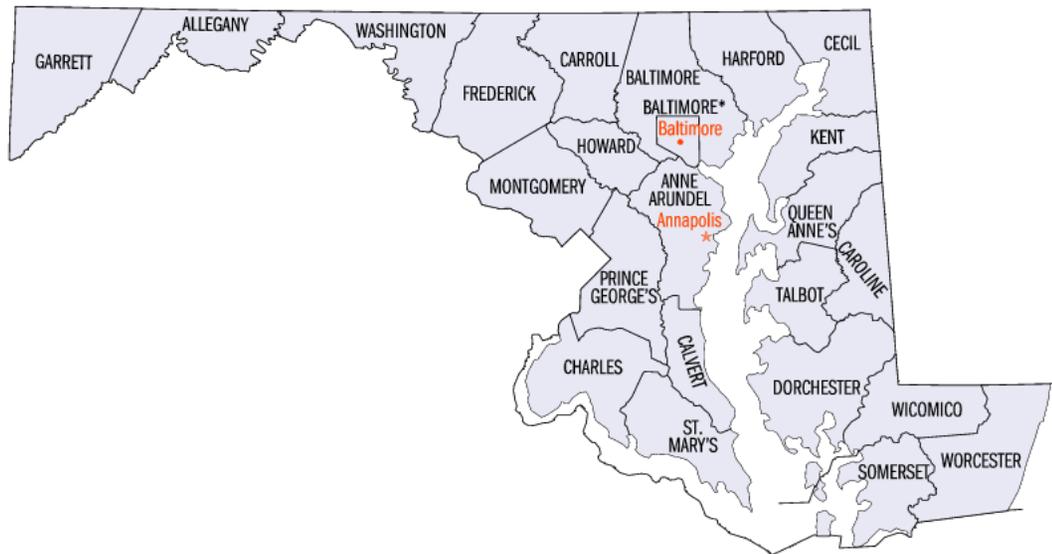


2005 Maryland Title V Needs Assessment Report for Children and Youth with Special Health Care Needs



Prepared by
The Office for Genetics and CSHCN
Maryland Dept. of Health and Mental Hygiene
July 2005

CYSHCN Needs Assessment Methodology

Conceptual Framework

Broad domains for assessing need were chosen by the needs assessment committee based upon the existing national performance measures for CYSHCN as well as the content areas utilized on the 2001 National Survey of CSHCN. The domains chosen were Health Care Needs and Access to Care, Impact on Family, Comprehensive Health Care Through a Medical Home, Adequate Insurance to Pay for Services, Community-Based Services Organized for Easy Use, Family-Professional Partnerships and Satisfaction with Services, Early and Continuous Screening, and Transition to Adult Life. Additional indicators/areas of interest under each of these broad domains were identified based upon input from Title V CSHCN Program staff and informal stakeholder input including families. Data was gathered from both quantitative and qualitative sources in an attempt to create a comprehensive picture of the needs of the CYSHCN population in Maryland.

Quantitative Data Sources

1. National Surveys

- National Survey of Children with Special Health Care Needs (2001, NCHS/MCHB)
- National Survey of Children's Health (2003, NCHS/MCHB)

2. State Surveys

- Needs Assessment of Individuals with Spina Bifida (2004, Chesapeake-Potomac Spina Bifida Association)
- Hemophilia Foundation Needs Assessment (2005, Hemophilia Foundation of Maryland)
- Barriers to Quality Child Care Survey (2003, Maryland Developmental Disabilities Council)
- Medicaid Managed Care Customer Satisfaction Survey (2003, Maryland Dept. of Health and Mental Hygiene)
- Maryland School Health Services Survey (2003, Maryland State Department of Education)
- Survey of Maryland Pediatricians on UNHS Program (2004, Maryland chapter American Academy of Pediatrics)
- Survey of Maryland Licensed Audiologists (2004, Maryland Dept. of Health and Mental Hygiene and Towson University)

3. Program Data

- Program Data, Office for Genetics and CSHCN, Maryland Dept. of Health and Mental Hygiene (Title V CSHCN Program)
- Program Data, Office of Health Services, Maryland Dept. of Health and Mental Hygiene (Maryland Medicaid Program)

- Program Data, Maryland Family Access Initiative/Parents' Place of Maryland
- Program Data, Mental Hygiene Administration, Maryland Dept. of Health and Mental Hygiene
- Program Data, Social Security Administration
- Program Data, Maryland State Department of Education

