bipolar, etc)	13.6%	Lupus	1.3%
Asthma	12.7%	Vision / Blindness	1.3%
Diabetes	8.9%	Epilepsy/Seizures	1.1%
Arthritis	8.2%	Surgery	1.0%
Not sure if chronic or acute; need more info	8.1%	Menopause	0.8%
Allergies	7.5%	Hysterectomy	0.6%
Headaches/Migraines	5.6%	Substance Abuse	0.6%
Thyroid Conditions	5.3%	Stroke	0.5%
Heart Condition/Disease	4.0%	Physical Disability	0.5%
Acid Reflux	3.4%	Mental Disability	0.3%
Stomach/Intestinal Problems	3.3%	Congestive Heart Failure	0.2%
Fibromyalgia	3.2%	Hearing / Deafness	0.1%
Sinus Problems	2.7%		

* Percentages do not add up to 100.0 because 29.5% of those id'd by Adult SHCN screener named 2 conditions and 27.5% named 3 conditions

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Appendix #4

3M Clinical Risk Groups (CRGs) for Classification of Chronically Ill Children and Adults

3M Clinical Risk Groups (CRGs) for Classification of Chronically Ill Children and Adults

Technical Summary

DESCRIPTION

Clinical Risk Groups (CRGs) are a clinically based categorical classification system that uses administrative data to identify children and adults with chronic health conditions. Proprietary software is used with claims and encounter records to group individuals into mutually exclusive, clinically-based categories. These categories comprise specific conditions or combinations of conditions as well as the associated severity of those conditions or combinations of conditions.

Individuals without chronic conditions are either assigned to a healthy group or, if they have a recent history of one of a set of serious acute conditions, to a significant acute group. While a complete claims history is optimal, CRGs can work with any amount of data. For payment purposes, a methodology is available which helps compensate for abbreviated enrollment histories.

CRGs were designed with four uses in mind:

1. Tracking congenital/chronic disease prevalence rates;
2. Profiling health service utilization and physician practice patterns;
3. Pricing and capitation risk adjustment;
4. Linkage to measures of patient satisfaction and experience of care for quality monitoring.

The classification system is intended for use across the healthcare delivery system. This includes, but is not limited to, planners, payers, providers, case and disease managers, etc.

CRGs differ from other risk adjustment methodologies in that each individual in a population is assigned to a single, clinically defined, severity adjusted, mutually exclusive group. This distinction is most apparent in how CRGs treat co-morbid conditions and differences within a single disease. Other risk adjustment methodologies assign multiple groups to individuals with co-morbid conditions or assign a single group based on the most expensive observed condition. CRGs also differ from other methodologies by recognizing the gradations of illness within a disease by explicitly assigning severity of illness levels to all chronic conditions and diseases. These characteristics allow individuals to be tracked and observed at multiple points in time for the purposes of measuring the impact of expenditures, the utilization of services, case management, and other indicators of care quality on clinical outcomes.

Conceptual approach

The CRG classification system employs a combination of diagnosis-based and consequences-based criteria to identify adults and children with ongoing or chronic health conditions. CRGs also make allowances for a subset of health conditions designated as “significant acute” which place individuals at-risk for increased health service needs in the future.

The presence of specific ICD-9 diagnostic codes, a limited number of procedure codes, the recurrence and recency of specified conditions, and numerous other factors are simultaneously taken into account to assign each individual to a single group.

Definitional criteria

The core of CRGs lies in its ability to identify and classify chronic conditions. The CRG definition of a chronic health condition has three components: a) physical, mental, emotional, behavioral, or developmental disorder; b) expected

to last at least 12 months or having sequelae lasting 12 months or longer; and c) requires ongoing treatment and/or monitoring.

The CRG classification system reads all diagnosis codes from claim and other encounter data. Each code is assigned to a body system first, and then to a diagnostic category. These diagnostic categories are classified as chronic or acute conditions with distinctions made within each condition based on clinical significance. Using diagnostic category assignments and a specified clinical logic, each individual's chronic conditions are identified and assigned a severity level. Depending upon the type and number of chronic conditions, each individual is assigned to a hierarchically defined core health status group, then to a specific CRG group and if chronically ill, to a severity level. If the individual has no chronic conditions, he or she is assigned either to the healthy group or one of the significant acute groups.

The CRG severity assignment algorithm is specific to each chronic condition category and takes into account a variety of factors associated with a more severe or advanced form of the condition. These include:

- A more severe form of the chronic condition as identifiable through ICD-9-CM diagnoses codes;
- Co-morbid chronic and acute conditions from the same body system;
- Co-morbid chronic conditions from other body systems when they are secondary to, and caused by what is judged to be the primary chronic condition;
- Acute illnesses from other body systems when specifically related to the chronic condition or an indicator of general health status;
- Age, if it relates to a specific disease progression and is relevant;
- Selected therapies and service utilization including hospitalization;

- The recency of the diagnosis (e.g., during last six months) where appropriate;
- The recurrence of a diagnosis (e.g., multiple encounters spanning 90 or 180 days) where appropriate.

BACKGROUND

The developers of CRGs integrated two systems: the Episode Grouper created by 3M Health Information Systems and the Classification of Congenital and Chronic Health Conditions designed by the NACHRI—the National Association of Children’s Hospitals and Related Institutions.

The development of CRGs was accomplished in four phases. First, the overall CRGs architecture was designed through a process of expert review and consensus. The criteria for the algorithm for assigning a CRG were strictly clinical with an emphasis the ability to identify individuals with disease in multiple organ systems and to explicitly specify the severity of illness.

Once the overall CRG algorithm was established, the actual clinical parameters for classifying diagnoses and procedures were specified. The assignment of diagnoses and procedures was based on their expected impact on an individual’s future medical care needs, and the likelihood of morbidity or mortality. Two clinical teams, working independently, established the initial parameters for adults and children.

