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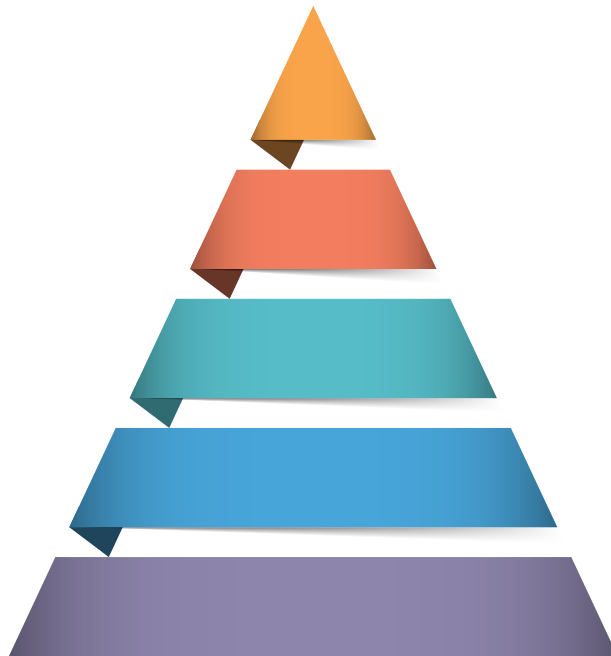*for* **Children's Health**

Report

Aligning Services with Needs

Characterizing the Pyramid of Complexity Tiering for Children with Chronic and Complex Conditions

Prepared By

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Introduction

As health care and financing systems become more sophisticated, anticipating and identifying which children are likely to be high utilizers of services is becoming more important. Anticipating the service needs of these children will allow the judicious provision of care coordination and other services where they will be most effective.

Children and youth with special health care needs (CYSHCN), comprising about 19 percent of US children, require more resources than most other children. The 0.5 to 1 percent with the most complex conditions account for as much as one-third of child health care costs. This becomes more significant as payers and health systems introduce alternative and risk-based payment models that require accurate assessment of resource needs for individuals and populations. Payers must anticipate needs across the population of patients they cover for budgeting, rate setting, and contracting. Health systems must identify which children might need enhanced care coordination services, to plan for hiring care coordinators and negotiating with payers.

"Risk tiering" — perhaps better called resource needs assessment — is a process that health care systems and payers in the United States increasingly use to group patients with similar degrees of health care resource needs. Families and care providers of children with special health care needs should understand the details of the process, as risk tiering may affect access to services these children need.

Families and care providers of children with special health care needs should understand the risk tiering process, as it may affect access to services these children need.

We define tiering as the use of risk stratification methods to group children according to the intensity of their health care service utilization and care coordination needs. Risk assessment typically begins by using data on classification of conditions and health care utilization patterns. This work has included modeling by academicians and children's hospitals;[1] diagnosis-based screener development by scientists associated with the Research Consortium on Chronic Conditions in Children; and the Agency for Health Care Research and Quality's childhood chronic condition grouper (among others). Research and literature on risk assessment is fairly well established, though consensus on a preferred methodology has not been achieved, and the choice of methods may reflect the intended use of the risk assessment.

Next, children are stratified into three to four "tiers," with healthy children in the lowest tier, children with catastrophic conditions (usually <1% of the population) in the highest, and others in between. Depending on the methodology, the third tier is sometimes designated to encompass the nearly 5 percent of children who have complex, but not catastrophic, health conditions.

Finally, these tiers can be used to establish policies around payment, so that capitated care for higher-risk children is reimbursed at a higher rate, or to determine eligibility for additional services such as enhanced care coordination. Decision-making based on tiering is beginning to be integrated into policies affecting adult health care, but child health care policy lags behind in this regard.

All current stratification methods have their base in clinical variations; none yet incorporate social determinants of health (SDH) and their impact on medical conditions or care needs. Current tiering depends on data that exist in administrative (mainly billing) databases and medical records. Prediction of needs based on these data requires assumptions that may not be accurate when applied to children. Patterns of chronic conditions in children and the service needs associated with these conditions differ from those in adults; in addition, children's needs change more rapidly.

