CATALYST CENTER
IMPROVING FINANCING OF CARE for Children & Youth WITH SPECIAL HEALTH CARE NEEDS

Risk Adjustment and Other Financial Protections for Children and Youth with Special Health Care Needs in Our Evolving Health Care System

By Carol Tobias, Meg Comeau, Sara Bachman, and Lynda Honberg

Introduction

This report has its origins in a one-day meeting held with an expert panel in September 2011 on risk adjustment for children and youth with special health care needs (CYSHCN). This meeting was sponsored by the Division of Services for Children with Special Health Needs, Maternal and Child Health Bureau, Health Resources and Services Administration, U.S. Department of Health and Human Services and facilitated by the Catalyst Center at the Boston University School of Public Health, with logistical support provided by John Snow, Incorporated. The purpose of the meeting was to:

- Review the historical work on risk adjustment for CYSHCN and discuss its relevance and application to health care reform;
- Better understand the challenges associated with the use of risk adjustment strategies for CYSHCN;
- Identify other strategies that can mitigate risks associated with health plan payments for CYSHCN;
- Identify gaps in the research and strategies to encourage implementation of risk-adjustment methodologies for CYSHCN.

Additional resources are provided in the Appendix to this brief. A list of participants is included on page 11.

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What is risk adjustment?

An insurance plan that attracts healthier people takes in more money in premiums than it pays out in claims, which helps keep the plan solvent. Risk adjustment is a corrective tool to "level the playing field" and protect insurers that attract a high-risk population, such as those with chronic conditions. For plans that enroll people who are more likely to have higher health care costs, risk adjustment ensures that there is additional revenue to pay for the services they require, beyond what the plan has collected in premiums. It helps remove the incentive for plans to discourage enrollment of individuals with chronic illnesses or disabilities, which in turn increases their access to health care coverage.

Why discuss this topic?

Risk adjustment is important for children and youth with special health care needs (CYSHCN) and their families when the purchasers of health insurance – employers, government agencies, or health exchanges – pay a set amount to health plans for each person enrolled in the plan. Why? *Because CYSHCN by definition use more health care services than other children and inevitably incur higher costs*. If payments to health plans are the same for all children, then families have little protection against health plan policies that might discriminate against CYSHCN and their families, such as strict medical necessity definitions or limited access to specialty care. Risk adjustment is an important tool for correcting health plan payments when a plan's medical expenses are higher or lower than average, as a result of serving individuals whose costs are substantially higher or lower than average.

To minimize the negative effects of adverse selection and foster a stable marketplace from year one, the Affordable Care Act (ACA) established transitional reinsurance and temporary risk corridor programs and a permanent risk-adjustment program to provide payments to health insurance issuers that cover higher-risk populations and to more evenly spread the financial risk born by issuers. State Medicaid programs are moving more individuals, particularly high-cost individuals, into managed-care plans, and states are implementing Health Exchanges that will use risk adjustment to set health-plan payment rates under the ACA. As a result, risk-adjustment strategies are being reviewed, discussed, and implemented across the country. This paper reviews issues to consider with regard to risk-adjustment strategies that address the needs of CYSHCN.

Why worry about risk adjustment and CYSHCN specifically?

To date, except for some work funded by the Division from 2000-2003 and a few researchers, little risk-adjustment work has been conducted with a focus on CYSHCN. A common rationale for this lack of focus is that the population of CYSHCN is small in number as compared to that of adults with disabilities and chronic illnesses, who are both significantly larger in number and much more costly overall. However, risk adjustment for CYSHCN is important for several reasons:

- Accurate risk adjustment reduces the incentive for health plans to avoid the enrollment of higher-cost children (favorable selection) because the plans will receive higher payment for these children.
- Plans have less incentive to have restrictive policies, such as medical necessity definitions, that limit care provided to children with high medical expenses or marketing practices that encourage families to change health plans.
- Another important reason for implementing risk adjustment for CYSHCN is to ensure that health plans include pediatric specialists and tertiary care hospitals in their networks, rather than excluding them in order to limit enrollment of children with complex care requirements.
- Furthermore, the health-insurance landscape is changing with implementation of the ACA, removing health-insurance practices, such as pre-existing condition exclusions, rescission, annual and lifetime benefit caps, and lack of guaranteed issue or renewal, that kept many high-cost children out of the health insurance market. As these practices are reduced or eliminated, high-cost CYSHCN will enroll in health plans or remain in plans when they were previously excluded from coverage. Thus, it is more important than ever that we find ways to promote adequate payment.
- Finally, on a more positive note, risk adjustment can facilitate the identification of CYSHCN earlier or more effectively, creating opportunities to target care coordination to this group of children, identify appropriate medical providers, and improve the quality of care provided.

What is the current state of the art for risk adjustment?

Historically, purchasers have used selected demographic characteristics to adjust risk for health payments, most commonly age, gender, and geographic location. In the past 25 years, researchers and actuaries have developed increasingly sophisticated risk-adjustment methodologies that incorporate clinical diagnoses or clusters of diagnoses, as well as demographics. More recently, data from pharmaceutical claims have also been incorporated into risk-adjustment strategies.

Risk-adjustment models have been refined over time with better modeling techniques and predictive power. There are also more models available in the market. See the table below for a list of current risk-adjustment systems.

Risk adjustment is particularly useful for addressing health care costs that are predictable from one year to the next, as is the case with certain chronic illnesses, and less useful for addressing costs that are unpredictable or catastrophic. Medicare currently uses a risk-adjustment system based on diagnostic categories with rules for counting (and discounting) multiple diagnoses to adjust risk in its Medicare Advantage plans. Twenty-two states now risk adjust their Medicaid payments to health plans using methods based on diagnoses (Gifford, 2011). Most use Chronic Illness and Disability Payment Systems, but a few use Adjusted Clinical Groups, Diagnostic Cost Groups, or Clinical Risk Groups. Some of the issues considered when payers choose a risk adjustment system include:

- The accuracy of the model and its specificity for the population being covered;
- Transparency of the model – how easy is it to explain and understand what is happening;
- Ease of use – both the software and the datasets upon which it is applied;
- The quality and quantity of the underlying data;
- How the model will be used – for payments and to whom, for clinical purposes, and/or for the identification of certain populations;
- The ability to up-code or otherwise game the model.

Risk-Adjustment Acronyms	Data Sources
Adjusted Clinical Groups (ACG)	Diagnoses
Adjusted Clinical Groups (ACG) with Prior Cost	Diagnoses + prior Rx costs
Chronic Illness and Disability Payment System (CDPS)	Diagnoses
Clinical Risk Groups	Diagnoses
Diagnostic Cost Groups (DCG)	Diagnoses
DCG Hierarchical Condition Categories (HCC)	Diagnoses
Ingenix PRG	Rx
MedicaidRx	Rx
Impact Pro	Diagnoses, Procedures, Rx + Utilization
Episode Risk Groups (ERG)	Diagnoses, Procedures, Rx

From: Healthcare Economist.com - blog post on risk adjustment models at http://healthcare-economist.com/2010/09/09/risk-adjustment-models/

How are costs distributed across CYSHCN?

Health care costs are skewed in all populations, and children are no exception (Knutson, 2007). The majority of children never get seriously ill or have relatively minor conditions and, therefore, do not use a lot of health care. Thus, their costs, on average, are predictably low. However, there is a wide variation in health care costs among children. Data from the Medical Expenditure Panel Survey (MEPS) show that the cost of health care services for children without special health care needs averages $717/year; while health care costs for CYSHCN average $2,399/year (Bethell, 2011). Thus, we can imagine how a health plan that enrolls a disproportionate number of CYSHCN might suffer financially if they were paid an average unadjusted rate based on the costs of the many children using $717/year and the costs of a few children using $2,399.