Qualitative Data Sources

1. Focus Groups

- Focus Groups on Health Care Transition for CYSHCN (2004-5, Maryland Dept. of Health and Mental Hygiene)
- Focus Groups on Medical Home (2005, Maryland chapter American Academy of Pediatrics)
- Focus Groups - Maryland Family Access Initiative (2004, Georgetown University Center for Child and Human Development and Parents' Place of Maryland)
- Focus Groups on Newborn Screening Communication (2004, Maryland Dept. of Health and Mental Hygiene and Louisiana State University Health Sciences Center)

2. Key Informant Interviews

- CSHCN Focused Needs Assessment (2003, Talbot County Health Department)

3. Town Meetings

- Town Meetings on Inclusive Child and After-School Care for CSHCN (2004, Maryland Department of Disability)

4. Mixed Methodology

- Somerset County CSHCN Needs Assessment (2003, Somerset County Health Department)
- Needs Assessment for Special Medical Services for Children (2000, Frederick County Office for Children and Families/Local Management Board)
- A Needs Assessment for CSHCN (2004, Caroline County Health Department)

Gaps in the Data

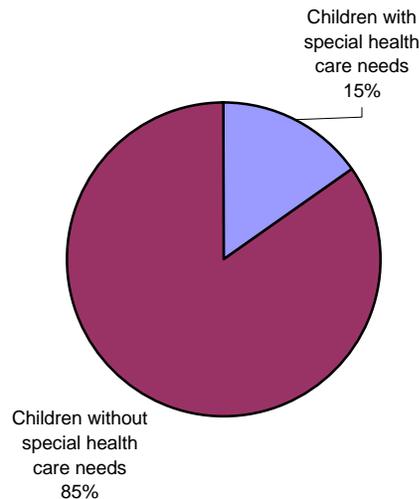
It is very difficult to collect data that is representative of the broadly defined population of CYSHCN on either a quantitative or qualitative basis. Quantitative data on this population outside of the large, national surveys has been generally limited to surveys of

specific condition groups. Qualitative data may be somewhat more representative. Maryland also lacks county-specific data for the CYSHCN population, with the exception of some programmatic data (ex. special education counts). There is also a general lack of data on minority groups, especially the Hispanic population. Content areas where there is a particular need for additional data include quality of life for CYSHCN, barriers to health care transition from the view of adult providers, screening and referral practices of Maryland physicians and scope of screening beyond early childhood, child abuse/neglect in the population of CYSHCN, and reimbursement issues impacting the care of CYSHCN.

Prevalence of Children and Youth with Special Health Care Needs in Maryland

According to the 2001 National Survey of CSHCN, the prevalence of CYSHCN ages 0-17 years in Maryland is 15.2%, corresponding to approximately 209,000 children and youth (see figure 1). This is significantly greater than the national prevalence of 12.8%. Almost one-quarter of all households with children in Maryland have one or more CYSHCN.

Figure 1: Prevalence of Maryland children with special health care needs ages 0-17 years



Newer data from the 2003 National Survey of Children's Health estimates the prevalence of CYSHCN in Maryland at 18.3%, compared with 17.6% nationally.