As with adults, behavioral health issues and social factors (e.g., housing, family stability, and food security) interact extensively with medical needs to affect the resources needed to maintain or improve the health of CYSHCN. Current data sources may not include data on behavioral health or SDH, and health care systems are not well equipped to deal with the complexity those factors contribute to care. Similarly, but on the other side of the coin, current tiering methods do not typically incorporate data about family strengths and resources that might mitigate risk and inform resource allocation. Despite these limitations, resource allocation for CYSHCN requires planning, which begins by using available data and augmenting those data when possible.

Recognizing the need for information about and improvements in the current state of risk tiering for CYSHCN, we undertook a nine-month project to understand current practices in tiering and make recommendations for policy and research. The project extended from December 2016 to August 2017, at the inception of which we assembled a panel of experts to identify key questions on the topic and begin the discussion of current status and future directions.

Key Questions

1. What are the relationships among medical costs, SDH, and behavioral health in children?

2. How do these relationships vary from adults and how do they inform policy recommendations specific to children?

3. What measures exist or are needed to make tiering effective for payment and care models?

4. What are the roles of pediatricians, care teams and coordinators, parents/care givers, community resource providers, and payers in developing and executing service plans guided by tiering methods?

5. How are SDH and/or behavioral health needs currently being integrated (if at all) into patient/ family centered care coordination and community resource connection?

6. How well do current systems of care and care coordination services reflect the diversity of need amongst CYSHCN? How are these services measured and allocated?

7. How do integrating behavioral health and SDH data into care coordination models improve their "fit" and prediction of service need? What changes are needed?

8. What is the current state of policy and practice about reimbursement to providers for providing SDH and/or behavioral health oriented screenings, services, and coordination?

9. How can tiering models be financed across public coverage sources? What policy and payment trends might help or hinder efforts to get children and families what they need?

Methods

The project advisory panel of 19 experts (see Appendix, Table 1) included pediatricians, researchers, family advocates, payers, with an emphasis on Medicaid representatives, and policy experts from around the country. We held a full-day, web-based meeting with the panel to develop and refine important questions related to tiering (see Key Questions box on page 4) that literature searches and key informant interviews could answer, and identify key informants who could address these questions.

Next, we conducted 17 semi-structured interviews (see Appendix, Table 2) and undertook an extensive literature search to answer these questions, recognizing that some of the questions might not yet have satisfactory answers. Given the expertise of our advisory panel, some interviews were with panel members. Ten key informants were leading academic and care delivery systems experts; two were state Medicaid medical directors, and five were experts in patient- and family-centered care and/or behavioral health, including family members of CYSHCN. We transcribed and analyzed the interviews for themes that might address the key questions.

Interviews and literature searches focused on current practices in tiering and their uses for resource allocation; assessment of SDH and/or behavioral health needs and incorporation of these into tiering; roles of stakeholders in creating a tiering system that is meaningful for patients and families, service providers and payers; differences in tiering and its uses between children and adults; and use of tiering for payment and policy. Literature searched included published journal articles and other documents that were publicly available online, such as those from government agencies and foundations.

As a final step, we held a second web-based meeting with the advisory panel to discuss findings from the interviews and literature reviews, develop key messages summarizing the work, and make recommendations for future research, practice, and policy.

Findings

In general, the ability of the literature searches and key informant interviews to answer the key questions posed was limited, primarily because of the formative state of research and application of tiering for children. While literature specific to tiering and its use in children's health care was sparse, approximately 30 articles out of more than 200 screened did address one or more questions to some extent.

Interviews, which can better capture ongoing work and developing practice and policy innovations, yielded rich data, with more than 150 separate themes identified related to the key questions. Groupings of themes in the interviews included: tiering techniques, current practices, and needed improvements; measurement of clinical and behavioral characteristics, SDH, and outcomes of tiering; lessons learned to date about tiering for care coordination and related resource allocation; and use of tiering in payment models, especially Medicaid programs.

