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Ways to Identify Children with Medical Complexity and the Importance of Why

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Children with medical complexity, although a small fraction of the pediatric population, are important due to their high levels of health care spending, unmet health care needs, substandard quality of care, and poor health outcomes.(1) Consistent with the Triple Aim, (2) these children are the focus of clinical, research, and policy initiatives seeking to: (1) improve their healthcare experience and quality of care, (2) improve outcomes (for themselves and their families), and (3) reduce the future healthcare costs that they might accrue.(3-8) Clinics, hospitals, states, and countries throughout the world are reforming the health system to optimize its performance for children with medical complexity. (9, 10)

Although the act of recognizing that a particular child is medically complex may seem straightforward at the individual level, identifying children with medical complexity at a population level is not straightforward. At the individual level, recognizing medical complexity is a subjective distinction (11), drawing on a person's experiences and perceptions of viewing a child as being medically complex. (12) When scaled up to population-level, three challenges emerge. First, the construct of medical complexity is regarded differently among parents, clinicians, researchers, and others. Second, individual-level details about the child that are evident or discoverable in a 1-on-1, in-person encounter (e.g., an outpatient clinic visit) are often not readily available in population-level data sources. Third, in contrast to their adult counterparts, children with medical complexity have a heterogeneous array of rare health problems without a select few that dominate in prevalence and impact.

With these caveats in mind, we review existing techniques and tools that can be used to identify children with medical complexity from a variety of health data sources, including

administrative billing data and parent- or provider-reported survey. We organize our review with Cohen et al children with medical complexity definitional framework of interacting characteristics, including complex chronic health problems, substantial healthcare needs, severe functional limitations, and high health resource utilization.(1) Moving stepwise through this framework, we focus on the advantages and disadvantages of various approaches to identify children with medical complexity.

Identifying the Complex, Chronic Health Problems Endured by Children with Medical Complexity

Most health problems endured by children with medical complexity are burdensome, severe, life-long, and incurable. Some health problems are inherently complex because their rarity and complicated pathophysiology preclude most clinicians from becoming proficient in understanding and managing them (e.g., ornithine transcarbamylase deficiency). Other health problems that may not be considered complex in isolation become complex in combination (e.g., asthma, depression, and type I diabetes mellitus) because of their clinical interactions, their additive effects on health status and quality of life, and the care coordination required to manage the problems among multiple providers.

Comprehensive identification of children with medical complexity is dependent upon methods that are capable of distinguishing these diagnosis situations and others that lead to complexity. We compare and contrast four examples of diagnosis classification systems that have been used to identify the health problems endured by children with medical complexity from International Classification of Diseases (ICD) diagnosis and procedure codes (Table I). Although other systems may exist, to our knowledge the four examples below are the most pertinent to the identification of children with medical complexity.

Complex Chronic Conditions (CCC)

CCCs are an open-source set of childhood complex, chronic health conditions that are strongly associated with mortality, morbidity, functional limitations, high health resource utilization, and use of a complex care clinical program.(4, 13-16) Publicly available are tables of CCC categories, their corresponding ICD9 and ICD10 diagnoses and procedure codes, and programs coded in Statistical Analysis Software (SAS) (Cary, NC) and Stata (College Station, TX) to apply CCCs to health data that contain ICD codes.

CCCs, by inception and purposeful design, do not include all chronic conditions of childhood. For example, CCCs do not include asthma, obesity, attention deficit hyperactivity disorder, or other behavioral health conditions (e.g., depression, bipolar disorder). Therefore, CCCs are not positioned to distinguish all children with medical complexity, especially those children with multiple chronic conditions of "less" complexity. Depending on the intent of their use, some CCC diagnoses, in isolation, may not be sufficient to label medical complexity (e.g., acute electrolyte disorders [hypophosphatemia]). Moreover, some CCC categories contain diagnoses with episodic severity and complexity (e.g., malignancy) that could be associated with transient high healthcare utilization.

