MATERNAL AND CHILD HEALTH BRIEF #4:

CHILDREN WITH SPECIAL HEALTH CARE NEEDS: THE COMMUNITY-BASED SERVICES SYSTEM

DECEMBER 2012

INDICATORS FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS AND THEIR FAMILIES

Delaware tracks a number of indicators specific to children with special health care needs and their families as part of its annual Maternal and Child Health Block Grant application. These indicators are:

- *The percent of children with special health care needs age 0-18 years whose families partner in decision making at all levels and are satisfied with the service they receive.*
- *The percent of children with special health care needs age 0-18 who receive coordinated, ongoing, comprehensive care within a medical home.*
- *The percent of children with special health care needs age 0-18 whose families have adequate private and/or public insurance to pay for the services they need.*

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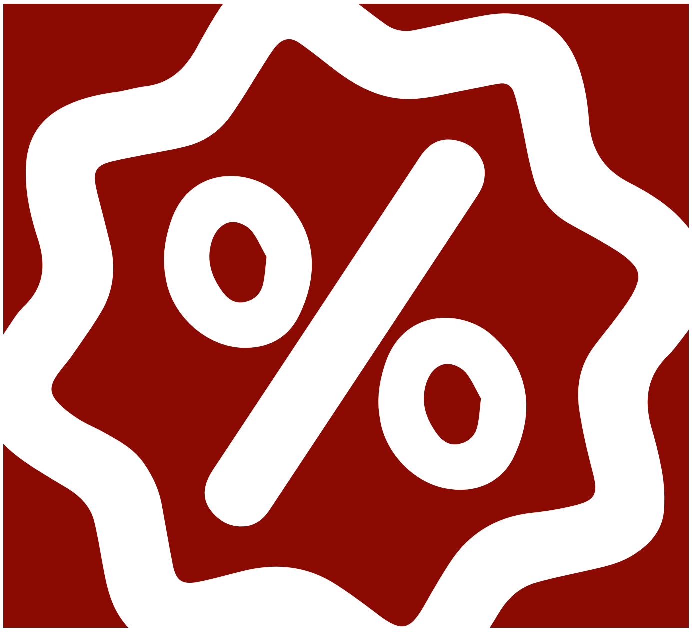
OVERVIEW

This Maternal and Child Health (MCH) Brief summarizes the latest data regarding family perceptions regarding the accessibility of the community-based services system for children with special health care needs. The brief also summarizes statewide initiatives in Delaware that support this performance measure.



2009/2010 NATIONAL SURVEY OF CHILDREN WITH SPECIAL HEALTH CARE NEEDS

The National Survey of Children with Special Health Care Needs (NS-CSCHN) measures ease of access and organization of the service system based on eligibility, availability of services within a geographic area, waiting lists or delays in securing an appointment for services, issues related to the cost of services, family perception of access to needed information, and family frustration with the services system. To meet the outcome of families reporting the community-based service systems are organized so they can use them easily, families must report having no difficulties or delays in getting services, and be only sometimes or never frustrated in efforts to get services for their children with special health care needs as reported on the NS-CSHCN.[ii]

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INDICATORS FOR CHILDREN *(CONTINUED)*

- *Percent of children with special health care needs age 0 – 18 whose families report the community based service systems are organized so they can use them easily.*
- *The percentage of youth with special health needs who received the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.*
- *The percent of health indicators that improve (child health, emotional and mental health, health care access and quality, and family health) for families and children with special health care needs in Delaware compared to health indicators among children without special health care needs.*

This brief focuses on the fourth of these measures, families' perceptions of the organization of community-based services and ease of use of these services.

Major challenges have been identified that confront families in accessing coordinated health and related services for their children with special health care needs. Differing eligibility criteria, duplication and gaps in services, inflexible funding streams and poor coordination among service agencies are concerns in Delaware, as well as across most states. Addressing these issues will lead to more efficient use of public funds and reduced family stress.[i]