Analyses of these themes found great importance ascribed to: integration of SDH and behavioral health data into tiering systems; measurement related to tiering and resource allocation; use of population vs. individual level tiering; and family perspectives. There was relatively little information on the current uses of tiering by payers.

Current Tiering Practices and Use

Risk assessment and stratification mainly use algorithms derived from diagnostic information in administrative data. Examples include the Johns Hopkins Adjusted Clinical Group (ACG) or 3M Clinical Risk Group (CRG) systems, or the newly created Pediatric Medical Complexity Algorithm (PMCA).[2] Some integrated health systems use such assessments to group patients into tiers, allocating care coordination and related resources based on the utilization patterns of those groups.

Pediatric tiers assume a pyramid shape, with the broadest tier comprising the roughly 70 percent of the pediatric population that is healthy. Healthy children are usually eligible for basic coordination assistance, such as access to health care supports through an electronic patient portal. Children in the next tier typically have single chronic, but relatively stable, conditions.

Children with high needs in a tier nearer the top of the pyramid comprise around 5 to 6 percent of the population. They are harder to characterize, as their medical problems result from a very heterogeneous array of conditions that are often unstable and often co-occur with behavioral health problems. Their needs are also particularly susceptible to personal and social factors. Children in this tier need individualized care coordination plans, and their needs cross physical, behavioral and social sectors.

Children in the highest tier (around 1%) may be eligible for packages containing more intensive care coordination services, such as frequent face-to-face contact with multiple team members such as a nurse or social worker. Clinical experts emphasized that needs assessments based solely on

diagnostic data should serve only as a starting point for resource allocation, and require adjustments, with resources tailored in response to clinician and family input. Individual strengths and needs may change the requirement for services within a tier or may serve to reassign children to a higher or lower tier; they often also change over time.

Stakeholder groups and systems will see different purposes for tiering, and these purposes must be made explicit if the needs of individual children are to be met. While organizations providing direct care may have more interest in identifying family needs for care coordination, payers may have more interest in predicting and controlling future costs based on patterns of past utilization. These two approaches will use and prioritize different data (for example, home health care needs and food insecurity for providers, and inpatient admission patterns for payers) and implement tiering differently. Moreover, a major purpose of care coordination is to prevent children's needs from increasing. Assessment of risk factors must include both those risks associated with worsening health and higher utilization and those that care coordination might improve.

> **Stakeholder groups and systems will see different purposes for tiering, and these must be made explicit if the needs of individual children are to be met.**

A leader of an integrated clinical system caring for poor adults and children in Colorado summarized a goal well: "The best tiering system combines financially meaningful and clinically actionable characteristics." Tiering itself works mainly to stratify cost as a first step; the intent of tying it to care coordination and related services is that placing people in higher tiers with increased services will both meet more needs for children and families and save money over time. How well tiering systems match and link individual patients to resources, and how well they assess and predict population needs, as opposed to individual needs, has had little evaluation so far; experts and the advisory panel emphasized the need to improve tiering systems iteratively, using data and feedback about their performance.

CYSHCN: A Unique Population

Two important distinctions were identified that must be kept in mind when applying tiering to CYSHCN: differences between tiering for individual resource needs vs. population management, and tiering for children as opposed to adults. One large pediatric accountable care organization (ACO) in Ohio[3] has learned that tiering applied at the population level, i.e., examining clustering of needs within neighborhoods or communities, is more reliable over time than tiering at the individual level. Population tiering can better inform resource allocation to clinics or health centers located in higher risk communities, as well as smooth the naturally large variation in resource needs for individual children over time. Of course, population-level tiering requires reliable population-level data.