This variation in costs is just as pronounced *among* CYSHCN. As with adults, costs for children with selected diagnoses are significantly higher than average. Research has shown that Medicaid-enrolled children with cystic fibrosis, muscular dystrophy, and spina bifida incur costs that are 20, 17, and 11 times greater, respectively, than the average costs for all children (Ireys, 1997). At the same time, there is as much variation *within* certain diagnostic groups (such as asthma) as between diagnostic groups (e.g., between asthma and spina bifida), limiting the value of diagnosis-based risk adjustment for most CYSCHN (Bethell, 2011).

There are other factors beyond diagnoses involved in understanding the variation in service needs and costs among CYSHCN. For example, researchers who developed the Children with Special Health Care Needs Screener (CAHMI, 2007) have looked at the relationship between screening results and costs. Fourteen percent of CYSHCN meet four of the five criteria for being a CYSHCN. These five criteria include:

- Being limited or prevented in ability to function;
- Prescription medication need/use;
- Need for therapies (OT, PT, Speech);
- More than routine use of medical care, mental health, or other health services;
- Need for counseling or treatment for an ongoing emotional, behavioral, or developmental problem *for at least 12 months*.

This 14% of CYSHCN have much higher costs than the average CYSHCN: $7,881/year as compared with $2,399/year (Bramlett, 2009). Another way of thinking about risk adjustment is to look at variation in the trajectory of costs over time. For example, John Neff and colleagues have identified four different trajectories that are applicable for CYSHCN:

1. Episodic chronic conditions (such as asthma) that last at least one year and are highly variable, but that can improve with treatment;
2. Lifelong chronic conditions that are typically stable, such as type 1 diabetes;
3. Complex chronic conditions in two or more body systems or conditions that have shortened life expectancy, such as cystic fibrosis, muscular dystrophy, and cerebral palsy with encephalopathy;
4. Malignancies, the highest cost category, but with more predictable costs due to protocols.

Using data from Washington state and New York from 2000-2007, they found that while all children averaged $1,000/year, and the 80% of children with no chronic conditions averaged only $600/year, the children with the types of conditions listed above average $2,000/year (episodic chronic), $10,000/year (lifelong chronic), $27,000/year (complex chronic) and $75,000/year (malignancies) respectively (Neff, 2011). Thus, it is easy to see how a health plan that includes the pediatric cancer center and the one or two physicians in the community who see children with cystic fibrosis could be financially at risk for becoming insolvent if they only received an unadjusted capitation rate of $1,000/year for all of these children.

Finally, to complicate matters further, the small numbers of CYSHCN and even smaller numbers of CYSHCN with complex conditions in any given community or insurance group make the job of predicting costs with any accuracy even more challenging. Despite all these challenges, it is critically important to address this variation in costs, otherwise we run the risk that health plans (and providers) will try to avoid serving the children who, by definition, need and use health care services the most.

Other financial protections for CYSHCN in capitated or global payment systems

Even under the best of circumstances, with more attention paid to risk-adjustment methodologies that are based on pediatric conditions, risk adjustment is unlikely to fully protect health plans and providers that are strongly devoted to serving CYSHCN well. For example, a health plan founded by a children's hospital in Texas that serves 50% of the Medicaid and CHIP-enrolled children in its service area has costs that are 27% higher than the average child cost. When adjusted for risk, its costs are still 7% higher than one would expect and 4 times as high as the plan with the lowest expenditures in the same service area. As they researched this issue further, it became apparent that the lowest cost plan enrolled a significant number of children who were non-users – children who did not even have a physical exam in the study year. Meanwhile, the plan associated with the children's hospital had more children who received the most expensive treatments (because their doctors ordered them).

What's the difference between a health insurance plan and a payer?

In the context of risk sharing, a *plan* refers to the health benefits package or product offered by an insurer. The *payer* can be a self-insured employer, a public benefit program or a private insurer. For example, say a state Medicaid program has a contract with a private managed-care company to serve its beneficiaries. The *plan* is administered by the managed-care company, but the state Medicaid program is the *payer*. Both plans and payers have a financial stake in covering individuals with high health care costs, so that is why sharing the risk between them can make sense.