The clinical parameters were then tested in databases from Medicare, Medicaid, and commercially insured populations. In the final phase, the CRG algorithms developed by the clinical staffs focusing on adult and pediatric populations were unified to create the full logic of the CRGs.¹

Since the CRGs require clinical information, the targeted population should be continuously enrolled for a period of time in a health plan or other program that

collects such data. Once identified, it is possible to stratify individual children and adults according to severity level and chronic condition status. These results can be used to profile diagnostic and utilization patterns, identify candidates for case management, predict resource requirements for the purposes of setting risk adjusted pricing, estimate and track prevalence, and monitor quality through linking to patient surveys and other data sources.

TESTING AND USE HISTORY

Testing

Three databases were used in the testing and refinement of the CRG classification system:

- A two-year claims database from the State of Washington Medicaid program with approximately 250,000 recipients, age 0 to 64;
- A four-year Medicare claims database with approximately 1,250,000 recipients, primarily over age 65;
- A four-year private sector claims database of adults and their dependents with approximately 250,000 recipients, age 0 to 64.

The utility of CRGs for risk adjustment purposes was established through comparison to other health status grouper systems, including the Disability Payment System (DPS), the Ambulatory Care Groups (ACGs), and the Diagnostic Cost Groups (DCGs).²

Additional information regarding the testing and development of CRGs can be found in the article, published in *Ambulatory Pediatrics*, and included in this appendix.³

Proportion identified

CRGs were used recently to analyze the administrative records from calendar year 1999 for the child population (age 0 to 18) in a mixed model health plan.⁴ All lines of business (e.g., managed care, fee-for-service, Medicaid, and private sector) were included. Among the 27,771 children having one or more claims, 12 percent were identified by CRGs as having chronic health conditions, 6.5 percent were assigned significant acute status, and remaining 81.6 percent were classified as healthy. Approximately 20 percent of the 34,544 eligible children had no claims recorded during 1999.

In a study of 253,621 Washington State Medicaid fee-for-service enrollees age 0 to 64, 10 percent were classified by CRGs as having one or more significant acute conditions and 19 percent with a chronic medical diagnosis.⁵ Included in the denominator are individuals for whom no claims were recorded. These results are for a non-institutionalized population and do not include Medicare/Medicaid dual eligibles. No age stratified results are available for dissemination at this time.

Comparable published studies using adult data are not currently available.

Use History

CRGs have been demonstrated and evaluated in the United State and Canada since the release of the software in 2000. Over two dozen demonstration licenses have been extended to users in a wide range of sites for a variety of purposes. The software is being purchased by users in HMO, physician groups, and case/disease management settings.

In addition to describing the diagnostic profile of pediatric populations,³ CRGs have been used in published research both to examine racial and ethnic variations among children with special health care needs⁶ and to compare results from survey-based screening methods.^{4,7}

Although no published studies on the use of CRGs in adult populations are currently available, several studies are under review in refereed journals.

Unpublished data do exist, however. The CRG classification system was recently used in a Medicaid population as part of a pilot study for an adult version of the CSHCN Screener.⁸ The study sample was predominately females (92%) between the age of 18 and 45 enrolled in Medicaid managed care in the State of Ohio through the Temporary Aid to Needy Families (TANF) program (n = 2,058). Of those with claims recorded, 26 percent were identified as having a chronic health condition by CRGs, and approximately 10 percent were classified as “significant acute.” Ten percent of the total sample had no claims recorded. Additional results from this study are presented in Appendix 3.

Ongoing study with CRGs includes their use with administrative data to identify children with special health care needs who are candidates for case management services.⁹

AVAILABILITY and COST

The CRG software is available for a fee from 3M Health Information Systems (3M HIS). For sales assistance, go to their web site at <http://www.3mhis.com/us/products/crg> .

TECHNICAL SUPPORT

A detailed user’s manual accompanies the CRG software with ongoing technical support provided by 3M HIS staff.

OTHER CONSIDERATIONS

The potential exists to link CRG clinical classifications and survey-based screening tool and/or patient survey results. This methodology would provide additional information about individuals with special health care needs. Several studies are currently underway to examine how these methodologies might be combined and the resulting data used for case management, quality monitoring, or other applications.

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***Journal
Articles***

3M CRGs

Identifying and Classifying Children With Chronic Conditions Using Administrative Data With the Clinical Risk Group Classification System

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Objective.—To identify and categorize children with chronic health conditions using administrative data.

Methods.—The Clinical Risk Groups (CRGs) system is used to classify children, aged 0–18 years, in a mid-sized health plan into mutually exclusive categories and severity groups. Enrollees are categorized into 9 health status groups—healthy, significant acute, and 7 chronic conditions—and are then stratified by severity. Utilization is examined by category and severity level based on eligibility and claims files for calendar year 1999. Only children enrolled for at least 6 months (newborns at least 3 months) are included.

Results.—This analysis of 34 544 children classifies 85.2% as healthy, including 19.6% with no claims; 5.2% with a significant acute illness; 4.6% with a minor chronic condition; and 4.9% with a moderate to catastrophic chronic condition. The average number of unique medical care encounters per child increases by chronic condition category and by severity level. Compared to national prevalence norms for selected conditions, CRGs do well in identifying patients who have conditions that require interaction with the health care system.

Conclusions.—CRGs are a useful tool for identifying, classifying, and stratifying children with chronic health conditions. Enrollees can be grouped into categories for patient tracking, case management, and utilization.