Key informants involved in Medicaid and health system tiering efforts in several states have learned that tiering methods that work well for adults do not work well for children. Adults tend to have a small number of prevalent chronic conditions, e.g., diabetes or vascular disease, that predict many of their resource needs, while children have a large number of relatively less common conditions, such as epilepsy or chronic lung disease, with variable impact on resource needs.[4] Thus, while tiering

systems for adults can succeed if they consider only a handful of diagnoses, more sophisticated condition grouping algorithms that involve analyses of diagnosis patterns are needed to establish a starting point for tiering systems in children.

Measuring the success of applying tiering systems to resource allocation for each child requires good process and outcome measures. Few measures exist that assess the coordination of care across medical, behavioral, and social sectors. Many currently available measures of care coordination focus on small parts of the process, such as transmission of information within the health care system, inpatient to outpatient care transitions, and follow-up medical visits, highlighting the lack of cross-cutting, interdisciplinary, multi-sector measures that are highly relevant to CYSHCN. Those few that do cut across processes and conditions are mainly survey-based,[5] so not typically available in administrative and claims databases. Measures are needed that address care coordination across disciplines, sectors, and conditions. These measures must be easily obtainable and accurately reflect family experience of care coordination and care integration to maximize relevance and usability.

Moving Beyond Diagnoses: Incorporating Social Determinants of Health (SDH)

SDH, such as poverty status, family functioning, food insecurity, and housing stability, all have a major impact on the health of children. Children with many negative SDH often have health care and coordination needs beyond what children in more favorable environments require.[6] Negative SDH are a major reason why children in ongoing tiering and resource allocation efforts are placed into a higher tier than their diagnoses alone would indicate.

Administrative databases lack most of this social and environmental information; however, a few state Medicaid efforts have incorporated some basic SDH data such as housing status and parent incarceration into tiering methods. The few tiering systems using SDH in an exploratory fashion have found that moving children with negative SDH into a higher tier than their diagnoses would otherwise indicate results in better matching of children with appropriate care coordination resources.

Barriers to including SDH in tiering systems include limited available data, limited experience in incorporating SDH information into tiering algorithms, limited clinical resources to respond to identified SDH, and discomfort about incorporating sensitive SDH data into electronic health records or administrative databases. However, there are strong recommendations[7] to include this information, and to increase collection and use of SDH data in health care settings to inform primary care interventions such as integrated social work, care coordination, and behavioral health services.

Conceptual models for extending this type of data collection to care at the organization and population levels exist,[3] raising the possibility that such data could become more widely available. Concerns about sharing sensitive SDH data have led to creating a non-specific "SDH flag" in children's data records in one Medicaid system, to enable children to have access to resources without revealing specific information. Balancing this need for privacy against the ability to more accurately plan for resources and payment will be an ongoing challenge as tiering efforts move from individual to population levels.

The Importance of Behavioral Health

Behavioral health diagnoses account for the highest amount of spending on health care for children in the United States.[8] Perhaps in response, tiering within behavioral health systems for children with the highest level of need is relatively well established, and often linked to defined packages of services for high-need children in a "fidelity wraparound" model.[9]

Developing an integrated approach to tiering and care coordination for physical and behavioral health needs is a logical next step.

Care coordination efforts focus on providing needed services while preventing use of higher levels of care (such as inpatient hospitalization), because of the acknowledged negative impact that hospitalization can have for children. Fidelity wraparound incorporates: a dedicated care coordinator working with a small number of children and families; dedicated family and youth peer support; a strength-based plan of care; and frequent monitoring of progress. Because of its specific activities, this model is more advanced than typical care coordination efforts for physical health, and may be able to inform those efforts. Unfortunately, children in lower tiers have much less well defined approaches to care coordination.

Given the synergy between physical and behavioral health needs, and movement toward integrating physical and behavioral health care as a best practice, developing an integrated approach to tiering and care coordination for physical and behavioral health needs is a logical next step. However, several barriers to integrating tiering systems for behavioral and physical health exist. One critical issue is that data sources and systems for behavioral and physical health are almost always separate. Consequently, administrative data in many state Medicaid systems often contain no behavioral health data, largely because of ubiquitous clinical and payment "carve outs" for behavioral services. Lack of data limits the feasibility and utility of tiering systems in determining resource needs.

