INDEPENDENT ASSESSMENT OF CONNECTICUT'S HUSKY PROGRAM:
Access and Quality of Care for Children with Special Health Care Needs

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Executive Summary

INTRODUCTION

On June 1, 2000, the Connecticut Department of Social Services (“the Department”) obtained its second waiver under section 1915(b) of the Social Security Act to operate a statewide Medicaid managed care program with mandatory enrollment for children and families. The waiver covered the period from June 1, 2000 to May 31, 2002, with an extension to June 30, 2002. In a letter approving the waiver, the Health Care Financing Administration (HCFA)\(^1\) required that the Department submit an independent evaluation of the waiver with respect to access to care, quality of services, and cost effectiveness. The Department asked the Children’s Health Council to conduct an independent assessment of the effect of the waiver on access to care and quality of services.\(^2\)

The Children’s Health Council conducted a retrospective qualitative review of the HUSKY A program that focused on aspects of the program that affect access to care and quality of care for children with special health care needs. The evaluation was designed to identify problems and emerging issues for children with special health care needs and to recommend policy and program improvements that will benefit both children with special health care needs and healthier children enrolled in HUSKY A.

Review criteria issued by HCFA were used as a framework for the investigation and the report.\(^3\) These criteria specify that States that mandate enrollment in capitated managed care organizations for children with special health care needs must ensure that these children have access to needed services by:

- Ensuring public input into program operation and monitoring;
- Developing a definition of children with special health care needs;
- Identifying children with special health care needs and assisting with enrollment;
- Monitoring provider and specialist network capacity;
- Requiring care coordination based on timely and comprehensive assessment of each child’s health care needs;
- Developing specific performance measures and performance improvement projects that address issues for children with special health care needs;
- Incorporating relevant policy guidance from HCFA;

\(^1\) The Health Care Financing Administration is now known as the Centers for Medicare and Medicaid Services (CMS).
\(^2\) The evaluation of the cost effectiveness of the waiver was conducted by William M. Mercer, Inc., and submitted by the Department to the Centers for Medicare and Medicaid Services (CMS) on April 12, 2002.

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• Developing a payment methodology that accounts for children with special health care needs; and
• Monitoring access to services, quality of care, coordination of care, and enrollee satisfaction for children with special health care needs.

In this Executive Summary, each section corresponds to one of these review topics and includes a summary of specific review criteria, a report on major findings, and recommendations for improving access to care and quality in HUSKY A.

THE HUSKY A PROGRAM DURING THE WAIVER PERIOD

• Enrollment: The number of children under 19 enrolled in HUSKY A increased 11%, from 176,602 to 196,589 children under 19 in June 2002.

• Participating managed care organizations: Children were enrolled in four managed care organizations (Blue Care Family Plan, Anthem Blue Cross and Blue Shield; Community Health Network of Connecticut; HealthNet; and Preferred One) that received monthly capitation payments based on age, gender, and county of residence, without adjustment for health status.

• Administration and oversight: The Department administered the HUSKY A managed care program and contracted with Affiliated Computing Services, Inc. (ACS) for enrollment, Qualidigm, Inc. for external quality review, William M. Mercer, Inc. for management of encounter data, and the Children’s Health Council for independent performance monitoring. The Medicaid Managed Care Council advises the Department on program administration.

• Terms and conditions of the 2000-2002 waiver: The State was required to develop and implement means for identification of enrolled children with special health care needs; provide for assessment of their needs and implementation of appropriate treatment plans; review complaints and grievances; monitor plan change; conduct a focused quality study; and report annually to HCFA.

RESULTS OF THE INDEPENDENT ASSESSMENT

PUBLIC PROCESS

Input from providers, advocates, and families in the development and implementation of a Medicaid managed care program is vital to assuring that the program is responsive to the needs of families of children with special health care needs. The State is required to have in place a public process for the involvement of advocates, providers, families, caregivers, consumer groups, state agencies, managed care organizations, and others who treat or serve children with special health care needs. The State must also assure that managed care organizations have a process to seek input from these same groups on a regular basis.