Clinical Risk Groups (CRG)

CRGs, developed by 3M Health Information Systems, are a proprietary system of hierarchical pediatric diagnosis groups (17-19) ranging from healthy children without a chronic condition [CRG groups 1 ("Acute Condition") and 2 ("Significant Acute Condition")] to unhealthy children with a catastrophic chronic condition that is associated with high morbidity and mortality [CRG group 9 ("Catastrophic Condition")]. CRGs distinguish children with minor, moderate, dominant, and catastrophic chronic conditions as well as children with single vs. two-to-three chronic conditions of all kinds. For children with multiple chronic conditions, CRGs' Episode Diagnosis Category feature can distinguish children's primary chronic diagnosis (e.g., cerebral palsy) from their comorbid conditions (e.g., gastroesophageal reflux). CRGs permit a diagnosis to be contained within multiple CRG groups, depending on the number of organ systems that are affected by the child's comorbid conditions.

A distinct demarcation of medical complexity is not inherent across the CRG groups. Prior studies of children with medical complexity have combined CRG groups 6, 7, and 9 to create a cohort of children with medical complexity with significant chronic conditions affecting 2 or more body systems and/or a complex or progressive chronic condition.(20, 21) Proposed federal legislation of Medicaid reform for children with medical complexity suggests inclusion of children in CRG groups 5b ("dominant chronic condition") through 9 ("catastrophic chronic condition").(22) CRG group 5b, in general, represents children with a single, lifelong chronic condition that affects one body system (e.g., cerebral palsy spastic diplegia with no comorbid conditions). Although in some projects, CRGs have been used only with hospitalization data, ICD diagnosis and procedure codes aggregated across the care continuum are recommended when using them. Moreover, three years of linked, healthcare data are recommended to accurately categorize children into each CRG, which may limit the CRGs ability to distinguish some infants and toddlers with medical complexity.(23)

Chronic Condition Indicators (CCI)

CCI, developed by the Agency for Healthcare Research and Quality (AHRQ), is an open source diagnosis classification system that dichotomizes ~14,000 ICD9 and ~68,000 ICD10 diagnosis codes into chronic and non-chronic conditions. (24, 25) Unlike the CCCs and the CRGs, CCIs are not specific to children. However, the CCIs are inclusive of most pediatric chronic conditions across the spectrum of complexity. CCI's 18 major clinical categories have been used to count the number of chronic conditions that a child endures as an indicator of medical complexity.(26) Health resource utilization correlates with the number of major clinical categories in which a child has a chronic condition.(26) Publicly available are tables of CCI distinction as well as the major clinical category and diagnosis subgroup assignments for each ICD code.(25)

The CCIs do not distinguish complex vs. non-complex chronic conditions. However, the CCIs can be integrated with other pediatric diagnosis classification systems designed to make that distinction (e.g., CCCs). Some of the fundamental diagnoses endured by children with medical complexity (e.g. scoliosis) are contained in CCI diagnosis subgroups with

vague titles (e.g. "other bone disease"), which limits the ability to discern which specific diagnoses are endured by children with medical complexity. Some of the major clinical categories in CCI contain a myriad of chronic conditions that affect multiple organ systems. For example, the major clinical category 14, "Congenital Anomalies," contains children with congenital heart, kidney, gastrointestinal, and other disease. As a result, some children with congenital anomalies in multiple organ systems may have only one CCI major clinical category.

Patient Medical Complexity Algorithm (PMCA)

PMCA, developed by the Seattle Children's Hospital Center of Excellence on Quality of Care Measures for Children with Complex Needs, is a new, open source, pediatric-specific, diagnosis classification system that uses ICD9 codes to group children into one of three categories: 1) complex, chronic disease; 2) non-complex, chronic disease; and 3) non-chronic disease.(27) The system allows the user to select how conservative they would like the assignments of complexity to be based on the number and timing of administrative claims associated with a particular chronic condition. A SAS program, freely available from the PMCA developers, specifies the assignment of ICD9 codes to each PMCA group.