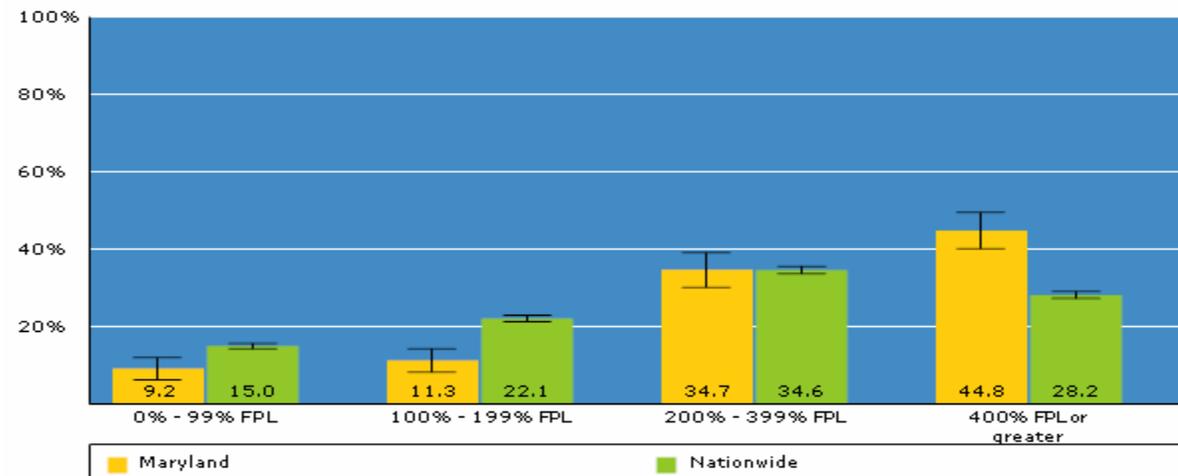
As expected, the prevalence of special needs is greatest in children and youth over the age of 5 years, reaching a high of 18.2% of children and youth between the ages of 12-17 years based on data from the 2001 National Survey of CSHCN. In Maryland, mirroring the nation as a whole, special needs are present more frequently in males than in females (17.9% versus 12.4%), and also appear to be diagnosed more commonly in multi-racial children and youth as well as in non-Hispanic whites. The highest prevalence of special health care needs by race estimated in Maryland was 19.2% for multi-racial children and youth.

Maryland data also suggests that there may be a disparity in prevalence of special needs by income level. The 2001 National Survey of CSHCN estimates that Maryland children at 0-99% FPL are significantly more likely to have special health care needs than children at all higher incomes; this is in contrast with the national as a whole where there is virtually no disparity in the prevalence of special health care needs by income.

Socio-Demographics of Maryland's Children and Youth with Special Health Care Needs

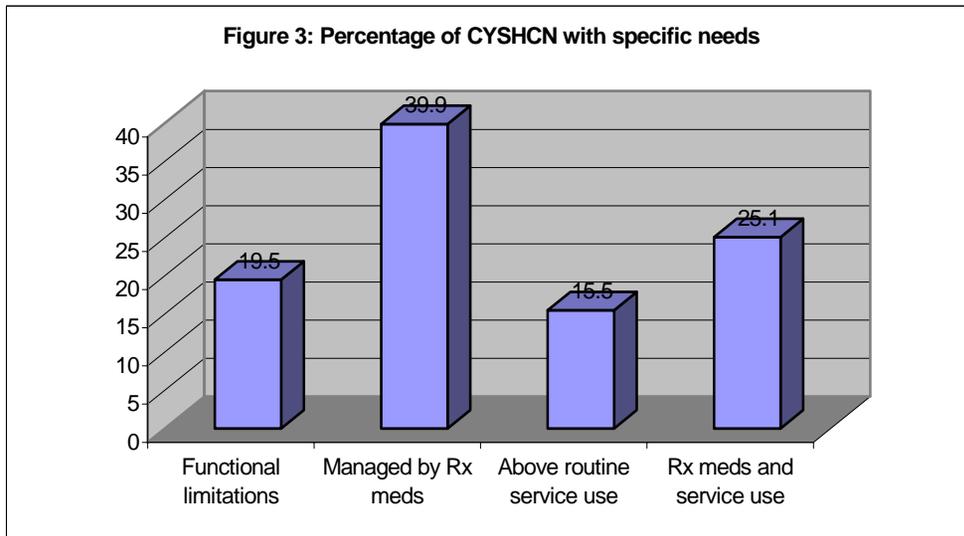
In the population of CYSHCN in Maryland, the majority fall between the ages of 8-14 years of age according to the 2001 National Survey of CSHCN. Over 60% are male and approximately 63% are non-Hispanic whites. Slightly over 9% of CYSHCN in Maryland live in households at 0-99% FPL while almost 45% live in households at 400% FPL or greater. This is quite different from the nation as a whole where more CYSHCN live in the extremes of poverty (15%) and many fewer live in the highest income category (about 28%) as estimated by the 2001 National Survey of CSHCN (see figure 2). This data likely reflects Maryland's status as one of the wealthier states in the nation.

