

Children with special health care needs (CSHCN) are “children who have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally.” Among children whose parents responded to the Health Care Survey of DoD Beneficiaries (HCSDB), 26 percent who use TRICARE Prime or Standard/Extra for most of their care were identified from survey responses as CSHCN<sup>1</sup>. Many CSHCN need a wide range of services and may be at risk for poor health outcomes because their care, coordination of needed services, or access to care are inadequate. Recent studies of CSHCN showed that 7 percent do not obtain needed specialty care (Mayer, et al. 2004); 11 percent do not receive needed therapy services; and 9 percent do not receive needed mobility aids (Dusing, et al. 2004).

According to American Academy of Pediatrics (AAP) guidelines, doctors and health plans serving CSHCN should be particularly attentive to the need for “accessible, comprehensive, continuous, compassionate and family-centered” care (American Academy of Pediatrics, 1999). Doctors and nurses must work to overcome families’ lack of information about resources, and to coordinate medical and non-medical services. With TRICARE, active duty parents of children with special needs are served by programs that provide access to needed services, assist parents when they must change duty stations, and provide financial and other assistance purchasing needed services or equipment (GAO, 2001).

### Health Care Ratings

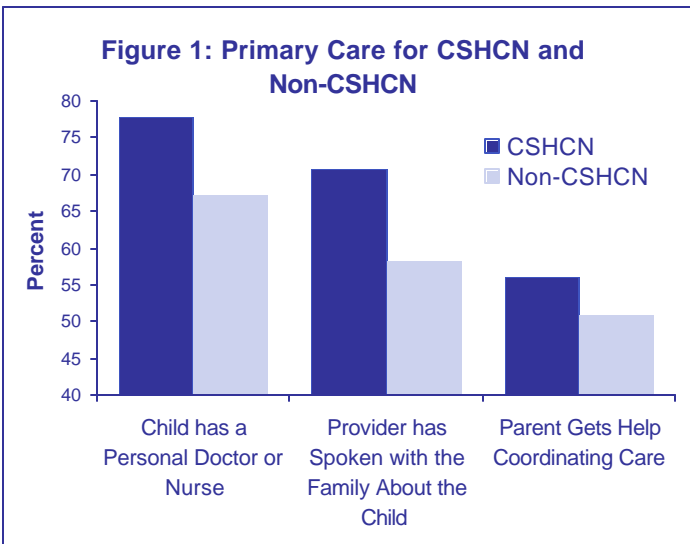
Most parents who rely on TRICARE give high marks for the health care their children receive. As shown in Table 1, among both CSHCN and non-CSHCN, about half of parents who respond give the highest ratings (9 or 10) on a 1 to 10 scale to their personal doctor or nurse (53 percent

<sup>1</sup> HCSDB questions that identify CSHCN concern children’s need for prescription medicine; use of care or educational services; or limitations in their ability to do the things most children of the same age can do. The questions are widely used by researchers into children’s health to identify CHSCN.

	CSHCN	Non-CSHCN
	Percent	
Health Care Rated 9 or Above	53	53
Personal Doctor Rated 9 or Above	53	50
Specialist Rated 9 or Above	55	52

for CSHCN and 50 percent for others), specialist (55 percent for CSHCN compared to 52 percent), and overall health care (53 percent for both).

In several dimensions of care that are particularly important to CSHCN, their parents report better care than do parents of non-CSHCN. As shown in Figure 1, 78 percent of CSHCN have a personal doctor or nurse compared to 67 percent of non-CSHCN. Similarly, parents of CSHCN are more likely than non-CSHCN parents to report that their child’s personal doctor has spoken with the family about how the child is feeling, growing, or behaving. However, these results also indicate that of CSHCN, who are the children most in need of a personal doctor, more than 20 percent did not have one.



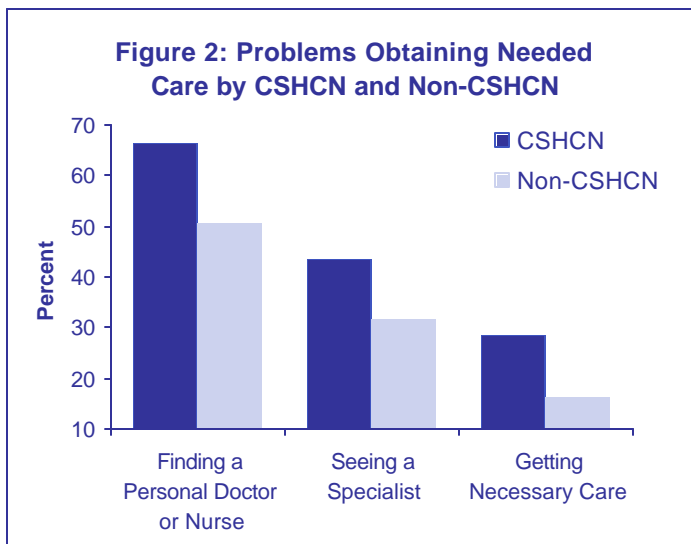
## Experiences of Children with Special Health Care Needs in TRICARE

Figure 1 also shows that 56 percent of families with CSHCN who got care from more than one type of provider or used more than one type of service got help coordinating their child's care compared to 51 percent of families with non-CSCHN. Though parents of CSHCN were more likely than parents of non-CSHCN to get help coordinating care, their responses indicate that nearly half of both CSHCN and non-CSHCN did not get the help they needed.

