



CHILDREN'S HEALTH COUNCIL

CHILDREN WITH SPECIAL HEALTH CARE NEEDS ENROLLED IN HUSKY Part A: Survey to Assess Access to Care and Satisfaction

Executive Summary December 2000

Families with children with special health care needs face exceptional challenges when trying to obtain care in a managed care program. In order to assess access to care and satisfaction among children with special health care needs who are enrolled in HUSKY Part A (Medicaid managed care), the Children's Health Council conducted a statewide telephone survey of their families. The survey was conducted on behalf of the Connecticut Department of Social Services (DSS).

RESULTS

- **One in five children continuously enrolled in one of the four HUSKY Part A health plans was identified as having special health care needs.** This group of children includes those defined as special needs children under the Balanced Budget Act of 1997 and other children who received health care in 1999 for diagnoses indicative of chronic, intensive health care needs.
- **The health and health care needs of these children are not uniform across this definition of children with special health care needs.** Children in the Title V program, children who receive Supplemental Security Income benefits, and children who have special diagnoses were sicker, more likely to use primary and specialty health care services, and more likely to need pharmaceutical, therapeutic, or enabling services, compared to children in foster care or subsidized adoption.
- **Families were generally satisfied with their health plans and with the quality of care from providers.** They were also satisfied with the choice of primary care providers, specialists, and dentists. Most families reported being involved in care decisions for their children and well informed by providers.
- **Access to care varied, depending on whether families are seeking primary care, medical specialty care, or behavioral health care for their children.** While nearly all children were able to get timely appointments with primary care providers, a third of families reported difficulties getting appointments with medical specialists in less than four weeks. Very few families reported problems getting referrals for medical specialty care. Among those whose children saw behavioral health care providers, one in four reported not getting enough approved visits. Some families tried to get approval to see out-of-network providers; two out of three said their requests were approved.

- **While most children needed and obtained prescription medicine, relatively few needed other pharmaceutical, therapeutic, or enabling services.** While the proportion of children who needed special services was small, some of their families report significant difficulties with physical access, obtaining special transportation, and getting interpreters.
- **Less than one in ten children with special health care needs reportedly had a case manager assigned by the health plan.**
- **While most families said they are aware that they can make a formal complaint about health plan services, less than half of those who felt the need to complain actually did.**
- **While few families reported having experienced a cutback in services for their children, only a third of those who did said they were notified in writing.**

RECOMMENDATIONS

The Children's Health Council has reviewed these findings and the literature on monitoring care for children with special health care needs. The Council recommends that the Department of Social Services:

- **Investigate the extent to which there are problems with access to primary or specialty care, availability of special transportation and interpreters, and compliance with notification requirements. The following areas could be systematically studied: Appointment availability, transportation subcontracts and policies, availability of bilingual staff, use of translation services, and administrative procedures for notifying families of denial, reductions or termination of services.**
- **Ensure that health plans systematically assess their members' needs for case management and that health plans provide individualized assistance with coordination of their children's special health care needs.**
- **Develop and implement an ongoing, comprehensive approach to monitoring access to services, quality of care, coordination of care, and satisfaction for children with special health care needs. Measures should allow for comparison with the experiences of other children enrolled in HUSKY Part A. The monitoring plan should include:**
 - **Collaboration with DPH for identification of children in the Title V program;**
 - **Collaboration with DCF for identification of children in foster care and adoption;**
 - **Use of HEDIS-like measures of process and outcome;**
 - **Periodic surveys of families to assess access and satisfaction;**
 - **Periodic surveys of primary care providers who serve children with special health care needs; and**
 - **Operations audits of health plan administrative procedures that affect access to enabling services, case management, and grievances/administrative hearing.**
- **Investigate the utility, feasibility, and cost of screening for special health care needs when children enroll in HUSKY Part A.**

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