Figure 2:
Prevalence of CYSHCN living in poverty, Maryland vs. nation



Characterizing the Special Health Care Needs Population

The 2001 National Survey of CSHCN classified CYSHCN in a noncategorical fashion by the consequences of their chronic condition including elevated service use, need for prescription medications, and functional limitations. In Maryland, 19.5% of CYSHCN are reported to have functional limitations due to their conditions on the 2001 National Survey of CSHCN. Almost 40% are reported to use prescription medications alone to manage their condition, and over 25% are reported to use prescription medications and have above routine use of services related to their special health care need (see figure 3). About 17% of Maryland CYSHCN require specialized therapies.



Mental health and developmental problems are particularly prevalent in CYSHCN, and may be increasing. According to the 2001 National Survey of CSHCN, over 28% of CYSHCN in Maryland have ongoing emotional, behavioral, or developmental problems; these children and youth are more likely than other CYSHCN to live in the poorest families. More recently on the 2003 National Survey of Children's Health, 31% of CYSHCN ages 3-17 were reported to have moderate or severe difficulties in the areas of emotions, concentration, behavior, or being able to get along with other people.

The 2003 National Survey of Children's Health reported state-specific data on 2 chronic conditions,

asthma and ADHD. In Maryland, 12.8% of respondents reported that their children had asthma, with 9.3% reporting that their child had experienced health effects from their asthma in the past year. Of children 2-17, 7.9% were reported to have ADHD, with 4.8% taking medication at the time of the survey.

Data from a number of programs serving CYSHCN in Maryland can also help characterize this population. In Maryland as of December 2003, there were 13,697 children and youth ages 0-17 years receiving SSI disability. Almost 66% of these children were receiving their SSI disability benefit under the category of mental disorders, which includes mental retardation. Data from the Mental Hygiene Administration, which administers the State funded mental health system, reports that it served 41,362 severely emotionally disturbed children under age 18 in FY03.

Data from the Maryland State Department of Education indicate that as of October 2003, there were 113,865 children ages 3-21 receiving publicly funded special education services in Maryland. This represents 13% of the population of children enrolled in Maryland public schools, a stable figure compared with 1998, and an increase from about 12% in 1993. Looking at the total enrolled population by ethnicity, students of Asian/Pacific Islander descent and Hispanic descent were underrepresented in the population of students receiving special education services. The majority of the children receiving special education services were male (68.5%) and white (52%). Children with specific learning disabilities account for the highest percentage at approximately 36%. There were 4,084 children receiving services under the autism category, about 2.5 times greater number of children than in 1998 and 14.5 times greater

than in 1993. The other high growth disability in Maryland over this time period is children with emotional impairments, increasing steadily from 5669 children in 1993 to 9727 children in 2003.

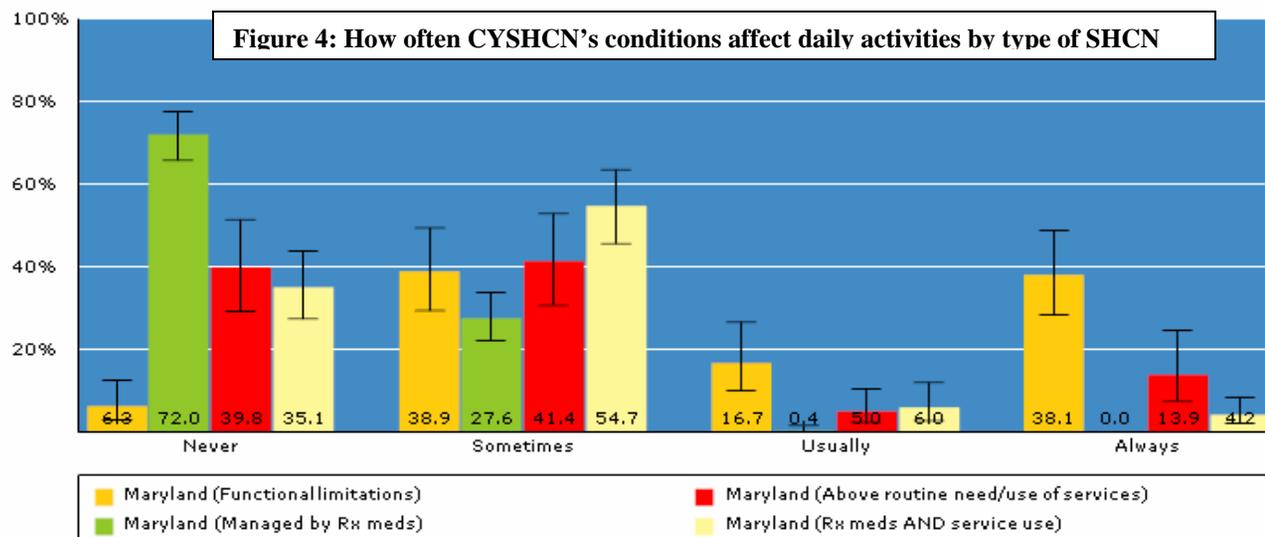
As of October 2004, there were 6,276 children ages 0-3 years receiving services through the Infants and Toddlers program in Maryland.

