Families Receive Needed Services

About the Title V Block Grant

The federal Title V Maternal and Child Health (MCH) Block Grant helps states ensure the health of all mother and children. As part of Minnesota's Title V Block Grant activity requirements, the MDH conducts a statewide needs assessment every five years. The needs assessment provides guidance to Title V activities for the next five years by identifying priority issues. This fact sheet describes one of Minnesota's priority issues.

Seriousness of the Issue

Many children with special health needs require services from multiple systems such as the educational system, mental health, programs for children with developmental disabilities, and specialized medical care program.[1]

The National Survey of Children with Special Health Needs provides some insight to the need for specific services families have as the result of the presence of a youngster with special health care needs: Respite care, genetic counseling, and family mental health counseling.

- The families of more than 33,000 (19%) CSHCN need at least one of these families support services. Twenty percent of those families have at least one unmet family support service need.
- 19% of the families of children with functional limitations and 13% of the families of children with emotional, behavioral or developmental issues identify a need for respite care. Nearly 40% did not get needed respite.
- The families of more than 26,000 (15%) children with special health care needs need mental health counseling and 20% of them can't get it. The need for counseling increases as income decreases.
- Fewer than five percent of families of CSHCN need genetic counseling, most particularly those whose children experience functional limitations. About 10% who need this service can't get it.[2]

The Children/Family Survey of the Health Services Research Institute and the National association of State Directors of Developmental Disabilities Services asked families of Minnesota children with mental retardation or developmental disabilities about MR/DD services.[3] The results include:

- 40.5% agree that the services offered by their MR/DD agency meet their family's needs all or most of the time.
- 47.7% of the families do not have a case manager or staff to help them figure out what they need as a family to support their child.
- 35% only some of the time have a case manager or staff talk to them about options to meet their families' needs;
- 15% never have someone talk to them about options to meet their families' needs.

The experience of living with a chronic childhood illness presents very real obstacles for the families of ill children. Just as children are challenged by their medical condition, so too are their families who often must make considerable changes in their living patterns to accommodate the special needs of their children. The presence of a chronic childhood illness affects not only long-term goals and planning for the family but also day-to-day decisions and activities. At one extreme, some families of chronically ill children have had to relocate to be geographically closer to needed medical services. Although beneficial for the child, such a change often comes at considerable financial, personal, and emotional expense for the entire family. At a more mundane level, routine tasks with which most families have little difficulty, such as finding child care or an occasional baby sitter, can become seemingly insurmountable chores for the family of a chronically ill child. [4]

From a practical perspective, however, we know that among Minnesota families of children and youth with special health care needs[5]:

- An estimated 79,784 receive 1 to 11 or more hours of health care services at home. These home health care services that are provided by their families.
- 12,821 of those children require at least 11 hours per week of care at home.
- Family financial problems due to the child's health care needs are reported for an estimated 32,450 of the children.

Minnesota Children with Special Health Needs Section
P.O. Box 64882
St. Paul, MN 55164-0882
(651) 201-3650 or (800) 728-5420
www.health.state.mn.us

- 37,445 children's conditions have caused family members to cut back or stop working to care for their child at home.

Although not all families of children with special health care needs require additional support services, some do. Of those who need support services, Minnesota has a higher percentage of families who can't get them than most other states. Only Oregon, Kansas and the District of Columbia have higher percentages of families with unmet needs for family support services than Minnesota.

In Minnesota, families without health care coverage are far more likely to have unmet need for support services than those who are insured.

Families of children with functional limitations are much more likely than those whose conditions are managed by medications alone to have unmet needs for service.

Just over half (59%) of children in Medicaid who are often affected by their special health needs were in system of care that their parents found to be organized and easy to use. [6]

Mothers of children with physical disabilities have a higher incidence of low back pain (71.1%) than mothers of children with chronic illnesses (43.5%). Increased depression in mothers is associated with the presence of low back pain among mothers of children with physical disabilities.[7]

Maternal depressive symptoms have been found to be strong predictors of emergency department visits in children with asthma.

