EXTRACT OF
Monitoring and Assessing Health Care Services Provided to
Children with Special Health Care Needs (CSHCN) in the
STAR Managed Care Organization (MCO) Program and the
Children’s Health Insurance Program (CHIP)

By Elizabeth Shenkman, PhD (ES)

WITH ANNOTATIONS OF HARRIS SDA RAC, ES, AND TPS CCWD (1- 5/05, 2- 9/05)

Background

The purpose of this document is to propose a plan to monitor and assess the quality of care provided to children with special health care needs (CSHCN) in the STAR Managed Care Organization (MCO) Program and in the Children’s Health Insurance Program (CHIP). The following Maternal Child Health Bureau (MCHB) definition of CSHCN\(^1\) is used in this proposal:

“...those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.”

The MCHB has developed six core outcomes\(^2\) related to the care of CSHCN that all State Title V Programs are expected to monitor. These outcomes are:

1) Families of CSHCN will partner in decision making and will be satisfied with the services they receive.
2) CSHCN will receive coordinated, ongoing, comprehensive care within a medical home.
3) Families of CSHCN will have adequate private and/or public insurance to pay for the services that they need.
4) Children will be screened early and continuously for special health care needs.
5) Community-based service systems will be organized so that families can use them easily.
6) Youths with special health care needs will receive the services necessary to make transitions to adult life, including adult health care, work, and independence.

The Maternal and Child Health Bureau (MCHB) developed a monitoring strategy for these core outcomes that primarily relies on data from the National Survey of Children with Special Health Care Needs (National Survey of CSHCN). This survey was designed to provide state and national estimates about the core outcomes.

The preceding core outcomes can be measured with telephone survey data routinely collected as part of the STAR MCO and CHIP ongoing quality assessments. In addition, the Institute for


Child Health Policy (ICHP) assesses the quality of care provided in the STAR MCO Program and in CHIP using administrative data provided by the health plans participating in the programs and by the enrollment broker (i.e., health care claims and encounter data and enrollment files). This document provides a strategy for measuring the MCHB core outcomes and other important quality of care measures for CSHCN.

Methods

In this section, the methods for identifying CSHCN will be described followed by a description of the quality of care measures that will be assessed and the data sources used to calculate those measures. The relationship of the quality of care measures to the MCHB core outcomes will also be delineated. This section also contains a brief discussion of other data elements that are collected and can be reported descriptively but are not recommended as part of the monitoring program. These items are discussed because they are frequently requested by consumers and advocates but there is not a sound basis for their use in an ongoing monitoring program.

1) Identifying CSHCN

We will use the Clinical Risk Groups (CRGs) to identify CSHCN. The CRGs is a software that classifies individuals into mutually exclusive clinical categories. The CRG software reads diagnosis codes from all health care claims, ignoring those associated with providers known to frequently report unreliable codes (e.g., non-clinicians and ancillary testing providers). It assigns all diagnosis codes to a diagnostic category (acute or chronic) and body system, and assigns all procedure codes to a procedure category.

Each individual is placed into one of the following categories: (1) healthy, (2) significant acute conditions such as head injuries, prematurity, and meningitis, (3) minor chronic conditions such as mild depression, attention deficit disorder, (4) moderate chronic conditions such as asthma, epilepsy, and major depression, (5) chronic pairs or triplets, which are conditions affecting two or more body systems, (6) metastatic malignant conditions, and (7) catastrophic conditions including cystic fibrosis, spina bifida, and respirator-dependent pulmonary disease.

These categories can be further collapsed into the following groups: (1) healthy, (2) significant acute conditions, (3) minor special health care needs, (4) moderate special health care needs, and (5) major special health care needs (includes chronic pairs and triplets, malignancies, and catastrophic conditions). The collapsed groupings were created based on recommendations from the developers. All quality of care findings will be presented for children in each of these five health status categories.

The CRGs address all components of the MCHB definition of CSHCN including identifying (1) the presence of a physical, mental, emotional, behavioral or developmental disorder; (2) expected to last at least 12 months or longer; and (3) requires ongoing treatment and/or monitoring. It also identifies children at risk for developing chronic conditions using the “significant acute” category.

RAC: include children in STAR+PLUS, CSHCN Program, and ICM.
CCWD1: assess quality of care for all CSHCN in state programs, including Medicaid, CHIP, ECI, Title V, DFPS, mental health programs, etc.