KEY WORDS: administrative data; children; chronic conditions; chronic illnesses; Clinical Risk Groups; prevalence; special health care needs

Ambulatory Pediatrics 2002;2:71–79

Identifying children with special health care needs (CSHCN) is an essential first step to providing and evaluating appropriate programs and services for this important population.^{1–3} In 1998, the Maternal and Child Health Bureau (MCHB) developed a broad and inclusive definition.⁴ This definition has become the standard for developing tools for identifying and classifying CSHCN.^{1,5–7}

Two basic approaches have been proposed for operationalizing MCHB's definition of children with special health care needs: categorical and noncategorical. The categorical approach identifies children based on their specific medical condition or defined condition status, whereas the noncategorical approach identifies children according to characteristics associated with having a special health care need, such as service use, medical needs, or functional status, independent of a specific diagnosis.

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Each approach has been demonstrated to have value in specific contexts. The categorical approach generally provides for more stratification of the population being analyzed (such as by specific conditions, condition severity, or number of conditions present). Since the categorical approach requires diagnostic information, it is most appropriate for classifying individuals and groups of individuals within health plans or programs that collect diagnostic and/or medical billing information for a predefined population. Such organizations can then use this CSHCN classification for tracking individuals and groups and for measuring costs and utilization. The noncategorical approach uses various survey tools to identify the consequences of having a special health care need, such as limitation in activities and increased medical or service needs, as reported by parents or caregivers to identify CSHCN. Because the noncategorical survey tools, by definition, focus on identifying the CSHCN population as a whole, they are not amenable to stratification and tracking of individuals and/or subgroups of the CSHCN population. No one approach can meet all possible needs for defining CSHCN in all situations.

Historically, categorical tools for identifying children and adults with special health needs have been limited to condition checklists and studies of sentinel conditions.^{8,9} Such condition lists do not provide for evaluating the severity of individual conditions, comparisons across groups of conditions of similar severity, or the occurrence of multiple chronic conditions. The National Association of Children's Hospitals and Related Institutions (NACHRI) developed a diagnosis-based pediatric classification tool in the early 1990s that included a severity component but

no means of assessing severity for children with multiple chronic conditions.¹⁰⁻¹³

This article describes a new categorical tool, Clinical Risk Groups (CRGs), for identifying children with special health care needs and its application in a single health plan's pediatric population. The primary objective of this study is to demonstrate how this classification system can be used to identify children with special needs and to stratify them by severity level and chronic health condition. Potential uses of these stratifications within the health plan and for more diverse organizations are also explored.

METHODS

CRGs are a categorical clinical classification system that uses proprietary computer software to group individuals into mutually exclusive hierarchical categories and to assign each person to a severity level if he/she has a chronic health condition. CRGs are an integration of 2 systems, the Episode Grouper developed by 3M Health Information Systems (3M HIS) and NACHRI's Classification of Congenital and Chronic Health Conditions (CCCHC).

NACHRI's CCCHC was developed as an ICD-9-CM code-based classification system for children.¹⁰ The CCCHC classified pediatric diagnoses as chronic (a condition expected to last at least a year and to have certain consequences) or nonchronic, based on the presence or absence of certain predefined ICD-9-CM codes in the child's medical encounter records. The chronic condition codes were further stratified according to 4 severity levels—mild, moderate, major, and extreme. Severity-level assignments of individuals into one of the 4 severity groups took into account the severity level of each individual diagnosis and disease progression. The pediatric division chiefs, including numerous pediatric specialists, of 2 medical schools, the University of Washington and Vanderbilt University, independently reviewed the specific codes and severity assignments. In general, the division chiefs at the 2 institutions agreed on the significant classifications and levels of severity of the conditions in their specialty. A medical advisory panel of NACHRI reviewed the final classification designation.

The CCCHC was tested on a State of Washington Medicaid database and combined encounter data from 11 private Washington health plans for 1993. Data for over 700 000 children were analyzed and demonstrated a correlation between severity level and charges.¹⁰⁻¹³

Independently, 3M had been working for several years to develop an episodic grouper designed for risk adjustment. There were several significant differences between the classification efforts of 3M and NACHRI. First, the 3M system ranked each individual into a single clinically defined risk category, whereas the NACHRI CCCHC placed each individual into a hierarchical severity group without defining the primary clinical condition. Second, the 3M system, with a few exceptions, required 2 encounters with the same diagnosis in order to classify that patient with a diagnosis, whereas the CCCHC system gen-

erally required only one encounter. Third, the 3M system evaluated not just the presence of a specific code for severity designation but also the time between code occurrences, age, gender, associated diagnostic and procedure codes, and numerous other complex relationships. Fourth, the 3M system was designed to be used at multiple levels of aggregation, from the full categorization (273 base categories, 1081 total cells) to Core Health Status Groups (9 base categories, 37 total cells), whereas the CCCHC simply defined a child's overall severity level. All of the components of the original 3M system were incorporated into the final combined system, CRGs.

The combined CRG system to be used for both adults and children was developed and tested jointly over a 4-year period.¹⁴ The developmental effort was an interactive process, with NACHRI and 3M HIS physicians and analytical staff reviewing multiple sets of test runs and revising clinical specifications. In areas of disagreement, the 3M internist usually deferred to the NACHRI pediatricians in issues concerning children, and visa versa for adult issues. The 3 test databases used in this combined testing process were 1) a 2-year claims database from the state of Washington Medicaid program with approximately 250 000 noninstitutional recipients, aged 0-64 years; 2) a 4-year Medicare claims database with approximately 1 250 000 recipients, primarily over age 65; and 3) a 4-year private sector claims database of adults and their dependents with approximately 250 000 recipients, aged 0-64 years. Recently, the CRGs have been used to analyze charges by severity level in the same study population reported in this study, the Northwest Washington Medical Bureau.¹⁵ All of these evaluations demonstrate a clear correlation of CRG category and severity designation with charges.