Similar to the CRGs, the PMCA developers recommend multiple years (i.e., minimum of two years) of prior data to classify children, however PMCA still performs well for identifying infants with medical complexity (e.g., infants with multiple congenital anomalies). PMCA performance varies across the types of children it seeks to identify. PMCA's sensitivity and specificity are 89% and 85%, respectively, for children with complex chronic diseases.(23) Because PCMA has been recently developed, additional strengths and nuances of using it may become more apparent with further assessment and use.

Identifying Functional Limitations in Children with Medical Complexity

For some initiatives, identifying a population of children with medical complexity solely on the type or number of chronic conditions may not be sufficient. For example, consider a state-wide initiative to determine which children may benefit from home nursing services. Data on functional limitations may be needed because children with severe functional limitations (e.g., dependence on tracheostomy and ventilator to breathe) may have the greatest need for home nursing services. Many of the chronic diseases endured by children with medical complexity can cause severe limitations in cognitive and/or physical functioning. These limitations can contribute greatly to a child's medical complexity. For example, cerebral palsy can severely affect a child's ability to communicate, eat, digest food, breathe, and walk independently. However, not all children with cerebral palsy have these functional limitations; those children without these functional limitations may not be considered, by some, to have medical complexity. Attention to functional limitations when ascertaining children with medical complexity is critical because information about the limitations can provide rich detail about a child's severity of chronic illness or fragility of their health status that may not be forthcoming in a description of the child's underlying diagnosis alone.(28)

On a population level, assessing the degree of functional limitations in children with medical complexity is challenging. Some functional limitations are poorly discriminated in health administrative data with ICD diagnosis and procedure codes because of the vagueness of the codes and inconsistencies in the use of the codes (e.g., developmental delay coded in a child with cerebral palsy who is unable to walk). ICD codes for the presence of medical devices, when present, can be a valuable indicator of function (e.g., v-codes for the presence of a feeding tube [gastrostomy] or breathing tube [tracheostomy]). The CCCs contain the ability to distinguish these devices in each subcategory of conditions.(16)

Unless health administrative data become better equipped to distinguish and quantify functional limitations in health, additional data sources and collection may be needed. Parent or provider reported surveys are likely the best method for understanding functional limitations that contribute to a child's medical complexity. Many such surveys have been developed. Some are specific to children with a single disease (e.g., the Gross Motor Functional Classification System for children with cerebral palsy).(29) Others are not forthcoming about the functioning that they assess because of their licensing agreement and terms of use. (30) Described below are two examples of surveys - with transparency in their assessments - that may have value when distinguishing functional limitations in populations of children with medical complexity (Table II).

National Survey of Children with Special Healthcare Needs (NS-CSHCN)

The NS-CSHCN is an open source, anonymous telephone survey that was developed to assess the national prevalence of CSHCN among children ages 0-17 years.(31) NS-CSHCN contains survey questions asked to parents about their child's functional limitations, including difficulty breathing, swallowing, digesting food, seeing, hearing, moving around, speaking/communicating, and taking care of themselves. Parents are asked to compare their CSHCN's functioning with other children of the same age. Because the NS-CSHCN quantifies these difficulties (i.e., no difficulty, a little difficulty, vs. a lot of difficulty) it can be used to assess the presence and severity of a child's functional limitations. When used in conjunction with the child's list of health problems, use of the NS-CSHCN could yield valuable information about the child's medical complexity.(31-34)

Pediatric Evaluation of Disability Inventory Computer Adaptive Test (PEDI-CAT)

PEDI-CAT is an electronic, clinical assessment of functional activities for use in infants, children, and young adults (i.e., up to age 21 years) that is applicable to all diagnoses and conditions (35-44). PEDI-CAT can be completed by parent/caregiver report or professional judgment of clinicians or educators who are familiar with the child. It can be used repeatedly with a child to assess trends in functional abilities. PEDI-CAT measures function in four domains - (1) daily activities, (2) mobility, (3) social/cognitive skills, and (4) responsibility - by combining elements of adaptive behavior measures used in early intervention, developmental disabilities, and special education programs with functional assessments used in pediatric rehabilitation. Abbreviated and full versions of PEDI-CAT are available, with 5-15 and 30 survey items, respectively, for each domain. PEDI-CAT produces normative standard scores of functional ability for each child, provided with an age percentile and T-score derived from data of an established normative standardization sample.