Additionally, while panel members agreed that the ideal tiering system would integrate behavioral health and SDH data, key informants cautioned against a "one size fits all" approach that combines care coordination for medical and behavioral needs, as the specific skills, activities, and community resources needed to meet needs in the two domains are different. Collaborative care that integrates services while providing expertise in multiple areas might make sense for children with dual needs, to address their physical and behavioral health conditions.

Tiering from the Perspective of Payers

Payers largely use tiering as a tool to predict utilization and costs. The utility of tiering models depends heavily on the payment models used. In a traditional fee-for-service payment model, where care coordination is typically not reimbursed, tiering within groups of patients has limited use. It is used primarily to assess and predict claims in order to enable risk adjustment, rate setting, and contracting. Alternatively, tiering models that might incorporate data about SDH and behavioral health would be more useful in an ACO model, where states, health plans and/or health care organizations assume risk for total cost of care for a population without carving out services.

A few states have begun to incentivize measurement of SDH and behavioral health screening as part of hybrid fee-for-service and population-based payment models; this will enhance the ability to assess risk and needs over time, but only if population-based payments adequately pay for the costs of screening and address the needs that screening uncovers.

Many payment systems pay little attention to children as a population, because spending for them averages much less than for adults. For the small group of children with complex needs, however, costs can be very high and will have continuing impact over time. For this group, costs can be very volatile from year to year,[10] yet they merit close and careful attention in service provision to limit unnecessary hospitalization and improve functioning.

Tiering from the Perspective of Families

Families have had relatively little input into tiering. While tiering has the potential to direct needed care coordination resources to children and families, family leaders mentioned that rigid implementation could have negative effects of requiring children to appear "eligible" in order to obtain services, or even to delay or deny services to children who need them, if data used for tiering are incorrect.

Panelists and key informants emphasized the importance of incorporating family input into the design of tiering programs, communicating their purpose, and evaluating their impact. Additionally, family experts recommended that assessment of family, community, and cultural strengths, which is often missing in care coordination programs, can identify previously unknown resources for children in their communities and limit duplication of services. Family to Family Health Information Centers, operational in all 50 states with funding from the Maternal and Child Health Bureau, were mentioned as important resources.

Several state Medicaid programs are actively working to identify community resources to help address service needs, especially those generated by negative SDH. As they move toward accountable care models of payment and service delivery, integration of family input in this process could be invaluable. As screening for family SDH increases and these data are incorporated into tiering systems, tiering for family needs in addition to individual needs of the child was suggested as a promising practice.

Recommendations

- Data to enable accurate tiering and subsequent resource allocation should accurately reflect children's health care needs and utilization. Information should be shared and usable across health care entities, as well as across service sectors like schools and community agencies. Information on physical and behavioral health diagnoses and utilization should be combined in risk stratification. Algorithms to adjust tiers using available information on SDH should be developed.

- Models of tiering and care coordination that integrate physical and behavioral health needs of CYSHCN should be developed, and information about SDH applied as data become available. Care models must recognize that community resources for SDH and behavioral health needs will often differ from those for physical health needs. Care coordination should follow best practices for children with the most intensive service needs, but also be responsive to the needs of children with less intensive needs, with the flexibility to individualize care as children's needs fluctuate. Full integration of physical, behavioral, and social resources across service sectors can enable the data collection, tiering, and collective thought needed to provide effective, efficient services.

- Measures that reflect the accuracy, usability, and outcomes of tiering for children, such as how well children in a given tier are matched with appropriate care coordination resources, need to be developed. The goal should be the most parsimonious set of measures that can be used to advance the value of tiering and resource linkages.

- The rationale for use of tiering systems by organizations must be made transparent to stakeholders, including families, acknowledging that tiering may be done for multiple purposes and yield different results.

- Development and refinement of tiering and resource linkage methods should include family input, to promote usability and acceptability, as well as to avoid unintended consequences of tiering such as inappropriate restriction of access to resources.