CRGs also have been evaluated in comparison to other systems with respect to their use for risk adjustment.¹⁶ In a comparative analysis of CRGs with 5 other health status groupers (Disability Payment System [DPS], Ambulatory Care Groups—version 3 and 4 [ACGs 3 and 4], Diagnostic Cost Groups [DCGs], and Hierarchical Coexisting Conditions [HCCs]) based on Washington State Medicaid SSI enrollees (1994-95 and 1992-93) and 2 years of data on Washington Medicaid non-SSI enrollees (1992-93), the authors conclude that "the most recent addition to the existing 'family' of groupers, CRG, generally performs as well as the other five and so offers another alternative measure of health status to researchers and payors."¹⁶

The CRG clinical logic requires 5 distinct analytic phases to generate an individual's final patient classification¹⁴ (Figure 1). In Phase I, each diagnostic and procedure code in the patient's medical record is evaluated and used to create the individual's disease profile and history of medical interventions. Each disease is classified into one of 533 Episode Diagnostic Categories (EDCs), and these, in turn, are grouped into 31 hierarchically ordered Major Diagnostic Categories (MDCs). Each MDC represents either a single organ system (such as respiratory, digestive, etc) or a major disease category (such as malignancies, trauma, and infectious diseases). Each EDC is

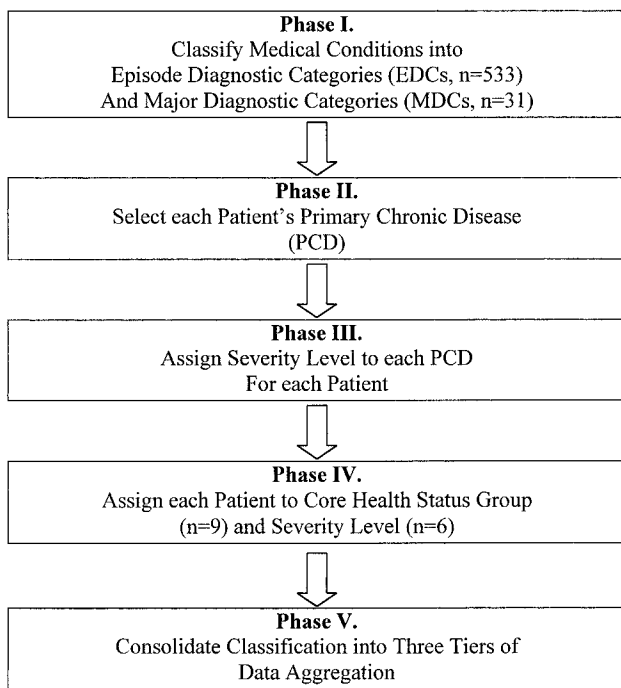


Figure 1. Outline of CRG Clinical Logic.

assigned to one of 6 groups: dominant chronic (60 EDCs), moderate chronic (65 EDCs), minor chronic (40 EDCs), chronic manifestation (99 EDCs), significant acute (151 EDCs), and minor acute (118 EDCs). Dominant chronic conditions are defined as serious medical conditions that often result in progressive deterioration of health and that also contribute to debility, death, and a future need for medical services. Moderate chronic conditions are those that are not progressive, that are highly variable, and that can contribute to individual debility, death, and a future need for medical care. Minor chronic conditions are those that can generally be managed throughout an individual's life with few complications. A manifestation of a chronic condition describes a condition that generally evolves from a primary chronic condition, such as diabetes with eye or circulatory manifestations. Significant acute conditions are those conditions that place an individual at risk for developing a chronic condition. Minor acute conditions are those that generally can be expected to be self-limited. There are 2 additional status groups formed out of the dominant chronic group, catastrophic and dominant/metastatic malignancies. The catastrophic are those chronic conditions that are expected to be life long, that are often progressive, and that require extensive services. Dominant malignancies are those that have a very difficult progression (eg, brain tumors) or that are fundamentally systemic (eg, leukemia). Other malignancies remain in their appropriate body system classification in the other chronic illness groups. This structure of the EDCs simplified, incorporating NACHRI's CCCHCs into the CRG logic. CCCHC severity levels 1–3, with little change, corresponded to the minor, moderate, and dominant CRG status groups, respectively. CCCHC severity level 4 matched with the CRG catastrophic status group.

Phase II of the CRG clinical logic focuses on selecting

a patient's Primary Chronic Disease (PCD). This is required for individuals with multiple EDCs in a single organ system. When an individual is found to have more than one chronic EDC present in an MDC, the most significant chronic condition under active treatment is selected as the PCD. Criteria used to perform this selection include a predefined hierarchy of EDCs in each MDC, developed through extensive clinical review, site of treatment (hospitalizations being weighted more heavily), and frequency and duration of treatment. For example, when asthma and cystic fibrosis are both present in the same patient, the PCD becomes cystic fibrosis; when seizures and a progressive neurological condition are both present, the PCD is the progressive neurological condition.

In Phase III, a severity level is assigned to each PCD for each individual. Severity levels describe the extent and progression of the patient's disease and are determined by the chronic manifestation EDCs, comorbid and acute EDCs from the same or other MDCs, patient age (when a condition has an age-related progression), procedural codes, and some utilization measures, such as multiple hospitalizations.

In Phase IV, each patient is assigned to one of 9 CRG core health status groups based on his/her PCDs and severity levels. The CRG core health status group provides a general categorization of the patient's clinical condition. CRG core health status groups are hierarchically ordered, as follows: Catastrophic Conditions (most complex), Dominant, Metastatic and Complicated Malignancies, Dominant Chronic Conditions in 3 or more organ systems (triplets), Dominant or Moderate Chronic Conditions in 2 organ systems (pairs), Single Dominant or Moderate Chronic Conditions, Minor Chronic Conditions in multiple organ systems, Single Minor Chronic Conditions, History of Significant Acute Conditions, and Healthy (including those with no medical encounters).