• Public input: The Department has not developed and implemented a process for ensuring public input into the administration of HUSKY A or the operations of the participating
managed care organizations as they affect care and other services for children with special health care needs. The Medicaid Managed Care Council and the Children’s Health Council, existing advisory and oversight entities that periodically address the needs of children with special health care needs, could serve as vehicles for obtaining public input on a regular basis. In addition, the Department could collaborate with Connecticut’s Title V program in order to ensure the involvement of families of children with special health care needs and their advocates.

**Recommendations**

The Department should establish a public process to ensure input for policy development and the operation of HUSKY A with regard to care and services for children with special health care needs.

The Department should require HUSKY A managed care organizations to participate in and seek input from this broadly representative advisory group on operational issues that affect children with special health care needs.

**DEFINITION OF CHILDREN WITH SPECIAL HEALTH CARE NEEDS**

Early identification of children with special health care needs and timely provision of assistance and special services is dependent on a meaningful and precise definition. The State is required to develop a definition that includes at a minimum the categories of children defined in the Balanced Budget Act of 1997 (BBA) as children with special health care needs. Under Connecticut’s waiver, those children are: children eligible for and receiving SSI benefits; children in foster care or other out-of-home placement; children receiving foster care or adoption assistance payments; and children receiving services under the state’s Title V program for children with special health care needs.

- **Limitations of definition:** In its contract with the managed care organizations, the Department has limited its definition of children with special health care needs to the four BBA-defined categories, resulting in a definition that is both under- and over-inclusive. The BBA definition is broad and imprecise. The definition creates problems for the Department and health plans in terms of identifying and enrolling children with special health care needs, providing care coordination, developing performance measures and quality improvement projects, and monitoring access to services, quality of care, coordination of care, and enrollee satisfaction.

**Recommendation**

The Department should develop a definition of children with special health care needs that goes beyond the Balanced Budget Act definition to include children who need ongoing specialty care and therapy, care coordination, and other services.

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IDENTIFICATION AND ENROLLMENT

Timely and accurate identification of children with special health care needs and special enrollment provisions are important for assuring that these children receive appropriate and necessary services in a risk-based managed care program. The State is required to identify children with special health care needs when they enroll in managed care organizations, using screening tools, linkages with other state agencies, Medicaid claims data, new member outreach, client surveys, or other means of identification. The State must also make special provisions for outreach, assistance with plan selection, continuity of primary and specialty care, disenrollment, and enrollment needs of children in out-of-home placement.

• **Contractual requirement to identify children**: Since July 2001, contracts between the Department and the managed care organizations specify that the Department will provide information to the managed care organizations that identifies children with special health care needs as defined by the BBA. However, the Department has not yet developed the means to identify all these children using enrollment data. The Department is working on but has not completed a data-sharing agreement with the Department of Public Health (DPH) that will provide the Department with enrollment data from the Title V programs. The Department is also working on but has not implemented a means of identifying children in state custody who are in the F25 coverage group. Until these projects are completed, the Department cannot identify all BBA-defined children with special health care needs for health plan operations, utilization monitoring, and program oversight.

• **Operationalizing the definition**: Staff of the managed care organizations reported that not every child defined as having special needs under the BBA definition has a mental or physical health condition that makes the coordination of medical, social, and educational services medically necessary. They expressed a preference for a uniform definition based more on clinical and diagnostic criteria rather than categorical eligibility for other programs. Each of the managed care organizations has developed other ways of identifying children with special health care needs to supplement the information provided by the Department.

• **Screening at enrollment**: During the waiver period, ACS call center representatives began asking families whether a child in the family has special health care needs (not defined). If the caller states that a child has special needs, ACS provides the caller with information on the Title V program. ACS also instructs the parent to notify the health plan that the child has special health care needs. No flag or indicator is added to the enrollment information to indicate that the parent or caretaker relative identified the child as having a special health care need.