- Data structures, analytic assumptions, and methods of tiering need to reflect the unique patterns of children's health and should also assess family and community strengths.

- Tiering systems designed to inform resource allocation need to incorporate periodic reassessment of children's needs to evaluate the fit between children, their assigned tier, and service packages, especially for children in "middle tiers" where needs may be more variable and change may be more frequent. Prevention of problems that lead to increasing tiers should be a goal. Moreover, the systems themselves need to be refined iteratively to enable learning about how they can best fit population needs and facilitate the best outcomes.

- Future research in this area should answer questions about how to predict children's care coordination needs from year to year, especially at critical transition points such as school entry and transition to adulthood.

Table 1: Advisory Panel Members.
*denotes those who were also interviewed as key informants.

Name	Institution/Organization
Christopher Stille, MD, MPH	University of Colorado School of Medicine Children's Hospital Colorado
James Perrin, MD	Harvard Medical School Massachusetts General Hospital
Richard Antonelli, MD, MS	Harvard Medical School Boston Children's Hospital Integrated Care at Boston Children's Hospital
Cindy Mann, J.D.	Manatt Group
Nora Wells, MSEd	Family Voices National Office
Eileen Forlenza	Colorado Department of Public Health and Environment Family Leadership Training Institute
Karen Spencer, MD, MS, MPH	Harvard Medical School Boston Children's Hospital
Margaret Tomcho, MD	Denver Health
Jill Morrow-Gorton, MD, MBA	Office of Clinical Affairs University of Massachusetts Medical School
Tyler Watlington, MD	Colorado Access Region 3 of the Accountable Care Collaborative
Mary Vostrejs, MD	Denver Health
Kate Conrad	Children's Hospital Association
Suzanne Fields	SAMHSA Administration on Health Care Financing
Beth Dworetzky	Center for Advancing Health Policy and Practice, School of Public Health, Boston University
Debjani Mukherjee	National Quality Forum
Judy Zerzan, MD *	Colorado Department of Health Care Policy and Finance
Jeff Schiff, MD, MBA *	Minnesota Health Care Programs, Minnesota Department of Human Services
Tom Rose *	Family Voices Colorado
Merrill Friedman *	Disability Policy Engagement for Anthem, Inc.

Table 2: Interviewed Key Informants

Medicaid Directors	
Judy Zerzan, MD	Colorado Department of Health Care Policy and Finance
Jeff Schiff, MD, MBA	Minnesota Health Care Programs, Minnesota Department of Human Services
Family and Behavioral Health	
Tom Rose	Family Voices Colorado
Merrill Friedman	Disability Policy Engagement for Anthem, Inc.
Patricia Nobbie, PhD	Anthem, Inc.
Lisa Lambert	Parent Professional Advocacy League, MA
Gary Blau, PhD	SAMHSA Center for Mental Health Services, Division of Service and Systems Improvement, Child, Adolescents and Family Branch
Academic and Care Delivery	
Dan Slater, MD	Atrius Health, MA
Simon Hambidge, MD, PhD	Denver Health and Denver Community Health Services General Pediatrics Denver Health
David Bergman, MD	Stanford University; Lucile Packard Children's Hospital
Kimberly Conkol, RN, BSN	Nationwide Children's, OH
Andrew Hertz, MD	Case Western Reserve School of Medicine Rainbow Care Coordination, University Hospital
Colleen Reuland, MS	Oregon Pediatric Improvement Partnership (OPIP) Pediatrics Department at Oregon Health & Science University (OHSU)
Rita Mangione-Smith, MD, MPH	Director Quality of Care Research Fellowship Center for Child Health, Behavior and Development Seattle Children's Hospital
Richard Grossberg, MD	Rainbow Care Coalition (OH)
Peter Szilagyi, MD, MPH	MACPAC Department of Pediatrics at the Mattel Children's Hospital, UCLA
Kelly Kelleher, MD	Nationwide Children's, Center for Innovation in Pediatric Practice

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