The Maryland School Health Services Survey completed for the 2002-03 school year reported 109,186 children ages 3-21 in the school system with chronic health conditions; this does not include data from 3 of the largest jurisdictions in the state. Among the conditions reported on the survey were almost 29,000 children with ADHD, over 44,500 children with asthma, 1,434 children with diabetes, 1,939 children with heart problems, and 2,265 children with orthopedic impairments.

Health Status and Quality of Life

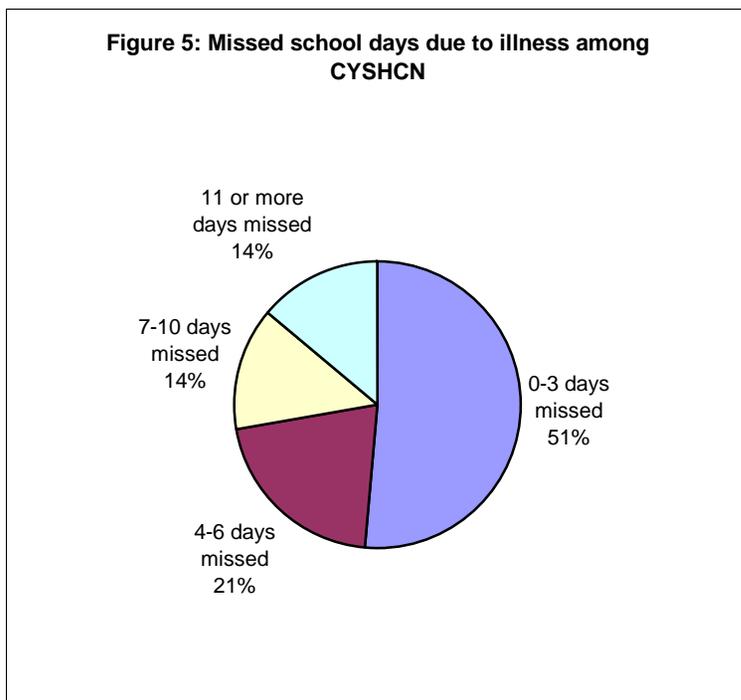
On the 2001 National Survey of CSHCN, almost half (47%) of parents ranked their child's condition as moderate, while about 20% ranked their child's condition as severe or most severe. The remaining 33% ranked their child's condition as mild. Children with functional limitations were most likely to be ranked as severe or very severe by their parents (over 43%), and children just managed by prescription medications were most likely to be ranked as mild (57%). Children at the extremes of poverty were most likely to have their condition ranked as severe or very severe by their parents as compared with children in other income categories.

Over 45% of parents reported that their child's condition never affects his/her daily activities, while about 16% reported that it usually or always does. Children managed by prescription medications alone were least likely to be affected in their daily activities, with 72% reported by parents to never be affected. As



expected, children with functional limitations were most affected in their daily activities, with almost 55% usually or always affected, and another 39% sometimes affected (see figure 4). Once again, children at the extremes of poverty were reported by parents to be most often affected by their conditions.

According to the 2001 National Survey of CSHCN, over half of children (51.5%) missed only 0-3 days of school in the year prior to the survey due to their condition. However, one in 7 CYSHCN were reported to have missed 11 or more school days (see figure 5). Children with functional limitations missed the most school.



The 2003 National Survey of Children’s Health looked at overall health status of children. As might be expected, children without special health care needs were more likely to have their health status reported as excellent or very good than CYSHCN, 91% versus 73%. Of note, on this survey, only 5.5% of CYSHCN had their health status reported as fair or poor.

There is limited data specifically looking at quality of life for CYSHCN. On the 2004 Needs Assessment of Individuals with Spina Bifida conducted by the Chesapeake-Potomac Spina Bifida Association, almost 74% of respondents rated their overall quality of life as excellent or very good.