**Recommendations**

The Department should work with the enrollment broker and health plans to develop and implement a uniform and systematic approach to identifying children with special health care needs as soon as possible after they enroll in HUSKY A.
The Department should develop and implement a data-based approach to identifying all children in HUSKY A who are in the care and custody of the Department of Children and Families.

The Department should execute a data sharing agreement with DPH in order to facilitate identification of children in the Title V program and inform their respective HUSKY A health plans.

PROVIDER AND SPECIALIST CAPACITY

Children with special health care needs are more likely to require specialty providers and may require primary care providers and dental providers with specialized skills and knowledge. The State must assure the adequacy of provider networks and monitor access to primary and specialty providers in participating managed care organizations; require certain specialist types and provisions for out-of-network care when necessary; and monitor access to specialty medical equipment and supplies that may be required by children with special health care needs.

• Monitoring provider networks: With the exception of behavioral health care, managed care contract provisions for provider networks and monitoring the adequacy of those networks do not specifically address specialty provider network capacity for children with special health care needs. However, all the managed care organizations acknowledge responsibility for sustaining a provider network with a full array of specialists and pediatric subspecialists as well as providers of durable medical equipment and supplies. Each managed care organization has procedures for obtaining out-of-network care when needed, although many families may not be aware that this option exists.5

• Adequacy of provider networks: Title V staff, DCF staff, and others reported problems with provider network adequacy, including difficulties finding primary care physicians experienced in caring for children with special health care needs; difficulties finding dentists and orthodontists willing to treat children with disabilities; waiting lists for inpatient and outpatient behavioral health care services, especially in more rural areas of the state; lack of home care, especially for technology-dependent children; lack of specialists for rare conditions; and difficulties finding pediatric ophthalmologists willing to provide care to children in HUSKY A.

• Specialty providers: The Department actively monitors primary care and dental care provider network capacity, but generally does not monitor the adequacy of specialty provider networks. During the waiver period, the Department’s external quality review contractor conducted a study of appointment availability and reported that 52% of calls to Child Guidance Centers and 60% of calls to mental health clinics did not result in appointments.6

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Recommendations

The Department should work with managed care organizations and dental subcontractors to ensure that children with special health care needs have access to preventive dental care and treatment.

The Department should develop and monitor contractual standards for specialty provider network adequacy in order to ensure that the provider networks include all the health care services required by children with special health care needs.

The Department and the managed care organizations should ensure that families of children with special health care needs receive clear, consistent information on the availability of out-of-network specialty care and procedures for obtaining needed care.

CARE COORDINATION

Children with special health care needs often receive services from multiple health care providers and may need special services from education and social service agencies. Their families often need assistance in locating providers, scheduling appointments, and arranging transportation. The State must assure that services provided to children with special health care needs are well-coordinated and provided in a timely fashion, with a comprehensive assessment of each child’s health care needs and implementation of a treatment plan; case management or care coordination; coordination with other systems of care that receive federal, state and local funding such as Title V, education, child welfare, and Birth-to-Three; and coordination of health care services with the services of other agencies, such as behavioral health, public health, schools, and child welfare, and with families, caregivers, and advocates.

- **Contract provisions**: Contracts between the Department and managed care organizations include a number of provisions for addressing the needs of children with special health care needs, including requirements for:
  - Assessment of medical needs of children identified by the Department and the managed care organizations in order to develop and implement a plan of treatment;
  - Systems for providing care management through a primary care provider or other means; referrals for medically necessary specialty care; EPSDT case management when medically necessary; and care coordination and case management services for children with special health care needs;
  - Policies and procedures for coordination of care and arranging, tracking and documenting referrals to specialty providers;
  - Assurances that EPSDT screening, diagnostic, and treatment services are provided, including providing assistance in scheduling appointments and providing and arranging transportation;
  - Coverage for comprehensive multi-disciplinary examinations within thirty days of initial placement for each child entering DCF care; and
  - Special initiatives, case management, care coordination, and outreach to members with special or multiple medical needs; assistance with locating services and providers that can accommodate the needs of members with hearing disabilities and physical disabilities.
• **Assessment of needs**: Managed care organizations report difficulties with systematically assessing the needs of children with special health care needs, in part due to limitations of the definition of children with special health care needs, inability to identify children in the Title V program and some children in state custody, and lack of a program-wide approach to early screening for special health care needs when children enroll. The contract provision requiring assessment of children with special health care needs was added without any additional guidance as to how it should be integrated with other provisions on care coordination and case management. In the absence of contractual clarity, each managed care organization has adopted its own approach to identifying children with complex medical needs, using a variety of methods based primarily on diagnosis and utilization indicators rather than identified needs.