In Phase V, the CRGs are consolidated into 3 tiers of aggregation, based on predefined hierarchical relationships between MDCs. Each tier represents a progressively higher level of aggregation, with the full set of 1081 categories (full CRG) being aggregated into Body Systems (413 cells, tier 1), Super Body Systems (149 cells, tier 2), and Core Health Status Groups (37 cells, tier 3). Tier 3, or Aggregated CRG3 (ACRG3), is the aggregation used in this analysis—the 9 Core Health Status Groups described above stratified by up to 6 severity levels, for a total of 37 cells. Each individual in the health plan is exclusively assigned to one of these 37 cells, and each cell represents a hierarchical health status group and severity level. Note that the number of severity levels defined varies across status groups (from 1 for Healthy and Significant Acute to 6 for the most complex groups) and that severity levels cannot be compared across status groups. That is, a severity level 2 for a patient classified as Minor Chronic is not comparable to a severity level 2 for a patient classified as Catastrophic.

Study Population

The Northwest Washington Medical Bureau (NWMB) is a health insurance plan in northwest Washington State.

It serves primarily 4 counties: Skagit, Whatcom, Island, and San Juan. The plan has contractual arrangements with virtually all of the practitioners in the region.

Through a mix of health plans, in 1999 the NWMB insured about 110 000 people, primarily in the 4 northwest counties. These plans included traditional fee-for-service, non-Medicaid managed care, Medicaid Capitated Managed Care (Healthy Options), Medicaid fee for service (those exempted from Medicaid Capitated Managed Care), Medicare supplement, and Washington's Basic Health Plan (the state-subsidized health insurance program). In these counties, all Medicaid recipients less than 19 years of age are required to enroll in capitated managed care (Healthy Options), except those who are institutionalized, enrolled in foster care or SSI, and a very small number with extraordinary special needs. Medicaid Behavioral Health Services are included in the managed care benefit package for up to 12 outpatient visits per year. All of the non-Medicaid plans include at least this benefit. Medicaid Managed Care patients who require more than 12 outpatient mental health visits or an admission for inpatient mental health care are referred to regional support services and are billed separately to the state. These additional services are not likely to show up as NWMB encounters. In 1999, NWMB insured 46 600 children, ages 0–18 years, representing about 45% of the population 0–18 years in the 4-county region. The NWMB insured children were covered as follows: Medicaid capitated managed care—37%, Medicaid fee-for-service—0.9%, non-Medicaid capitated managed care—17%, non-Medicaid fee-for-service—45%. All providers are required to submit claims to NWMB for all services provided, regardless of the type of health plan—capitated or fee-for-service—covering the patient's medical care.

Analysis

Eligibility and paid claims files for all children born on or after January 1, 1982 were obtained from NWMB on a strictly confidential basis without identification of individual children. The initial enrollment file indicated an enrollment of 48 013 children. Eleven thousand four hundred and eight of these children were identified as being covered by more than one health insurance policy (ie, were included multiple times in the enrollment file). Unique patient identifiers, independent of parent's membership, were created for all children, so that those covered by multiple policies were represented by a single unique identifier. These "unique" children were then screened for eligibility. Children over 1 year of age were required to be enrolled for at least 6 months during the 1999 calendar year; children born during 1999 had to be enrolled for at least 3 months. After creating unique patient identifiers and removing children who did not meet eligibility requirements, the resultant population for analysis included 34 544 unique children (48 013 total enrollees minus 11 408 with multiple coverage minus 3061 not meeting eligibility requirements). A Patient File containing a unique patient identifier, date of birth, gender, and

period of eligibility was created from the NWMB eligibility data for CRG analysis.

The paid claims file for all children's claims processed through NWMB during calendar year 1999 contained 310 679 records. Of these, 293 626 were for the 34 544 eligible children identified above. After recoding to meet CRG specifications, a Claims File containing a unique patient identifier, date of service, site of service, provider type, diagnosis (ICD-9-CM) codes, procedure codes and type (ICD-9-CM, CPT, HCPCS), and principal diagnosis flag was created for CRG analysis.

These 2 files—the Patient File and the Claims File—were analyzed using 3M CRG Software (Windows NT version 1.0). The CRG software produces a number of different output records. The Grouping Results provide 4 distinct levels of aggregation. For the purposes of this article, classification results are reported at the highest level of aggregation, ACRG3, which identifies core health status group and severity level only. The CRG software also generates output information on how each claims record was used, all diagnostic categories identified for each patient (both for Major Diagnostic Categories and Episode Diagnostic Categories), counts of records per patient, and several different error records (ie, medical code errors, missing data).

Estimation of prevalence rates for specific medical conditions required identifying all Episode Diagnostic Categories recorded for each child, not just the dominant condition, since many children have more than one chronic condition. Within each specific medical condition group—whether at the Major Diagnostic Category level or the Episode Diagnostic Category level—unique patient identifiers were checked to insure that children were not counted multiple times within diagnostic groups.

RESULTS

CRG classification results for the NWMB calendar year 1999 data are summarized in Tables 1 through 4. Table 1 summarizes the CRG classification of the 34 544 eligible, unique children covered by NWMB at the CRG's highest level of aggregation: CRG core health status group by severity level (ACRG3). The 29 446 children (85.2%) classified as healthy include 6 773 children (19.6%) who had no claims recorded by the health plan during calendar year 1999. Children with no claims are more likely to be older than those with claims; 86.7% of children with no claims were 5–17 years old, compared to 71.2% in the claims group ($P < .001$). The remaining 5098 children were classified by CRGs as having either significant acute conditions (1807 children; 5.2%) or one or more chronic conditions (3291 children; 9.5%). Note that of those children classified as chronically ill, 1585 (4.6% of all children) have minor chronic conditions singly or in pairs, and 1706 (4.9%) have moderate to catastrophic chronic conditions singly or in pairs. Note also that Table 1 does not show all 37 cells of the ACRG3 aggregation. The chronic pair and chronic triplet status groups were merged, since very few children exhibit more than 2 dominant chronic conditions. Likewise, relatively few children