Health Care Needs and Access to Care

Key Findings

- On the 2001 National Survey of CSHCN, over half of Maryland families reported that their child needed 2-4 different types of health services in the past year, and over 45% needed greater than 5.
- While the majority of CYSHCN received all of the services they needed, about 1 in 6 families reported one or more unmet needs.

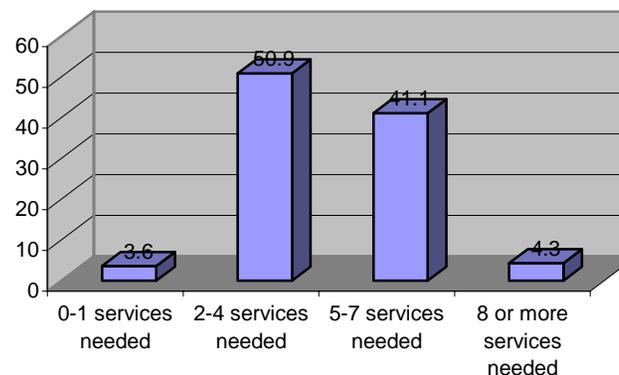
Disparities

- Uninsured CYSHCN and those without adequate insurance were more likely to have one or more unmet needs.
- Hispanic CYSHCN were also more likely to have one or more unmet needs.

Health Care Needs

CYSHCN often require access to a wide range of health and related services. On the 2001 National Survey of CSHCN, slightly over half of Maryland families reported that their CYSHCN required 2-4 services in the past year, while over 45% needed greater than 5. Eight or more services were required by 4.3% of CYSHCN (see figure 6). Children with functional limitations generally required higher levels of services than other CYSHCN. The services required most by CYSHCN were prescription medications (90.4%), routine preventive health care (81.7%), dental care (81%), specialty care (52.6%), vision care or eyeglasses (38%), and mental health care/counseling (27%).

Figure 6: % of CYSHCN reporting need for specific health care services

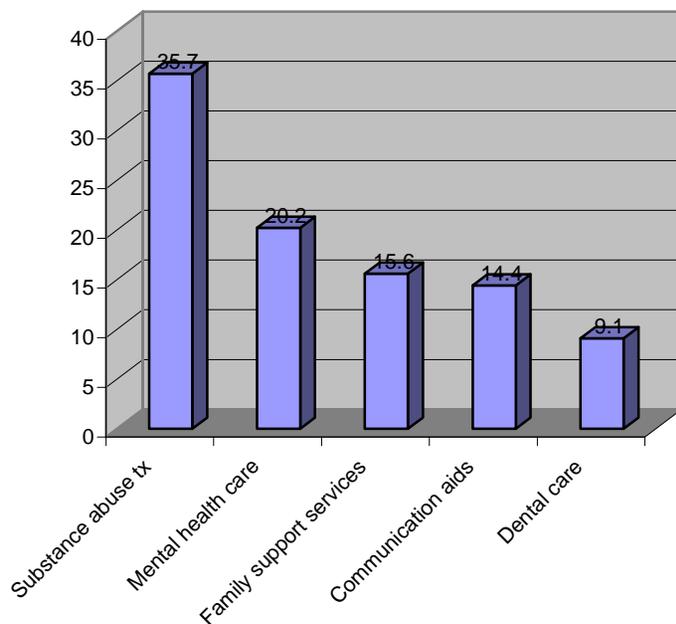


Unmet Need

While the majority of CYSHCN received all of the services that they needed, over 16% had one or more unmet needs for health services in the past year, and 4.5% had 2 or more unmet needs. There were similar findings from the 2004 Needs Assessment of Individuals with Spina Bifida where almost 16% reported unmet need for health and related services. According to the 2001 National

Survey of CSHCN, uninsured CYSHCN, those with inadequate insurance, Hispanic CYSHCN, and CYSHCN without medical homes are more likely to report one or more unmet needs.

Figure 7: % of CYSHCN needing specific services who reported unmet need



Of those families whose child needed specialty care on the 2001 National Survey of CSHCN, almost 27% reported problems getting a referral. Of note, only 3.5% of families reported an unmet need for specialty care. Other services with relatively high unmet need were substance abuse counseling (almost 36% of families whose child needed substance abuse counseling reported unmet need), mental health care or counseling (over 20%), family support services (almost 16%), communication aids or devices (14.4%), and dental care (over 9%, see figure 7). The 2003 National Survey of Children’s Health reported an unmet need for preventive dental care in 6.8% CYSHCN, compared with only 4.1% of children without special health care needs.