There are strengths and weaknesses when using questionnaires to assess functional limitations in children for use in distinguishing children with medical complexity. The major strength of questionnaires is that they can provide information on functional limitations and other attributes (e.g., healthcare needs) that are not typically available in standard health administrative datasets. The major limitation of using questionnaires to distinguish children with medical complexity is that the data collection required can be labor intensive and expensive to implement. In available, using the short version of a questionnaire (e.g., the NS-CSHCN screener(31)) could help overcome this limitation. Moreover, although suspected to be very valuable, using a survey to distinguish children with medical complexity for enrollment in clinical initiatives to optimize their health has not been validated. Nonetheless, pediatric providers of children with medical complexity are routinely, in essence, assessing functional limitations of their patients by asking screening questions to parents about the limitations during health encounters with their patients. The NS-CSHCN and PEDI-CAT could have a strong role in helping to standardize and document this assessment in clinical practice for children with medical complexity ascertainment and study on a population level.

Identifying Health Care Needs of Children with Medical Complexity

For many children with medical complexity, the sheer presence of a complex diagnosis with or without functional limitations does not underscore the child's true complexity. In reality, the nature and amount of healthcare necessary to manage and treat the severity of a child's diagnoses and functional limitations - as well as optimize health and quality of life – may contribute the most to the magnitude of medical complexity. Healthcare includes medical treatments (e.g., diet, medications, durable medical equipment, therapies, etc.) and health services (e.g., pediatric specialty care, home nursing care, care management, etc.). Some parents and providers feel strongly that social, familial, and educational needs (e.g., transportation to appointments, activation of benefits available through the Family Medical Leave Act, or an individualized educational plan for use in school) can greatly contribute to and heavily influence a child's medical complexity; these attributes are also important to consider when identifying children with medical complexity.

Capturing the breadth and intensity of healthcare and other needs is important to consider when targeting which children with medical complexity could benefit the most from initiatives to optimize their health (e.g., enrollment in a community care management program). Consider, for example, two children with cerebral palsy and epilepsy. One child's epilepsy is controlled well with a modest healthcare need: a single antiepileptic medication. The other child's epilepsy is controlled well with more substantial healthcare needs: multiple antiepileptic medications, the ketogenic diet administered through a gastrostomy tube, weekly urinary tests, and quarterly blood testing. The diagnoses of cerebral palsy and epilepsy may not distinguish the dramatic variation in complexity of healthcare between these children. Some may find that the latter child may benefit more from enrollment in a care management program.

Together, health administrative and questionnaire data may be equipped to distinguish health care needs that may be indicative of medical complexity (Table III). For example, health

plans and payors are likely to have health care claims in their administrative data for payments made for specific treatments (e.g., use of special diet formulas, medications, durable medical equipment, and therapies) and health services (e.g., home nursing; specialty care) across the care continuum. One could argue that the use of these treatments and health services implies that the children are "in need" of them. The NS-CSHCN questionnaire asks parents whether their child has used similar treatments and health services to the ones described above. The NS-CSHCN also asks parents if their child needs care coordination and respite care, which are two types of needs that may not be routinely included in health plan or payor data.(31) Moreover, the NS-CHSCN also asks parents whether their child has one of these needs but it has not been met.(31)

Identifying High Health Resource Utilization of Children with Medical Complexity

Beyond the use of specific forms of healthcare and other services, overall high levels of health resource utilization is a non-specific attribute of children with medical complexity that can occur for several reasons.(1) For many children with medical complexity, high health resource utilization is a direct manifestation of the complex interactions among the children's health problems, functional limitations, and healthcare needs. Together, these attributes lead the children to experience recurrent health service encounters that, cumulatively, could result in high health resource utilization. For other children with medical complexity, high health resource utilization could occur because of unmet health care needs and/or the receipt of substandard quality of care. These things could lead the child to "get sick" more often and therefore increase the number of health services encounters (e.g., urgent care visits, emergency department visits, and hospitalizations) experienced by the child.