Table 1. CRG Classification of NWMB CY99 Medical Billing Data for Eligible Members Ages 0–17 Years*

Status	Level of Severity					Totals	
	0	1	2	3–4	5–6	#	%
Healthy	29 446					29 446	85.2
Significant acute	1807					1807	5.2
Single minor chronic		1345	165			1510	4.4
Multiple minor chronic		52	2	21		75	0.2
Single dominant or moderate chronic		1010	435	94	7	1546	4.5
Pairs & triplets		70	24	24	8	126	0.4
Malignancies		1	11	5	0	17	>0.1
Catastrophic		6	3	8	0	17	>0.1
Totals by level of severity	31 253	2484	640	152	15	34 544	100.0
Percentage distribution by level of severity	90.5	7.2	1.9	0.4	0.0	100.0	

*Note that the Healthy category includes 6773 eligible children with no encounters during calendar year 1999. Pearson Chi-square significant at $P < .001$ for distribution. CRG, clinical risk groups; NWMB, Northwest Washington Medical Bureau.

are classified in the higher severity levels. For the NWMB pediatric population, only 44 of the 34 544 children (0.13%) were classified at severity level 4 and above.

Table 2 provides examples of the primary chronic health conditions identified within each of the single condition CRG status groups along with their frequency in the NWMB pediatric population. Of the 1510 NWMB children classified as having a single minor chronic con-

dition, three fourths of the children were diagnosed with either Attention Deficit Hyperactivity Disorder (ADHD), minor musculoskeletal conditions, minor eye problems, or minor mental health, including non-major depressive conditions. In the single dominant/moderate CRG status group, asthma is the most frequent condition at both severity level stratifications illustrated. Mental health conditions, including conduct and major depressive condi-

Table 2. Examples of Primary Chronic Diagnoses (PCDs) by Selected Clinical Risk Group (CRG) Status Groups and Severity Levels

	Total No. of Children	Percent of Category (%)
Status group 3—single minor chronic condition		
Attention deficit/hyperactivity disorder	617	40.9
Chronic joint/musculoskeletal diagnosis—minor	248	16.4
Chronic eye diagnosis—minor	150	9.9
Depression (nonmajor)	114	7.5
Chronic mental health diagnoses—minor	45	3.0
All other conditions in single minor	336	22.3
Total for all single minor chronic (34 conditions)	1510	100.0
Status group 5—single dominant or moderate chronic, severity levels 1 & 2		
Asthma	591	40.7
Conduct, impulse control, other disruptive behavior disorders	161	11.1
Depressive and other psychoses	60	4.1
Diabetes	46	3.2
Curvature or anomaly of the spine	45	3.1
Chronic mental health diagnoses—moderate	44	3.0
Chronic alcohol abuse	41	2.8
All other conditions in this status/severity category	463	31.9
Total for status group 5, sev 1 & 2 (68 conditions)	1451	100.0
Single dominant or moderate chronic, severity levels 3 & 4		
Asthma	39	41.1
Chronic metabolic & endocrine diagnoses—major	6	6.3
Complex cyanotic & major cardiac septal anomalies	5	5.3
Diabetes	5	5.3
All other conditions in this status/severity category	40	42.1
Total for status group 5, sev 3 & 4 (28 conditions)	95	100.0
Malignancies & catastrophic conditions, severity levels 1–4		
Spina bifida	6	17.6
Acute lymphoid leukemia	5	14.7
Cystic fibrosis	4	11.8
Other malignancies	4	11.8
All other conditions in this status/severity category	15	44.1
Total for status groups 8 & 9 (17 conditions)	34	100.0

Table 3. Distribution of Average Number of Unique Encounters* per Member by Clinical Risk Group (CRG) Status and Severity Level, NWMB CY99 Eligible Members Ages 0–17 Years

Status	Level of Severity					Status Group Totals
	0	1	2	3–4	5–6	
Healthy	3.4					3.4
Significant acute	11.7					11.7
Single minor chronic		10.5	18.2			11.4
Multiple minor chronic		16.5	21.0	24.3		18.8
Single dominant or moderate chronic		13.4	18.4	26.4	27.6	15.7
Pairs & triplets		26.8	36.7	53.3	104.4	38.6
Malignancies		22.0†	77.1	80.0		74.7
Catastrophic		17.2	43.0	40.9		32.9
Totals by level of severity	3.9	12.3	20.2	32.9	68.5	5.0

*Unique encounters were defined as a specific patient visiting a specific provider at one location on a particular date. Multiple billings associated with a single visit are counted as one encounter.

†Not an average, as only one individual in this cell. ANOVA between group differences significant at $P < .001$ level for group totals for both status groups and severity levels. NWMB, Northwest Washington Medical Bureau.

tions and other moderate chronic mental health diagnoses, are the PCDs identified for over 18% of the children classified as severity level 1 or 2 with a single dominant or moderate chronic condition. In the dominant/moderate CRG status group, severity levels 3 and 4, asthma is again the most common condition. The other diagnoses in this group are predominantly non-mental health conditions that occur at very low frequencies. Children in the catastrophic and malignancy CRGs are most likely to be diagnosed with spina bifida, cystic fibrosis, acute lymphoid leukemia, and other malignancies, all at extremely low overall frequencies.