On the 2003 Maryland Medicaid Managed Care Customer Satisfaction Survey, the percentage of CSHCN members who were reported to have no problems getting needed care ranged from 67-79% compared with 75-89% for non-CSHCN child members. In addition, only 52-58% of parents of CSHCN members reported on this survey that their child always got care quickly.

Barriers to Care

There are many barriers to needed care for CYSHCN. On the 2001 National Survey of CSHCN, the 5 most frequently cited reasons for delaying or foregoing needed care in descending order were lack of money to pay provider, type of care not covered by health plan, appointments conflicted with other home and work responsibilities, could not get approval from plan/doctor, and could not get appointment soon enough. Further discussion of specific barriers to care for CYSHCN can be found in the corresponding section of the CYSHCN needs assessment report.

Impact on Family

Key Findings

- Mothers of Maryland CYSHCN are significantly less likely to have mental and/or physical health rated as excellent or good than mothers of children without SHCN on the 2003 National Survey of Children's Health.
- Over 27% of families have cut down on work hours to care for their CYSHCN, and over 12% have a member who has stopped working due to their child's condition, according to the 2001 National Survey of CSHCN.
- About 1 in 6 families report that their child's health condition has caused financial problems for their family.

Disparities

- The families most likely to report financial problems due to their child's condition are Hispanic families, families who live at the extremes of poverty, and families whose child has functional limitations.
- The poorest families are also more likely than others to have cut back on work hours or stop working due to their child's condition.

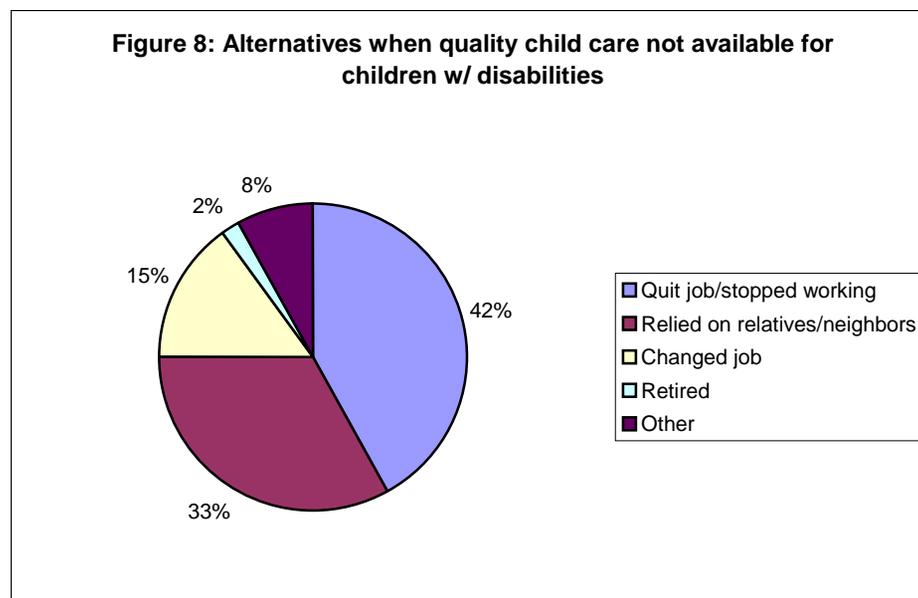
Impact on Employment

Caring for CYSHCN can have a significant impact on families. The needs of CYSHCN can vary greatly. For instance, some children receive care from several providers and have frequent medical appointments. Some are dependent upon technology and may need assistance with basic activities of daily life such as feeding. Others may need to take medications. While the majority of families spend less than one hour per week providing and/or coordinating their child's care, about 1 in 11 families spends 11 or more hours per week doing this, according to the 2001 National Survey of CSHCN. As a result, some families find that it is necessary for a family member to cut back on work hours in order to be able to meet the multiple demands of caregiving. Over 27% of families have cut down on work hours to care for their CYSHCN, and over 12% have a member who has stopped working due to their child's condition, according to the 2001 National Survey of CSHCN. The poorest families are more likely than others to cut back on work hours or to stop working.