2009/2010 SURVEY *(CONTINUED)*

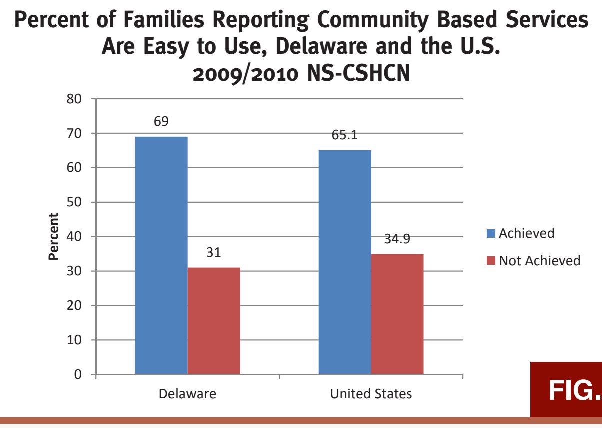

FIG.1

As seen in Figure 1, Delaware is similar to the nation in the percentage of families reporting the community-based service systems for children with special health care needs is organized in a manner which makes them easy to use (69% in Delaware vs 65.1% nationwide, n.s.). In Delaware, there were no significant differences by child sex or race/ethnicity. However, families with children aged 12-17 were significantly more likely to report meeting the objective than families with children aged 6-11 years (see Figure 2).

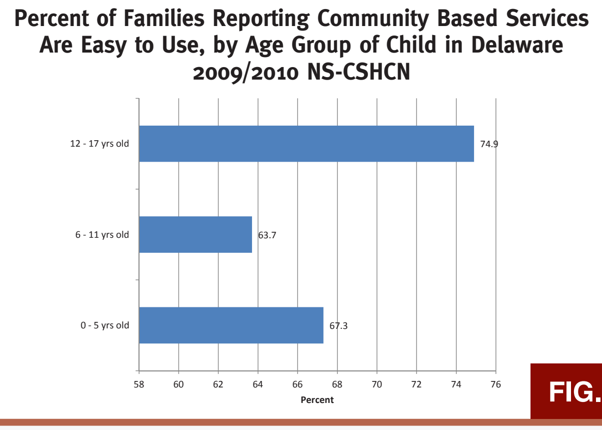

FIG.2

Other notable differences in terms of factors associated with families' perceptions of ease

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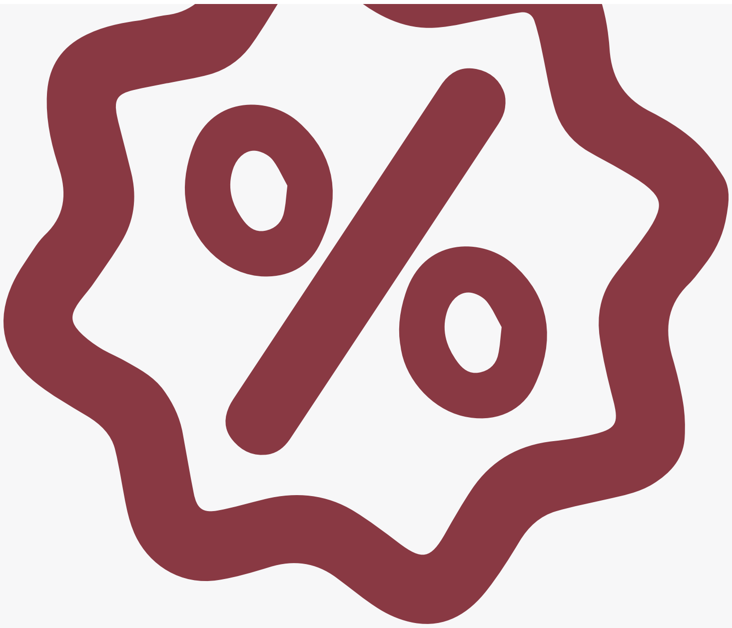

2009/2010 SURVEY *(CONTINUED)*

of use of community services were: perceived adequacy of current insurance; the presence of an emotional, behavioral or developmental issue for the child; and the intensity of services required for the condition. As seen in Figure 3, 77.2% of families with adequate health insurance reported the community-based system of services was easy to use, compared to 49.2% of families without adequate health insurance.