Table 3 summarizes the average number of unique medical care encounters recorded in the health plan's administrative data for each child during calendar year 1999 by CRG status group and severity level. These figures are not synonymous with total encounters, as "unique encounters" do not reflect multiple billings from the same provider on the same date (eg, multiple lab tests or hospital physicians). Unique encounters are defined here as a

specific patient visiting a specific provider at one location on a particular date. Children classified as healthy had an average of 3.4 unique encounters during 1999, including the 23% of healthy children with no encounters. Note that although CRGs are based in part on numbers of encounters, frequency alone does not correlate with severity level or status group. Those classified as significant acute averaged about the same number of unique encounters as those in the single minor chronic group. Whereas the average number of encounters generally increases as severity increases within each chronic condition status group, and the average number of encounters generally increases across core health status groups as medical complexity increases, this pattern is certainly not perfectly consistent, nor is it expected to be. Other encounter characteristics, such as type of provider, site of service, specific medical procedures performed, and time between both similar encounters and procedures are significant factors in the CRG classification algorithm.

In addition to identifying a person's PCD, CRGs also

Table 4. Prevalence Rates for Selected Chronic Condition Groups, All Diagnoses Recorded for Each Child

Diagnosis-based Condition Groups	Number of NWMB Children*	% of NWMB Children	Prevalence from Literature Review (%)	Reference Citations
Asthma	682	1.97	4–6 (a)	20–22
Attention deficit hyperactivity disorder	789	3.08 (b)	2.5–4.0 (b)	23
Cystic fibrosis	4	0.03	0.02 (c)	24
Cerebral palsy	6	0.02 (d)	0.2–0.5 (d)	25–27
Diabetes	58	0.17	0.1–0.2	28
Learning disorder	101	0.39 (b)	>5 (b)	29
Malignancies	25	0.07 (e)	0.08	30
Mental health conditions	999	5.54 (f)	6–12 (f)	31
Mental retardation	64	0.25 (b)	0.4–3 (b, g)	32–34
Total unique children analyzed	34 544			
Total children with chronic conditions	3291			

*Note that these are *unique* children *within* conditions groups (ie, each child is only counted once per condition group, but may appear in multiple condition groups in the table). NWMB, Northwest Washington Medical Bureau. Parenthetical letter designations are as follows: (a) National asthma prevalence of 4–6% for children 0–17 years from National Health Interview Survey [20,22]; estimated at 4.9% for children 1–17 years using administrative data and a single outpatient or inpatient asthma diagnosis [21]; (b) school-aged children, ages 5–17 years; (c) Washington State Cystic Fibrosis Registry, 1999; (d) ages 0–10 years; (e) Washington State Tumor Registry, 1999; (f) mental health conditions includes children in NWMB with both chronic and acute conditions identified through clinical risk groups (CRGs). 541 of the NWMB children had at least one chronic mental health conditions; 458 children had acute mental health conditions only. National estimate relates to "emotionally disturbed children." Age range for both estimates is 9–17 years; (g) .4% represents severe mental retardation, IQ < 50 [32].

provide for identifying all chronic conditions identified in the medical encounter records for each individual. Table 4 summarizes prevalence rates for selected chronic condition groups based on all chronic conditions identified at the Episode Diagnostic Category level for each NWMB child. Although asthma and ADHD continue to show high frequencies of occurrence—as they did at the patient level (Table 2)—mental health conditions, excluding ADHD, affect a particularly large percentage of NWMB children. Mental health conditions classified by CRGs as chronic affect 541 NWMB children, ranking third in terms of frequency of chronic health condition, behind asthma and ADHD. CRGs also identify another 458 children as having acute mental health conditions—conditions that are expected to be self-limiting but that have the potential to become chronic. These diagnoses include stress, anxiety, adjustment, and neurotic conditions. Taken together, the combined chronic and acute mental health conditions affect more children than any single physical chronic health condition. Examples of conditions included in the mental health combined group are eating disorders, depression, conduct and bipolar disorders, and schizophrenia. Such conditions often occur in combination with other physical or mental chronic conditions but may not always be identifiable from the individual's final mutually exclusive CRG category. Several examples can help clarify this. When an individual has multiple mental health conditions, only the diagnosis selected as primary will show in the final CRG classification. If a child has both ADHD and a depression or anxiety disorder, the child is classified within the mental health hierarchy as having ADHD, with the depression or anxiety disorder taken into account in the severity level assignment. If a child has a moderate chronic physical condition and a minor chronic mental health condition, the final CRG assignment will be a single moderate chronic physical condition, with the minor chronic mental health condition taken into account in the severity level assignment. If a child has both a moderate chronic physical condition and a moderate chronic mental health condition, the final CRG assignment will be a chronic pair category. This pair may specifically identify the presence of a mental health condition, or it may be more broadly defined (because of low case volume constraints).

DISCUSSION

Claims data collected and maintained by health plans are a source of clinical and procedural information that can be used to identify and classify children having a wide range of chronic health conditions. Using 3M's CRG software and these data, we have shown how each child can be classified into mutually exclusive clinically based categories, defined by health status and relative severity. CRGs also can be used for estimating the prevalence of specific chronic health conditions in a population by analyzing the system's output at the EDC level, identifying all chronic conditions found in the medical record of each patient, as opposed to the PCD. These applications have been demonstrated in a case study of children enrolled in the NWMB, a mid-sized health plan in Washington State.