Another dimension of care particularly important to CSHCN is "family-centeredness." Table 2 shows that, for families that have had to make decisions about their child's health care, families with CSHCN and non-CSHCN report very similar experiences. About four-fifths of both groups say their doctors consistently involve the family as much as the family wants in decisions about their child's care. Approximately three-fourths of parents for both populations, report their doctors offer choices about the child's health care; 80 percent of parents report that these doctors discuss the pros and cons of their child's treatment options; but only 71 percent of CSHCN parents and 70 percent of non-CSHCN, say their doctors ask what choice the family prefers.

### Access to Care

Many parents report that children who rely on TRICARE for their health care encounter access problems. As they do in the civilian population, CSHCN in TRICARE encounter problems more frequently than do other children. For example, as shown in Figure 2, 51 percent of parents with non-CSHCN felt it was a problem to find

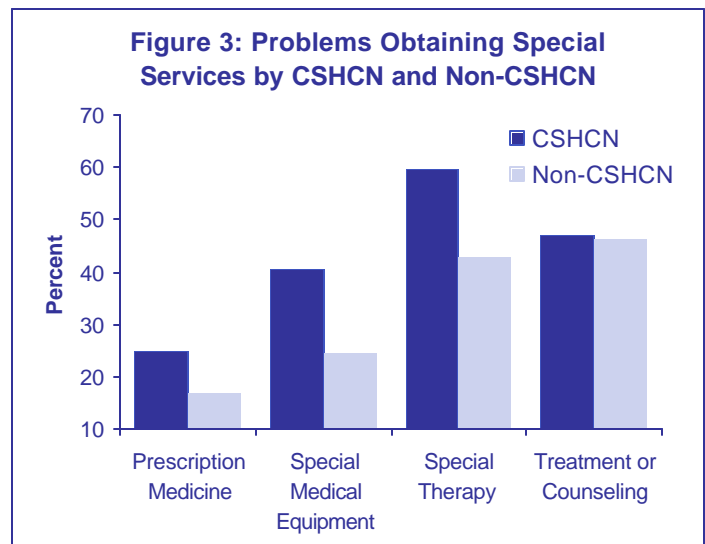


**Table 2.  
Getting Help With Children's Special Needs**

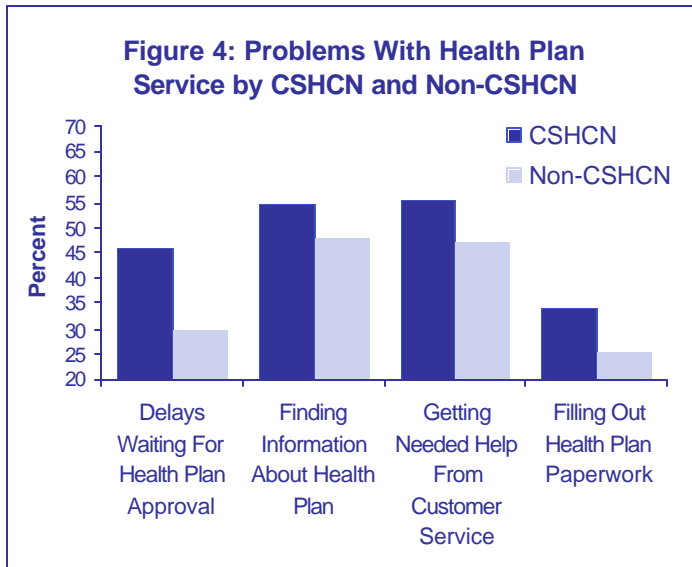
Doctors usually or always...	CSHCN	Non-CSHCN
	Percent	
Involve the Family	82	81
Offer Choices	77	76
Discuss Pros & Cons	80	80
Ask Family What They Prefer	71	70

their child a personal doctor or nurse with whom they were happy but 67 percent of families with CSHCN reported that problem. More parents of CSHCN than parents of non-CSHCN also report it is a problem to see a specialist or to get tests or treatments that their doctor thinks are needed.

Similarly, when children need special services, more CSHCN than non-CSHCN encounter problems meeting their needs. As shown in Figure 3, parents of CSHCN report more problems getting prescription medicine (25 percent compared to 17 percent), special medical equipment (41 percent compared to 25 percent), and special therapy (60 percent compared to 43 percent).