Percent of Families Reporting Community Based Services Are Easy to Use, by Adequacy of Insurance 2009/2010 NS-CSHCN

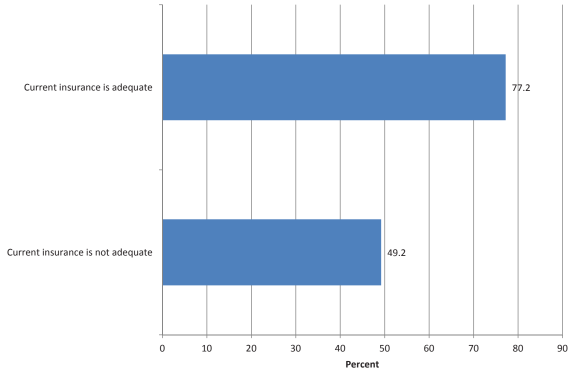

FIG.3

Families with children with no emotional, behavioral or development issues co-occurring with their special health care needs were more likely to report that community-based services were easy to use than families with children with emotional, behavioral or developmental issues as noted in Figure 4 (76.4% vs. 53.6%, respectively).

Percent of Families Reporting Community Based Services Are Easy to Use, by the Presence of an Emotional, Behavioral or Developmental Issue in Delaware 2009/2010 NS-CSHCN

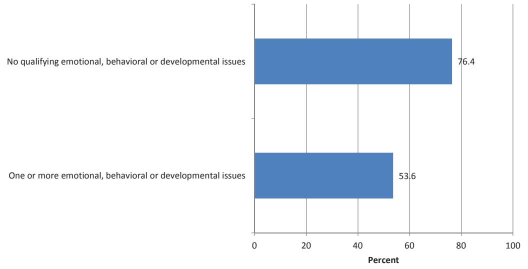

FIG.4

Though there were no significant differences between families with children who had functional limitations, families with children who required prescriptions and additional services, and families with children who required more than routine services, there was a significant difference between these three groups and families with children who could be managed with prescriptions only in terms of perceived ease of use of community services. (See Figure 5, 57.1%, 57.9%, 61.4%, respectively for the first three groups vs. 82.1% for families with children managed with prescriptions only).

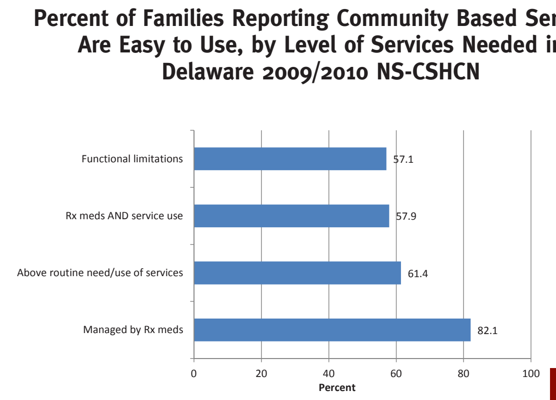

FIG.5

CHILDREN WITH SPECIAL HEALTH CARE NEEDS AND MATERNAL AND CHILD HEALTH PROGRAMS

The Title V Maternal and Child Health Block Grant Program requires states to set aside at least 30% of its federal funds for Children with Special Health Care Needs. In Delaware, a large portion of this set aside funding is allocated to Family SHADE.

Family SHADE is an alliance of 40+ organizations and agencies committed to working together to improve the quality of life of children with special health care needs by improving access to information and services in Delaware. Family SHADE was formed in response to a needs assessment of families and service providers conducted by Delaware's Maternal Child Health Bureau. The results of the needs assessment indicated the need to strengthen, expand, and coordinate a system of family supports that are easily accessible, avoid duplication, use resources efficiently, and prevent gaps in services to families of CSHCN throughout Delaware. To address these recommendations, organizations, agencies and family members came together to form Family SHADE, an "umbrella" organization that is specifically dedicated to sharing information, resources and expertise to benefit and support families of CSHCN.

REFERENCE

[i] HRSA, Title V Maternal and Child Health Block Grant Guidance

[ii] 2009/2010 National Survey, retrieved electronically on November 15, 2012 from www.childhealthdata.org

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DELAWARE HEALTH AND SOCIAL SERVICES

Division of Public Health

Center for Family Health Research and Epidemiology

DELAWARE DIVISION OF PUBLIC HEALTH
MATERNAL AND CHILD HEALTH PROGRAMS

Jesse Cooper Building

417 Federal Street Dover, DE 19901

(302) 744-4551

http://www.dhss.delaware.gov/dhss/dph/chca/dphmchhome.html