**ES: STAR+PLUS can be included**

RAC: expand beyond Clinical Risk Groups to use the available CSHCN screener (already in Medicaid)

**ES: can use for children with limited claims if receive screener information**

CCWD1 >> no, use screener for all.

CCWD2: worry about CRGs as under-representing kids with poor access to subspecialty care, without claims coded. Also, ES expressed concern of physicians NOT coding chronic illness when child seen for routine care; stated that CRGs are based on ANNUAL claim data. Consider statistical correction for CRGs, eg by

1. MCO report to identify CSHCN; noted variance between MCOs in their case management processes. This process would leave out kids on PCCM.
2. Provider reports, as done by Title V. Concern expressed by JH of cost.
3. Possible to put ideas together: eg state requires MCO to survey PCPs about a sample of all members.
4. Note that parent report good for limitation of activity... probably better than provider.

From AM 9/12: worry about neonate identification, about morbidity and mortality

RAC: concern about sample set representative based on phone survey only.
CCWD1 expressed similar concern, and willingness to help develop.

**ES: discussion about validity of phone surveys, relevant questions.**

>> what about using a validity cohort of those unreachable by phone, particularly an issue for urban/rural.

CCWD1, CCWD2: how are clients included in sample who are intermittently in/out of coverage, or who die.

CCWD2: ES notes need for continuous enrollment of 6-9 months, but does allow one month gap in coverage. Think about doing focused study eg in CHIP enroll/disenroll. Pull death information from state vital statistics, Medicaid eligibility, as well as family interview.

CCWD1: Recommended implementing HHSC’s own recommendations in its report, “A Model for Integrating Children with Special Health Care Needs into Medicaid Managed Care”, authored by Maureen Milligan and published in April 2003. Those were:

- A combination of administrative data, medical record review data and parental reports should be utilized to assess the quality of care for CSHCN.
- Non-categorical quality of care indicators that should be considered when measuring CSHCN include: the provision of a medical home, preventive care, health care use, family satisfaction with care, unmet health care need, health status, and end-of-life care.
• Condition-specific processes and outcomes of care for CSHCN should be addressed in addition to the non-categorical quality of care indicators.
• Quality of care measures should be assessed within the context of the health care delivery system, a child’s health status, and the community for a better understanding of how these factors influence care.
• Focus studies can serve as a good mechanism to further examine and analyze certain quality of care issues.

CCWD2: what about ICF disability and handicap and relationship to impairments.

CCWD2: JS suggested considering web-based survey of families. ES responded has studied and poor response rate, and worries about selection bias, although access to computers is greater than expected. ES reported that has studied incentives for family responding and took up to $15-$20/respondent to impact response rate.

2) Recommended Measures, Their Significance, and Their Data Sources

Table 1 contains a summary of the recommended quality of care measures, their significance, and the data sources that will be used to calculate the measures. The recommended measures rely on two types of data: 1) telephone survey data obtained from families whose children are enrolled in the STAR MCO Program, PCCM, or CHIP; and 2) enrollment files and health care claims and encounter data for the children.

The telephone survey sampling for the STAR MCO Program and CHIP is structured so that comparisons can be made between the MCOs participating in each of the programs. The PCCM telephone survey relies on a statewide sample. The sample size does not permit comparisons between regions of the state.

The measures that rely on the enrollment files and the health care claims and encounter data are predominantly Health Employer Data Set (HEDIS) measures. The HEDIS technical specifications are followed to calculate the measures and supplemented by local codes as needed. All children who meet the HEDIS criteria for inclusion in the measure are assessed. Compliance with the measure will be reported for each of the CRG health status categories. In addition, an indicator recommended by the Institute of Medicine to assess access to care is included.

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Table 1. Recommended Quality of Care Measures for CSHCN