# Experiences of Children with Special Health Care Needs in TRICARE

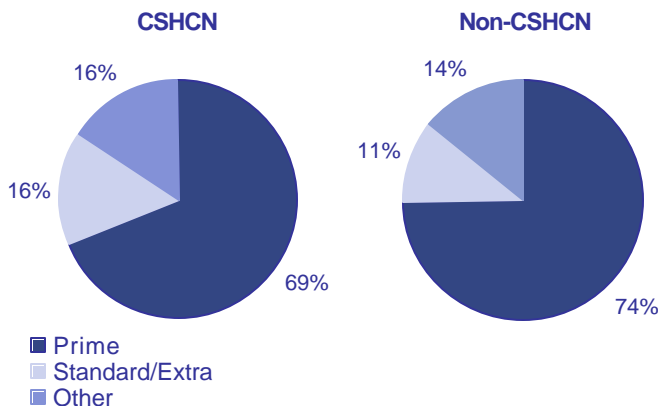


## Working with Health Plans

Because they must interact frequently with their health plans to get access to the treatments their children need, parents of CSHCN experience more problems with their health plans than do parents of non-CSHCN.

As shown by Figure 4, families with CSHCN are more likely than other families to encounter delays caused by waiting for health plan approval. Forty-six percent of CSHCN parents report problems with delays compared to 30 percent of non-CSHCN parents. Compared to other families, more families with CSHCN encounter problems in finding information about how their health care plan works (55 percent compared to 48 percent), getting needed help from customer service lines (55 percent compared to 47 percent), and dealing with paperwork (34 percent compared to 25 percent).

**Figure 5: Choice of Health Plan**



## Choice of Health Plan

From the health plan choices available through TRICARE, 16 percent of CSHCN rely on TRICARE Standard/Extra for most of their care compared to 11 percent of non-CSHCN (Figure 5). Fewer CSHCN than non-CSHCN are enrolled in TRICARE Prime (69 percent compared to 74 percent). As shown in Table 3, parents of CSHCN rate health care from their health plans similarly to parents of non-CSHCN but care from Standard/Extra is rated higher than care from Prime by parents from both groups.

Forty-four percent of both populations gave the best ratings (a 9 or 10 on a 1 to 10 scale) to care received through TRICARE Prime and 59 percent of both populations gave high ratings to care received through

**Table 3. Health Care and Health Plan Features**

	Prime		Standard/Extra	
	CSHCN	Non-CSHCN	CSHCN	Non-CSHCN
	Percent			
<b>Health Care</b>				
Health Care Rated 9 or Above	44	44	59	59
Child Has Personal Doctor or Nurse	75	66	89	78
Provider Understands Condition Affects Family	74	67	86	85
No Problem Getting Needed Care	70	83	79	88
No Problem Seeing A Specialist	55	67	64	78
<b>Health Plan</b>				
Health Plan Rated 9 or Above	41	44	30	31
No Problem With Paperwork	68	77	59	64
No Problem With Delays Awaiting Approval	52	69	62	80
No Problem With Customer Service	46	54	41	45

## Experiences of Children with Special Health Care Needs in TRICARE

TRICARE Standard/Extra. By contrast, health plan ratings are higher from parents relying on Prime for their children's care than from parents relying on Standard/Extra.

In spite of large differences in ratings of health care and health plan between Prime and Standard/Extra, ratings of their plans by CSHCN parents are generally consistent with ratings by non-CSHCN parents. As shown in Table 3, parents of children enrolled in TRICARE Standard/Extra, whether CSHCN or non-CSHCN, are less likely to report access problems, and are more likely to report favorably on interactions with doctors and the family centeredness of their care than parents of children enrolled in TRICARE Prime. Parents of children enrolled in Prime rate their health plan higher than do Standard/Extra users and have fewer problems getting information about their health benefits. However, Prime enrollees are more likely than Standard/Extra users to experience delays waiting for approval.

### Conclusion

The quality of health care for CSHCN who are enrolled in TRICARE or who use TRICARE Standard/Extra appears to be equal to, or better than, that of other children who use these health plans. However, care can be improved in many ways important to children with special health care needs. Many CSHCN, particularly in Prime, do not have a personal doctor, and their parents do not get information or help in coordinating care that they need. Also, like children in civilian health plans, more CSHCN than non-CSHCN encounter problems in accessing needed care and interacting with their health plan. Parents of CSHCN who use Standard/Extra rate their child's health care and access to care higher than do Prime users, but have more problems than Prime users getting information and dealing with paperwork. For parents who rely on Prime to provide care for their CSHCN, the goal of coordinated, family-centered care may be promoted by ensuring that such children have a personal doctor.

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