Several strategies might mitigate this effect. First, payers can offer *performance incentives* (pay-for-performance) to plans that meet a threshold for primary care visit penetration rates, annual physical exams, or Early Periodic Screening, Diagnosis, and Treatment (EPSDT) visits. Second, payers can remove the extremes (highest cost and no cost) from the data used to calculate rates. For example, several states remove the rare, but highest cost individuals or procedures from the capitation rate and pay for these services as they occur (*carve-outs*). Examples include organ transplants, neonatal intensive care unit costs, and hemophilia medications.

Another form of financial protection is *risk sharing*. Under risk sharing, the plan and the payer share risk according to a formula – for example, the plan might be at risk for 5% of any losses, and the payer would then assume risk for the next 5% or 10% of losses. Similarly, the plan would only be able to keep 5% of the profits; profits beyond that would accrue to the payer. Under risk sharing, the management of high-cost services stays with the plan, but the full risk of the costs does not. Health plans can also purchase *reinsurance policies or stop-loss coverage*, either on the private market or from the payer. Stop-loss coverage can cover expenses beyond a specific dollar amount, such as $75,000 or $100,000 for any given individual who incurs extraordinarily high costs, or can cover aggregate expenses that a health plan incurs beyond a specified dollar amount.

Another strategy for providing financial protection includes Medicaid buy-in programs. Most insurance plans in the private market (and presumably in the Health Insurance Exchanges established in each state) do not offer the same level of coverage provided under Medicaid. However, some CYSHCN are likely to be enrolled in plans through the Exchanges and need this additional level of coverage. Medicaid buy-in programs offer families the opportunity to purchase Medicaid coverage as a wrap-around to their private insurance.

Conclusion

As noted above, much of the research on risk adjustment has focused on the larger, more costly, adult population. The expert work group identified a need for additional research to develop more accurate risk-adjustment systems that address the cost variation among children and can be used to optimize their health outcomes. But given the urgency to implement systems in the short term, existing risk-adjustment systems can be paired with other strategies to mitigate some of the inaccuracies inherent in even the best of risk adjustment systems. The strategies described above are well worth considering as states and Exchanges plan their next steps. It is important to recognize the role that Medicaid programs have played as the trailblazers in implementing managed-care risk adjustment. This role is likely to continue into the future, and those concerned with quality and costs should be actively engaged in these discussions to ensure that the methods selected do not cut off access to high-end services, or underfund low-end services, such as basic primary care.

It is important to emphasize that effective risk adjustment is not just in the best interests of plans. It also has a positive impact on families. If plans are not incentivized to discourage enrollment of CYSHCN, children will have greater access to quality coverage and there will be less incentive for plans to pass costs back onto their families. Title V policymakers can play an important role in ensuring that the needs of CYSHCN are part of the conversation as their counterparts in state Medicaid programs or the Exchanges consider risk-adjustment methodologies.

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Neff, J. (2011). *Health care needs of CYSHCN and why financial protection is important* [PowerPoint slides in PDF format]. Retrieved from http://hdwg.org/sites/default/files/PediatricHealthcareSlides.pdf

Resources from the meeting

A compilation document containing the three presentations listed below is available at http://hdwg.org/catalyst/risk

- Presentation by Carol Tobias: Welcome: http://hdwg.org/sites/default/files/ExpertWorkgroupMeetingWelcome.pdf
- Presentation by John Neff: Health care needs of CYSHCN and why financial protection is important: http://hdwg.org/sites/default/files/PediatricHealthcareSlides.pdf
- Presentation by Christina Bethel: Aligning financing and quality for CYSHCN: http://hdwg.org/sites/default/files/RiskAdjustmentPowerpoint.pdf

Poster Presentation: Taking stock of the CSHCN screener: Key design features & application issues: http://hdwg.org/sites/default/files/CSHCNScreenerPoster.pdf

Additional resources

Hall, M. A. (2012). Regulating stop-loss coverage may be needed to deter self-insuring small employers from undermining market reforms. Health Affairs 31 (2). Retrieved 3/26/12 from http://content.healthaffairs.org/content/31/2/316

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About the Catalyst Center

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