<table>
<thead>
<tr>
<th>Recommended Measure</th>
<th>Data Sources</th>
<th>Reporting Frequency</th>
<th>RAC</th>
<th>CCWD1</th>
<th>CCWD2</th>
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<td>Families’ satisfaction with their children’s medical homes. Families’ satisfaction will be assessed for the following medical home dimensions: (1) access to a personal doctor or nurse; (2) accessible care; (3) family-centered, compassionate care; (4) coordinated care; and (5) culturally sensitive care.</td>
<td>Telephone surveys are conducted biannually with parents whose children are enrolled in STAR MCOs, in CHIP, and in the Primary Care Case Management Program (PCCM). The Consumer Assessment of Health Plans Survey (CAHPS), Version 3.0 is used and will be scored using an alternative scoring method designed to group items to assess family satisfaction with their child’s medical home.</td>
<td>Every Other Year – STAR MCOs and PCCM assessed in one year and CHIP in the alternate year.</td>
<td>Recommended annual assessments. [ES: cost issue]</td>
<td>Recommended annual assessments for this and other measures, with the concern that frequent measurements are necessary for program planning and to make programmatic adjustments.</td>
<td>ES: sample size based on 300 enrollees per health plan at HHSC request. Could lower cost by doing state-level survey in alternate years. Possible HHSC will request annual assessment for all programs beginning fiscal 2007. (new plans in rollout not affected until then). ES noted NCQA would require annual assessment of commercial plans.</td>
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<td>Families’ reported access to specialty services to include physician specialists, therapies, and support services.</td>
<td>The CAHPS contain items asking about access to physician specialty services, therapy services, respite care, and other specialty services. The items ask if the child needed the service, if the child received the service, and whether the parent encountered difficulty obtaining the service. The results from these items will be reported.</td>
<td>Every Other Year – STAR MCOs and PCCM assessed in one year and CHIP in the alternate year.</td>
<td>Be sure to include access to social worker, financial counseling, community-based care coordination, school support, DME. Need to add parent hassle factor (time to access service) as well as satisfaction. [ES: we have these questions, but will add time to survey and cost more]</td>
<td>Similar concerns of matching Plan services offered and perceptions of family to access and delivery.</td>
<td>Both reviewing groups see this as critical. ES reports consortium has developed, in addition to CAHPS, could add up to 6 min to telephone survey. ES agreed that could do limited study, not 300 per plan but at state-wide level to get data.</td>
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<td><strong>HEDIS Preventive Care Measures to Include:</strong></td>
<td>Enrollment files for the STAR MCO Program, PCCM, and CHIP. Health care claims and encounter data for the preceding programs.</td>
<td>Annually</td>
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<td><strong>JZ noted few CHIP kids less than 15 months, so expect small samples, at least at health plan level. Adolescent well-care 12-21 year olds. ES currently doing. Probably undercoding adol well-child visits (eg if sports physicals)</strong></td>
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<td>Well Child Visits for 15 Month Olds</td>
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<td>Well Child Visits for 3, 4, 5, and 6 Year Olds</td>
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<td>Adolescent Well Care Visits</td>
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<td><strong>HEDIS Access to Primary Care Practitioners (PCPs)</strong></td>
<td>Enrollment files for the STAR MCO Program, PCCM, and CHIP. Health care claims and encounter data for the preceding programs.</td>
<td>Annually</td>
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<td><strong>ES says HEDIS looking for certain CPT codes and ICD9 to determine if access to PCP. DP: asks if plan-identified PCPs wouldn’t count for every visit; ES states provider files not clean. RA: look at time to first encounter BEFORE PCP; would have to look at new enrollees – CAHPS survey might address; HEDIS wouldn’t since requires continuous access.</strong></td>
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<td><strong>Inpatient and Emergency Room Use for Ambulatory Care Sensitive Conditions (ACSCs)</strong></td>
<td>Enrollment files for the STAR MCO Program, PCCM, and CHIP. Health care claims and encounter data for the preceding programs.</td>
<td>Annually</td>
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<td><strong>JZ: lots of discussion among MCO MedDirectors. Worry about accuracy of dataset … doubt that this is meaningful as is. Critical to use 4-5 digit ICD9 codes, not 3. (eg don’t look at just asthma, 493). ES: inpatient admissions studied from AHRQ list for ASSCs are gastroenteritis/dehydration, asthma, bacterial pneumonia and UTI. RA: question is how to capture OTHER ASCs specific for CSHCN, eg therapy</strong></td>
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<tr>
<td>Inpatient and Emergency Room Use for Ambulatory Care Sensitive Conditions (ACSCs) (Continued)</td>
<td>Health outcome measures, specifically hospitalizations, annual hospital days, mortality, parent-reported health status[ES: hospital days, hospitalizations doable with little cost. Would need vital statistics data]</td>
<td>Incorporate the national CSHCN survey questions to address this and other concerns.</td>
<td>Consider focused study- eg asthma- of school absenteeism by parent report due to illness, not routine appts (NHIS, bed days, limited activity days as well)</td>
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<td>Provider assessment of systems of care, including such factors as: access to services, funding, hassle factor, and their ability to provide added value-services under MMC</td>
<td>JZ: there are provider surveys done by MCOs, but no common way to report. Anticipate differences by service area. JZ and AG positive, MCOs might do, provide data to ES. JS suggested web-based. JZ suggested TPS sponsor. JH thinks idea for future. “now. “if costs one penny more, can’t do it.” RW: maybe it’s possible to “trade”…. JH: tell us your suggestions and priorities. DD: ICHP does a PORTION of this assessment; our priorities can be used by HHSC to look at all possibilities for assessment.</td>
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<td><strong>HEDIS Use of Appropriate Medications for People with Asthma</strong></td>
<td>Enrollment files for the STAR MCO Program, PCCM, and CHIP. Health care claims and encounter data for the preceding programs. Pharmacy data.</td>
<td>Annually</td>
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<td><strong>Adolescent Transition to the Health Care Delivery System</strong></td>
<td>The inpatient and ER use will be assessed using enrollment files for the STAR MCO Program, PCCM, and CHIP. Health care claims and encounter data for the preceding programs. The STAR MCO, PCCM, and CHIP surveys will be modified to include the transition questions from the National Survey of CSHCN.</td>
<td>Annual for the health care use measures and <strong>every other year</strong> for the survey measures</td>
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<td>Emphasized the importance of these questions; how is transition being defined? (see this as a developmental process, rather than a transfer in care)</td>
<td>ES: feels these questions not well done, are being revised. Zarin – CHIP out at age 19. Desiree: consider financial planning.</td>
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<td>Measure for adequacy of funding [ES: actual to expected health care use and expenditures based on the childrens case-mix or illness burden]</td>
<td>Sample providers for their assessment of systems (reimbursement, hassle factor, drop-out rate, difficulty in provider signup)</td>
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<td>Measure for early and continuous screen for CSHCN [ES: annual interviews with MCOs in STAR, CHIP, STAR+PLUS /- doesn’t address PCCM]</td>
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<td>JH: PCCM will go away in urban areas, RW – question of ICM.</td>
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<td>Family satisfaction with model of care – reason for choice, and movement [ES: can add to survey at additional cost]. Comment: at this time, likely few families with this experience.</td>
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<td>Harris RAC – Millwee “prudent” to do pre-post study of transfer in care.</td>
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DATA ANALYSIS:

RAC asked for sample size calculations based on primary outcomes, i.e. difference between the STAR MCO and PCCM. [ES: sample size sufficient for state-wide comparison; not adequate to make geographical distinctions.

CCWD1 felt these regional distinctions were critical, and that sample size should be adequate in at least some regions, e.g. Dallas, San Antonio, Houston.

From AM 9/12: ES reports cost consideration of over-sampling for specific areas.

CCWD1 pointed out this is important to meet the requirements of SB1165.

CCWD1 emphasized the importance of selection of outcome measures that provide both statistics and functional information for program improvement.

OTHER IDEAS FROM CCWD2:

1. Keep records of CSHCN electronically, ultimately providing electronic personal health record.
2. Encourage MCOs to provide outcomes data voluntarily on their site – and develop it … would it improve outcomes of others? I.E. peer pressure, pay for performance
3. Priorities from stakeholders for consideration and recommendations

NEXT STEPS FROM CCWD2:

1. TPS to develop suggestions and priorities, and HHSC will review. Anticipate action in October 2005 post end September CCWD meeting.
2. No commitment from HHSC to provide details about current contract
3. HHSC plans to publish more data, including about CSHCN. Davis noted that since 2003, no report from ICHP has been posted, and also less information to health plans than agency would wish. Reports HHSC plans to publish information in the “near future”. Note that Balland and Millwee said at last Harris SDA RAC would be “transparent.”
4. J Hellerstedt asked for no other immediate help, but stated “all partners” … “Not much wrong with Medicaid that more money wouldn’t solve.” Asked for TPS help in getting Legislature to buy in. Asked that we work with the provider community to emphasize the importance of their providing accurate information (eg coding correctly).
5. What is source of questions? HEDIS, CAHPS, and NIHS of CSHCN.

In CCWD2 comments, remarks attributed as follows:

AG:  Angelo Giardino, MD
DD:  Diane Davis (HHSC)
ES:  Elizabeth Shenkman, PhD (ICHP)
JH:  John Hellerstedt, MD (HHSC)
JS:  Joe Schneider, MD
JZ:  Jerald Zarin, MD
RA:  Richard Adams, MD
RW:  Robert Warren, MD