In recent years, there has been increasing attention to recurrent hospital care as an indicator of medical complexity in children.(14) Some care management programs for children with medical complexity purposely target children who have recently experienced recurrent hospitalizations (e.g., 3 or more hospitalizations in the last year) because it is presumed that these children need better care management.(4) It remains unknown whether most children with medical complexity with recurrent hospitalizations continue to experience such frequent hospitalizations over time. The validity and benefit of using multiple hospitalizations (or multiple encounters of another type of health service, such as 10 or more annual outpatient visits across pediatric specialists) as an indicator of medical complexity or an identifier of which complex patients are in need of better care management on a population level has not been assessed. Most children with medical complexity are not hospitalized at all in a given year, much less hospitalized multiple times. (45)

Despite this, the use of high resource utilization to distinguish and optimize the health of children with medical complexity warrants further investigation. Given the labor and expense of using questionnaires to assess functional limitations and healthcare needs, an empirical threshold of resource use (e.g., the most expensive 20% out-of-hospital spending of children with cerebral palsy) could be used as a proxy for these attributes, should it be

shown that children meeting the threshold have a much higher likelihood of having functional limitations and healthcare needs that are congruent with medical complexity. Variation in health resource utilization experienced by children with medical complexity with particular types of health problems, functional limitations, and healthcare needs might indicate variation in the quality of care received by the children. Further exploration of that variation may be a starting point to assess best practices for children with medical complexity. Until the stability and the reasons for high resource utilization in children with medical complexity are explored further, caution should be taken when using it to identify children with medical complexity.

Discussion

Any initiative designed to optimize the health and well-being of children with medical complexity on a population level should consider all of the attributes that contribute to the construct of medical complexity, including the child's health problems, functional limitations, healthcare needs, and high resource utilization. Recognizing that medical complexity is a continuum of subjective, intersecting attributes, users should craft a process for children with medical complexity identification that best serves the purpose of their initiative. A theoretical example of collecting information on multiple attributes to assign care managers to children with medical complexity within a state Medicaid program is provided in Table IV.

We acknowledge that using multiple tools (e.g., a diagnosis classification scheme and a questionnaire) with different types of data (e.g., administrative and survey data) to identify children with medical complexity may be unfeasible for some initiatives to undertake. Moreover, although this suggested process has sound construct validity, its criterion validity has not been assessed. The questionnaire tools, in particular, were not designed for use this way. Despite this, clinical providers of children with medical complexity, in essence, ask questions like the ones in the questionnaires described in this article during one-on-one encounters with their patients to assess the functional limitations and healthcare needs of their patients. Further investigation is needed to translate this process in a standardized way to help population health initiatives for children with medical complexity. In the interim, initiatives to improve the health and well-being of children with medical complexity should move forward to identify the children - as best as they can - using the data and resources that are available with a sound understanding of the advantages and disadvantages of relying on health problems, alone.