Researchers suggest that maternal psychological distress diminishes the mother's ability to cope with her child's asthma and is a marker for greater negative impact of the child's illness on the family. The conclusion is that improved maternal mental health would not only improve the quality of life, but may also decrease unnecessary emergency department visits.[8]

Models suggest that an individual's adjustment to chronic illness is influenced by a number of variables including the characteristics and resources of the family.[4]

A number of studies have found significant relationships between maternal adjustment measures such as anxiety and depression and child behavior problems in children with special health care needs suggesting that failure to address mental health issues in parents adversely impacts child functioning at home, school and in the community.

Research also finds that having an intact biological family decreases the risk of behavior problems in children with diverse chronic illnesses, suggesting the importance of attending not only to the child's medical needs, but to the broader needs of the child-family system including services that support the parental relationship.

Evidence-Based Strategies

Families whose children have a medical home appear less likely to need other family support services, most particularly mental health counseling for the family. Seven percent of families with a medical home v. 23% without a medical home have identified a need for family counseling.

The evidence clearly shows that lack of health insurance is hazardous to one's health.[9] In Minnesota if families don't have health insurance there are two main health programs for children. These health care programs are: Medical Assistance (MA or Medicaid) and MinnesotaCare. Under Medicaid, income eligibility for infants is up to 275 percent of the federal poverty line. Under "regular" Medicaid, income eligibility for children ages 2-19 is up to 150 percent of the federal poverty line.

MinnesotaCare is for families and children who do not have access to affordable health insurance, either on their own or through their employers. MinnesotaCare provides basic health insurance coverage such as primary care, hospitalization, dental care, mental health care, chemical dependency services, and prescription drugs through managed care plans. Families pay a monthly premium that is based on family size, coverage and income.

The Tax Equity and fiscal Responsibility Act (TEFRA) Option gives Medical Assistance to certain children with disabilities or long-term health conditions who live at home with their families, but their families are above income for MA.

Minnesota families of children with developmental disabilities overwhelmingly agree that services and supports help keep their children at home (71.9%) and that family supports improve their ability to care for their child (65.3%).[10]

The Family Support Grant Program though the Minnesota Department of Human Services provides state cash grants to families of children with developmental disabilities of up to $3060.00 per year. The goal of the program is to prevent or delay the out-of home placement of children and promote family health and social well-being by facilitating access to family-centered services and supports. The grant must be spent on services and items that are directly related to caring for the child with a disability. Only expenses that are over and above the normal costs of caring for the child if the child did not have a disability may be covered. There are often waiting lists at the local county for the Family Support Grant.

The Consumer Support Grant (CSG) program is a state-funded alternative to Medicaid reimbursed home care. This program specifically includes the home care services of home health aide, personal care assistant and private duty nursing services. Medicaid is a service system that mixes together both state and federal money. The Consumer Support Grant Program allows a recipient to convert the state portion of payments for specific home care services into a cash grant. Eligible participants receive monthly cash grants to replace fee-for-service home care services payments. With county assistance, consumers can manage and pay for a variety of home and community-based services. The CSG Program provides consumers with greater flexibility and freedom of choice in service selection, payment rates, service delivery specifications and employment of service providers. Parents, spouses, family members, trusted neighbors or friends can be paid for service, as well as employees of traditional home care provider agencies. To be eligible for CSG, a person must be a recipients of or eligible for Medical Assistance and be eligible to receive home care services from the Medical Assistance Home Care Program. In addition, CSG program participants must demonstrate limitations in everyday functioning, such as, self-care, language, learning, mobility, self direction, capacity for independent living and economic self-sufficiency and require ongoing supports to live in the community.