• **Definition of case management**: The Department has not adopted a uniform definition of care coordination or case management in HUSKY A, so each managed care organization has developed its own approach to providing this service. Although case management or disease management programs in each health plan are small relative to the number of children with special health care needs, each program appears to be well-designed for delivering a high level of services to the children in the program. However, these care coordination activities may not be well-connected to the efforts of the pediatric primary care provider.

• **Monitoring case management**: The Department monitors case management in two ways. First, Department staff conduct quarterly site visits to review each health plan's case management processes and treatment plans for children with special health care needs. In addition, the Department developed and recently implemented a semi-annual case management report focused on nine diagnostic categories. This report focuses on the provision of health care services rather than the coordination of health, educational, and social services; it does not include information with which to assess the quality of case management.

• **Coordination with other programs**: The Department’s contract with the managed care organizations requires the development and execution of memoranda of understanding (MOUs) with a number of agencies, including the Birth-to-Three program and programs operated by the Departments of Children and Families, Education, Public Health, Mental Health and Addiction Services, and Mental Retardation. All but one of the managed care organizations has MOUs in place as required by the contract; most were executed prior to the waiver period and need to be updated.

**Recommendation**

The Department should clarify and enhance contractual provisions regarding assessment, care coordination and case management for children with special health care needs.

The Department should assess and report on the quality of case management services to supplement monitoring of the numbers of children served and types of services provided.
QUALITY OF CARE

The quality of health care received by children with special health care needs can best be conceptualized in terms of access, appropriateness of care, comprehensiveness, coordination of services, continuity of care, relation to the community, and degree to which services and the service system are family-centered.7 The State must have specific performance measures that may be developed in concert with the Title V agency and specific performance improvement projects that address issues for children with special health care needs.

The Department has invested considerable time and resources into program oversight, including development of a systematic, data-driven approach to monitoring care; health plan contract requirements for utilization reporting; external quality review of health plan operations and data quality; and support for independent performance monitoring in HUSKY A. However, the Department has not taken full advantage of this oversight approach in order to develop and use specific performance measures or quality improvement projects for children with special health care needs.

- **Utilization reporting**: Under contracts with the Department, managed care organizations are required to report regularly on utilization of selected health services, using measures developed by the National Committee on Quality Assurance (NCQA) for the Health Employer Data Information Set (HEDIS) and modified for use in HUSKY A. However, in the absence of a uniform approach to identifying children with special health care needs, utilization rates for children with special health care needs cannot be determined nor can they be assessed across health plans, compared to rates for healthy children, or tracked over time.

- **External quality review**: Most studies of care in HUSKY A conducted by Qualidigm, Inc., under its contract with the Department focused broadly on aspects of health plan performance that affect access to care, utilization, and quality for all members. However, results of two studies are useful for understanding just how children with special health care needs fare in Medicaid managed care. One study of EPSDT in HUSKY A showed that most infants and children were not screened for special physical, developmental, and behavioral health care needs in the course of primary care visits.8 Results of another study showed that psychotropic medications, mainly stimulants and anti-depressants, were prescribed at a rate of 5.2 per 1,000 member months.9 Many of the children did not have visits with mental health specialists, but received behavioral health care and prescriptions from primary care providers. Among children taking psychotropic medications, 42% had prescriptions for more than one drug.