Acknowledgments

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Table 1

Four Examples of Tools to Identify the Health Problems Endured by Children with Medical Complexity

Attributes	Complex Chronic Conditions	ICD Code Diagnosis Classification Systems		Pediatric Medical Complexity Algorithm
		Clinical Risk Groups	Chronic Classification Indicator	
Developer	Feudtner and colleagues	3M Health Systems	Agency for Healthcare Research and Quality	Seattle Children's Hospital Center of Excellence on Quality of Care Measures for Children with Complex Needs
Specific to pediatric patients	Yes	Yes	No	Yes
Number and type of clinical categories	12 major categories 75 subcategories	9 major categories with numerous subcategories	18 major categories 567 subcategories	3 major categories 7 subcategories *
Clinical categories specific or relevant to children with medical complexity	All	Major Categories 5b-9 or 6-9	No	1 major category
Contains a definition of a complex health problem:	Yes. A complex chronic condition is one that: "can be reasonably expected to last at least 12 months (unless death intervenes) and to involve either different organ systems or 1 organ system severe enough to require specialty pediatric care and probably some period of hospitalization in a tertiary care center."	No	No	Yes. A complex chronic disease is: "a significant chronic condition in 2 or more body systems" or "a progressive condition that is associated with deteriorating health with a decreased life expectancy in adulthood" or "associated with continuous dependence on technology lasting for at least 6 months" or "a metastatic or progressive malignancies that affect life function, [excluding] those in remission for >5 years"
Can identify "non-complex" chronic conditions	No	Yes	Yes	Yes
Populations of children not included	Children with behavioral / mental health, non-complex chronic conditions, or no chronic condition	All children can be included **	All children are included	All children can be included **
Capable of identifying children with multiple chronic conditions	Yes, for children with multiple, complex, chronic conditions only	Yes	Yes	Yes
Capable of distinguishing discrete diagnoses	Yes, with the subcategories	Yes, with the subcategories (i.e., episode diagnosis categories)	Yes, with the subcategories (i.e., lowest-level CCS categories)	Yes
Open-Source	Yes	No. Licensing costs are determined by the number of patients on which the CRGs will be used.	Yes	Yes
Compatible with ICD-10	Yes	Yes	Yes	No
Amount of data recommended for use	ICD diagnosis codes from any single medical encounter	ICD codes aggregated across a three-year period of time from both inpatient and outpatient data sources.	ICD diagnosis codes from any single medical encounter	ICD codes aggregated across a two-year period of time from both inpatient and outpatient data sources.
Examples of Use in Children with Medical Complexity	• Predicting death (15) • Predicting hospital readmission (46, 47) • Describing the clinical characteristics of palliative care patients (48) • Describing children enrolled in a complex care program (4) • Describing healthcare use and spending for	• Assessing population growth of patients in children's hospitals (20) • Describing healthcare use and spending for populations of children in health plans (21) • Stratifying children by medical complexity	• Assessing risk factors for hospital readmission in children (26) • Describing the number of chronic conditions in children with medical complexity (45)	• Identifying CMC using Medicaid claims data (27)

Attributes	ICD Code Diagnosis Classification Systems			
	Complex Chronic Conditions	Clinical Risk Groups	Chronic Classification Indicator	Pediatric Medical Complexity Algorithm
Information Source	Free Pubmed Article: http://www.ncbi.nlm.nih.gov/pubmed/25102958	3M Website: http://solutions.3m.com/wps/portal/3M/en_US/Health-Information-Systems/HIS/Products-and-Services/Products-List-A-Z/Clinical-Risk-Grouping-Software/	AHRQ Website: http://www.hcup-us.ahrq.gov/toolssoftware/chronic/chronic.jsp	Pediatrics Article: http://pediatrics.aappublications.org/content/early/2014/05/07/peds.2013-3875.abstract
	populations of CMC (13, 49)			

*
the 3 major categories are tiered system of children without a chronic condition, children with a non-complex chronic disease, and children with complex chronic disease.

**
although all children of any age can be included, multiple years of data are recommended to use the system. This should be kept in mind when assessing infants and toddlers with medical complexity.