Health plans are under increasing pressure to identify chronically ill populations for case management.¹⁷ Categorical identification tools, such as CRGs, are particularly useful for such applications, as they are specifically designed to stratify the chronically ill population. In contrast, noncategorical identification tools do not discriminate between levels of severity or identify children with specific chronic conditions that might be targeted by specific disease management programs by health plans. CRG classification can assist a health plan to identify those children who have complex chronic conditions or who are at increased risk for developing such conditions and can use this information to help determine which children should receive case management services. In the case study presented here, case management services might be targeted at several different levels: 1) all children identified with a chronic condition = 3291 children, 9.5% of child population; 2) those identified with very severe chronic conditions, for example, severity levels 5 and 6, = 15 children, <1% of population; 3) by specific condition categories such as asthma, diabetes, malignancies, cystic fibrosis, ADHD, or mental health conditions (Table 4); 4) those children identified as being at risk of developing chronic illnesses (significant acute) = 1807 children, 5.23% of NWMB child population; 5) children with dominant high severity (severity level 3 or above) or complex chronic conditions (pairs, triplets, malignancies, or catastrophic) = 261 children (Table 1).¹⁸

Since there is currently no gold standard for validating identification of children with chronic health conditions, it is difficult to assess the accuracy of CRGs used for this purpose. In a case study of 497 randomly sampled NWMB children classified using 2 noncategorical survey tools as well as CRGs, the 3 tools agreed in most cases (ie, in identifying the individual child as either having or not having a chronic health condition). CRG chronic classification agreed with the one survey screener for 85% of the children and with the other screener for 90% of the children.⁷

Another way to validate the CRG classification results is to compare the prevalence rates for specific conditions estimated using CRGs with those found in the general pediatric literature. Prevalence comparisons are demonstrated for 9 chronic conditions or condition groups in Table 4. Certain of these conditions—asthma, ADHD, learning disorders, mental health conditions, and mental retardation—were selected for comparison because of their relative frequency in children. The other 3 conditions—cystic fibrosis, cerebral palsy, and diabetes—were selected because they can be considered sentinel chronic conditions that are resource intensive and life-long.⁹

The comparisons in Table 4 indicate that, from an overall population prevalence standpoint, CRGs appear to do well in identifying children with ADHD, cystic fibrosis, diabetes, malignancies, and mental health conditions. The NWMB prevalence rates calculated from CRG classification are consistent with those found in other studies. In contrast, asthma appears to some degree to be underreported. Cerebral palsy, learning disorders, and mental re-

tardation seem to be significantly underidentified. With the possible exception of cerebral palsy, these results are consistent with the characteristics of the administrative data that form the basis of the CRG system. Conditions that require frequent interaction with the health system, especially if they require physician contact, hospitalization, or clinical tests, are much more likely to be identified in administrative data than those that do not generally require medical intervention. Treatment for learning disorders and mental retardation is rarely the primary purpose of a medical visit, and thus, these conditions are not often coded in health-plan administrative data. The underidentification of cerebral palsy might be explained by the existence of separately funded neurodevelopment centers where these children might be receiving most of their care.

CRG classification logic may also explain some of the relative underidentification of some conditions, such as asthma. CRGs require a minimum of 2 coded diagnoses during a 12-month period for identification. The comparative studies cited either relied on parent report or only required one diagnostic encounter to achieve their higher prevalence rates. CRGs also do not evaluate prescription use as an indicator of an ongoing chronic condition. Some children who have been diagnosed with asthma only rarely experience asthma attacks requiring medical attention and might only be identifiable in health plan data through pharmacy claims. Whereas the NWMB prevalence rate for mental health conditions is within the low range of the prevalence rates found in the literature, this may not be true for other health plans, as coding of any condition is at least partially determined by the medical provider's expectation of reimbursement. Health plans that do not provide reimbursement for certain types of services are unlikely to find those services consistently appearing in their administrative data.¹⁹ Conversely, plans that provide a richer set of mental health benefits may observe a higher prevalence of these conditions. In comparing prevalence rates for specific conditions derived from administrative data, regardless of the classification methodology, it is important to understand local reimbursement characteristics, coding, and practice patterns.

There are certain inherent limitations in this tool as well as in any other tool that uses only administrative data to identify and classify children with chronic illnesses. Any tool used to classify individuals will need to be updated periodically to account for changes in technology and therapy and to incorporate new and revised codes. No encounter-based system can be used to develop full population prevalence figures for a geographic area. It only can be applied to the population covered by that specific encounter database and by those who meet the tool's eligibility requirements. No diagnosis-based tool will identify individuals who are enrolled and eligible but who for some reason do not use health services reimbursed by their health plan. For our NWMB population, 19.6% of the children meeting eligibility requirements had no encounters during calendar year 1999 in the plan's administrative database. To the extent that services are received

outside of the health plan, such as through a child's school or the public health system, such services will not be recorded in health-plan administrative data. Many children with speech or learning disorders, who receive most or all of their care through a school or public health system, and those with mental health conditions, who are cared for entirely in separate mental health programs not billed through their health plan, will not be captured in the plan's administrative database.

Given these data limitations and methodological constraints, it is not surprising that compared to noncategorical survey tools, CRGs identify a smaller percentage of children as CSHCN. Overall, CRGs classified 9.5% of the eligible NWMB children as having a chronic condition. In contrast, analysis of the National Health Interview Survey found that 12% of the children met the full MCHB definition of CSHCN, and 18% met all or part of the definition.⁵ CRGs perform especially well in identifying children who have moderate to severe chronic conditions requiring regular medical intervention. In our study population, CRGs identified 4.9% of the children as moderate to severe in this group, a figure that is conceptually comparable to the 6.5% estimated by others to have a chronic condition that compromises their ability to perform usual age-appropriate activities.⁶

This study represents the first application of CRGs for identifying and classifying CSHCN in a specific health plan. To the extent that comprehensive medical encounter data is available, we believe it provides an appropriate methodology for identifying CSHCN and for stratifying those children with respect to severity and medical complexity. CRGs can be a useful tool for case identification for targeting disease-specific programs for case management, even though there may be limitations in the system and the underlying data. No one CSHCN identification system is likely to meet all possible epidemiological, public health, case management, and risk adjustment needs. The CRG system, which is categorical and based on medical encounter information, is one tool that can effectively address the need to identify specific children for case management and program planning. This tool will require updating at least every 3 to 5 years to incorporate information gained from further utilization and to accurately reflect medical technology, therapy, and coding. To the extent that the quality of data collected through administrative databases and the tool improves over time, the utility and validity of CRGs as a CSHCN identification tool will also improve.

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