- **Health care utilization**: Results of health care utilization monitoring by the Children’
Health Council showed that in a one-year period, children with special health care needs

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received well-child care, preventive dental care, emergency care, and care for asthma at rates similar to other children in HUSKY A. They were more likely than other children in HUSKY A to have been hospitalized, with longer average length of stay. They were more likely than other children in HUSKY A to have been hospitalized for asthma, perhaps due to co-morbid conditions that place some asthmatic children at greater risk.

- **Satisfaction with care:** Results of a statewide survey of families with children with special health care needs in HUSKY A, conducted by the Children’s Health Council, revealed significant differences in health status, health care utilization, need for special services and need for support services in comparisons of responses for children in DCF custody, in the Title V program, or on SSI. These results indicate that aggregate measures of health status, health care need, and utilization will mask very significant differences between the different groups of children with special health care needs.

- **Problems for children in state custody:** In a recent report on the health and health care of children in state custody who are enrolled in HUSKY A, the Children’s Health Council reported significant problems with enrollment and health care. Children in state custody were more likely to change health plans in a one-year period. They are at risk for losing coverage when changes in DCF involvement affected eligibility. Utilization analyses showed that compared to other children in HUSKY A, children in DCF custody were disproportionately likely to have behavioral health care needs and more likely to have had emergency care or been hospitalized for behavioral health care. With respect to the quality of care, foster care and adoptive parents reported that they are generally satisfied with HUSKY A health plans, access to care, and the quality of the care their children receive.

**Recommendations**

The Department should develop a systematic, comprehensive, and integrated approach to assessing the quality and appropriateness of care and services in HUSKY A for children with special health care needs.

**PAYMENT METHODOLOGY**

The State must develop a payment methodology that accounts for children with special health care needs enrolled in Medicaid managed care and provide CMS with information on any future plans to institute additional risk adjustment for children with special health care needs.

- **No risk-adjusted rate:** Connecticut has not developed a special payment methodology that accounts for children with special health care needs enrolled in HUSKY A, nor are there

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13 Children in Medicaid coverage groups D01 and D02; other children in state custody in HUSKY A cannot be identified without manual review of all enrollment files with data on authorized representatives.
current plans to develop risk-adjusted rates. According to an analysis of Medicaid managed care contracts in place in 1999, Connecticut is the only state with mandatory enrollment of SSI children that did not adjust the capitation rates for these children.\textsuperscript{14}

- **Effect of low reimbursement:** Difficulties finding primary care, dental and mental health providers for children with special health care needs are reportedly due to low reimbursement rates for the often labor-intensive care these children need.

**Recommendations**

The Department should investigate the potential effect of a specialized payment methodology for improving access to primary care and specialty care providers who care for children with special health care needs.

Depending on the results of this investigation, the Department should develop an actuarially sound method of risk-adjusted payments to managed care organizations, with performance measures that show expanded provider network capacity, increased percentages of children with special health care needs who receive case management, and increased utilization of preventive health services.

**PLAN MONITORING**

Managed care contracts are the tools with which state Medicaid agencies can establish the safeguards needed to ensure that the complex physical, developmental, and mental health needs of children are met.\textsuperscript{15} The State must have in place a process for monitoring children with special health care needs for access to services, quality of care, coordination of care, and enrollee satisfaction. Contracts must specify what constitutes medically necessary services for children with special health care needs, require compliance with ADA access requirements for enrollees with disabilities, specify responsibility for age-appropriate care, and require approval/authorization of services in a timely fashion. Then the State must monitor managed care organizations’ service authorization policies to ensure that the criteria are consistent with the medical necessity contract specifications and any practice guidelines adopted by the MCO that are relevant to children with special health care needs.

Here again, the Department has invested considerable time and resources into plan monitoring, but has not developed specific performance measures for determining how well managed care organizations serve the needs of children with special health care needs.

- **Medical necessity:** In Connecticut, contracts with managed care organizations clearly define medically necessary care, using a definition that is consistent with federal requirements.