Table 2

Two Examples of Surveys that Could be Used in Children with Medical Complexity to Identify Functional Limitations

Attributes	Surveys	
	National Survey of Children with Special Healthcare Needs (31)	Pediatric Evaluation of Disability Inventory Computer Adaptive Test (52)
Developer	Child and Adolescent Health Measurement Initiative	Health and Disability Research Institute, Boston University School of Public Health
Respondent	Parent	Parent or healthcare provider
No. of Questions Related to Functional Limitations	13 *	Up to 120
Functional Status Measurements	Physiologic General Functioning Eating Breathing Swallowing and digesting Circulation Seeing Hearing Pain Activity Mobility Using Hands Dressing Bathing Social/Cognitive Communicating Socializing	Daily Activities Dressing Keeping Clean Home Tasks Eating and Mealtime Mobility Basic Movement and Transfer Standing and Walking Steps and Inclines Running and Playing and Wheelchair Social/Cognitive Interaction Communication Everyday cognition Self management Responsibility Organization and planning Taking care of daily needs Health management Staying Safe
Developmentally appropriate	One set of questions for children ages 0–17 years	Validated to respond to changes in development over time
Information Source	http://www.childhealthdata.org/learn/NS-CSHCN	http://pedicat.com/category/home/
Licensing and Use	Open source	One year license = $89
Example of Use	Quantifying the number and types of functional limitations endured by CSHCN (53) Stratifying CSHCN into subgroups of complexity based on the presence of functional limitations (32) Correlating functional limitations with increased healthcare needs and increased healthcare utilization (33)	Distinguishing children with and without a disability (40) Distinguishing children who use wheelchairs and walking aids for mobility impairment (37)

*
The NS-CSHCN Screener, a short version of the NS-CSHCN, contains one question on limitations in ability to help quickly assess functional limitations in children.

Table 3

Two Examples of Information of and Data Sources for Healthcare Needs of Children with Medical Complexity

Domain of Healthcare Need	Helpful Information to Distinguish CMC	Availability of Information on the Healthcare Need	
		Payor Administrative Claims Data	National Survey of Children with Special Healthcare Needs(31)[*]
Specialty Care	Type of each specialty provider; total number of specialists	Yes	Yes
Medications	Name for each; acute vs. chronic use; total number used	Yes	Yes
Medical Equipment	Type (e.g., digestive, respiratory, mobility, etc.)	Yes	Yes
Nursing	Home nursing; school nursing	Yes	Yes
Diagnostic testing	Laboratory and radiographic testing for chronic disease management	Yes	No
Diet/Nutrition	Enteral formulas; parenteral nutrition	Yes	No
Therapies	Occupational, physical, speech, etc.	Maybe[**]	Yes
Care Coordination	Case management, medical home	Maybe[***]	Yes
Education	Individualized education plan	No	Yes
Social and Family	Transportation; Respite care; Family medical leave	No	Yes

[*] For many healthcare needs, the information in the survey may be limited to the presence of the healthcare need only (e.g., the need for care care coordination) without specifying further details (e.g., the specific need for case management)

[**] Some payor data may contain claims for these therapies

[***] Some payor data may contain claims related to care management (e.g., CPT codes)

Table 4

A Theoretical Example of an Integrative Approach to Identify Children with Medical Complexity for Enrollment in a Clinical Initiative.

Consider, theoretically, the following approach to identify and assign CMC in Medicaid a case manager through a new clinical, state-wide initiative.

Step 1: To begin, the state Medicaid program queries the ICD diagnosis codes in their health administrative records to identify children with a complex chronic condition (CCC).

Step 2: Understanding that there is variation in functional limitations, healthcare needs, and health resource utilization across the population of children with a CCC, the initiative decides to analyze Medicaid claims data to limit the initiative to children who use one or medications, who use one or more devices of medical equipment, and who had one or more emergency department visits in the last year.

Step 3: For the children identified in steps 1 and 2, the initiative then works with the Child and Adolescent Health Measurement Initiative to adapt and use, by-phone, their NS-CSHCN questionnaire to identify and target the children with unmet care coordination needs to receive access to a case manager.

By assessing attributes of medical complexity beyond the diagnosis of a CCC, the Medicaid initiative refined their intervention to the 10% of children with a CCC that they felt would benefit the most from a case manager.