Minnesotans with disabilities or chronic illnesses who need certain levels of care may for the state's home and community–based waiver programs. Medicaid home and community-based service (HCBS) waivers afford states the flexibility to develop and implement creative alternatives to placing Medicaid-eligible persons in hospitals, nursing facilities or Intermediate Care Facilities for Persons with Developmental Disabilities (ICF/DD). HCBS waivers allow states to put together various service options that are not available under regular Medical Assistance. These service options are available to persons in addition to services covered by Medical Assistance. Generally, these services are targeted to people with specific needs or diagnosis.

Current Resources and Capacity

As efforts of advocacy organizations and the decisions of court cases began to dismantle the institutional model of caring for persons with developmental disabilities, it became clear that it is possible to support people with significant disabilities to live in the community. As services became available to support adults in the community, the irony that families were not supported to stay together became clearer.

There were calls for investing public money in supporting the family rather than replacing it. Policymakers were called on to provide some form of community services and supports to help "alleviate the stress of raising a child with a disability." We began to see the growth of respite programs, parent counseling and other support services.[11]

Most family-support programs are available to individuals with functional limitations or those with only the most severe chronic illnesses. Gaps have continued to exist for families of children with moderately disabling conditions and those who do not meet financial eligibility criteria for the programs.

As state budgets have come under pressure, so too have family-focused support programs. Waiting lists for services have grown, fees families pay for services have increased, and the types of services eligible for reimbursement have come under increasing scrutiny at the very least and been eliminated at most.

Public health provides leadership in infrastructure and capacity building of the community around health issues. These skills can be used to develop, support and maintain a system for supports for families and their children with special needs.

Public health conducts an assessment of community needs and resources. The problem area to be assessed is the lack of availability of support services child/youth/their families/young adults with disabilities.

Through a needs assessment process the problem areas for this population will be identified leading to the development of goals, strategies and a community

response to address this problem. The activities may include education of the community about the needs of this population and organizing the community to meet the needs of this population.

Under the assurance core public function, public health has a "safety net" responsibility to assure that every child/youth/their families/young adults is connected to or has access to the services they need. On a system level, public health assures that gaps in community services are identified and solutions developed which are population-based.

---

[1] A Picture of Needs for Children with Special Health-Care Needs: What we are Learning from the National Survey, Journal of Pediatric Nursing Vol. 20, No 3 June, 2005 pg 207-210

[2] National Survey of Children with Special Health Care Needs (2005/06) www.childhealthdate.org.

[3] Core Indicators Project. *Child/Family Survey Summary Report 2000.* National Association of State Directors of Developmental Disabilities Services and Human Services Research Institute. 2001.

[4] Miceli, P., Rowland, J., Whitman, T., (1999) In Whitman, T., Merluzzi, T., White, R (Eds) *Life-span Perspectives on Health and Illness*. (Chapter 9) Mahwah, MJ; Lawrence Erlbaum.

[5] National Survey of Children with Special Health Care Needs: Utilization and Unmet Needs (Survey Section 4) 2006-06

[6] The Institute of Medicine (2001), *Crossing the Quality Chasm*: A new health system for the 21st century. Washington, DC: national Academy Press.

[7] Tong, H., Haig, A., Nelson, V., Yamakawa, k, Kandala, G., Shin, K., *Low Back Pain n Adult FemaleCaregivers of Children with Physical Disabilities.*Archives of Pediatrics and Adolescent Medicine. (137) 1128-33. Nov 2003.

[8] Bartlett, S., Kolodner, K., Butz, A., Egglestion, P., Malveauz, F., Rand, C., *Maternal Depressive Symptoms and Emergency Department Use Among Inner-city Children with Asthma.* Archives of Pediatrics and Adolescent Medicine. 2001;155:347-353.

[9] Institute of Medicine report: Children's Health, the Nation's Wealth: Assessing and Improving Child Health June 24, 2004. Accessed 8/21/09.

[10] *Child/Family Survey Summary 2000.*

[11] Curriculum Highlights *Supported Living/Home of Your Own*. Partners in Policymaking. www.partnersinpolicymaking.com/curriculumliving.html