\textsuperscript{15} Fox HB, McManus MA. Improving state Medicaid contracts and plan practices for children with special needs. The Future of Children, 1998; 8 (2): 105-118.
• **Children in state custody:** Contracts with health plans clearly spell out administrative and financial obligations for the special needs of children in state custody, including coverage of comprehensive multi-disciplinary examinations within 30 days of initial placement; training for foster parents on use of special equipment or medication; coverage for placement medications; notice of action when services are reduced, denied or terminated; and collaboration with providers, DCF staff and behavioral health care providers (5.a-f). Compliance with these aspects of the contract has not been formally evaluated.

• **External quality review:** During the waiver period, the Department contracted with Qualidigm, Inc., an external quality review organization, for audits of health plan compliance with contract provisions. The audit, which covered June 2000-June 2001, was not focused on care for children with special health care needs nor did the audit provide much information beyond the fact that each health plan has case management programs with written procedures and appropriate documentation.

• **Monitoring grievances and requests for administrative hearings:** The Department developed specific policies and contractual provisions for notice, complaints and dispute resolution. In 2000-2001, many of the grievances and requests for administrative hearings filed on behalf of children with special health care needs in 2000-2001 concerned access to durable medical equipment and other medical supplies. Qualitative analysis of these cases could provide important information about how the program serves children with special health care needs.

• **Monitoring consumer satisfaction:** Under contracts with the Department, managed care organizations are required to conduct an annual survey of member satisfaction among HUSKY A and B members, using the Consumer Assessment of Health Plans Survey 2.0 (CAHPS), administered by a National Committee on Quality Assurance (NCQA)-certified vendor. Each health plan conducted two surveys during the contract and waiver period. Despite contractual provisions aimed at generating comparable results for each health plan, the survey methods were not uniform, not specific to children’s health care; and not stratified by health status and special health care needs. In addition, the survey results have not been compiled and reported publicly by the Department.

• **Role of Managed Care Liaisons:** Department staff are assigned as liaisons to health plans and are responsible for conducting health plan site visits, participating in contract compliance audits, monitoring denials, and reviewing grievances and requests for administrative hearings. They work with Children’s Health Infoline Care Coordinators who are having difficulties resolving access problems for families that call. Managed Care Liaisons facilitate communication between health plans and providers who experience difficulties getting paid. Recently, one Managed Care Liaison was assigned to oversee plan performance with regard to children with special health care needs. Unfortunately, the Department is seriously understaffed, so Managed Care Liaisons have limited time and resources for systematic identification of program-wide problems and policy development.
Recommendation

The Department should develop an integrated, focused plan for monitoring access to care and quality for children with special health care needs.

CONCLUSION

The 2000 to 2002 Connecticut waiver was the first Medicaid managed care waiver period subject to the provisions in the Balanced Budget Act of 1997 that require special protections for children with special health care needs who are enrolled in mandatory Medicaid managed care programs. During the waiver period, the Department took some important steps toward addressing the needs of these children, particularly by adding contract provisions for identification, assessment, and treatment planning.

For the most part, however, the Department has not focused its efforts and resources on children with special health care needs in either administration or monitoring of the program. In some areas, such as enrollment and coordination with other programs, contract provisions that pertain to all enrollees are sufficient to protect children with special health care needs. In other areas, such as public input, quality assurance, plan monitoring, and care coordination, a more focused approach is needed to ensure that children with special health care needs have access to comprehensive, quality health care services.

The Department’s ability to monitor care for children with special health care needs in accordance with the CMS review criteria and these recommendations is heavily dependent upon seriously depleted staff resources. However, the Department can redirect existing resources in order to enhance assurances for children with special health care needs. This shift can be made through health plan contract provisions, external quality review activities, stratification of utilization reporting, and consultation with Title V and oversight entities.

In conclusion, we recommend that the waiver authority granted to the Department under section 1915(b) of the Social Security Act be allowed to continue. However, we also recommend that the Department marshal its existing resources to maximize the probability that children with special health care needs will receive comprehensive, quality health care services within the HUSKY A program.