Access to Child Care

Lack of quality child care certainly contributes to the impact that having CYSHCN can have on employment. In 2003, the Maryland Disabilities Council surveyed families of children with disabilities about child care issues; 83% of respondents reported difficulties in

finding, obtaining, or keeping child care. When asked what their alternative was when they were unable to find child care, 42% reported that they had stopped working, and 33% had changed jobs to accommodate their lack of child care (see figure 8). The number one barrier to obtaining and/or keeping child care reported on the Developmental Disabilities Council survey was lack of provider willingness to accept the child, presumably based on the child's disability. Also ranked highly were concerns about quality of care available for their child and lack of provider knowledge about how to meet the child's special needs. The lack of quality child care for CSHCN is supported by data from the 2003 National Survey of Children's Health, where almost half of families with CSHCN ages 0-5 reported problems with child care, significantly greater than reported by families whose children did not have special health care needs. Data from the Developmental Disabilities Council as well as from town meetings across the state on Inclusive Child and After School Care also support the need for appropriate after school care programs for CYSHCN.



Financial Impact

Cutting back on work hours or stopping work altogether can significantly impact a family's finances. In addition, the costs associated with providing care for CYSHCN can be great. About 1 in 11 families reported out-of-pocket health care costs between \$1001-\$5000 per year on the 2001 National Survey of CSHCN. Based on 2004 focus group data from the Maryland Family Access Initiative, depending upon the child's diagnosis, out-of-pocket expenses could reach up to \$10,000 per year. It is not surprising, therefore, that about 1 in 6 families reported that their child's health condition has caused financial problems for their family, according to the 2001 National Survey of CSHCN. The families most likely to report financial problems due to their child's condition were Hispanic families, families who live at the extremes of poverty, and families whose child has functional limitations.

Family Health and Respite

The issues discussed above can put stress on family members of CYSHCN. According to the 2003 National Survey of Children's Health, mothers of CYSHCN are significantly less likely to have mental and/or physical health rated as excellent or very good than

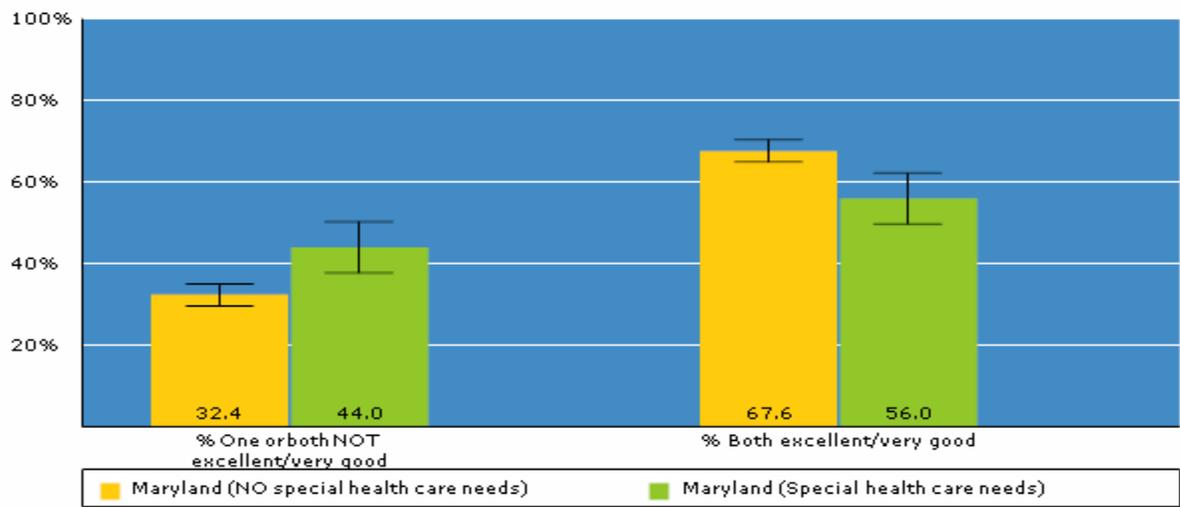


Figure 9: Children & youth w/ mothers whose mental and physical health are BOTH excellent/very good

mothers of children without special health care needs (see figure 9). The need for regular respite activities for families is a recurring theme in all local health department needs assessments. On the 2004 Needs Assessment of Individuals with Spina Bifida, over 20% of respondents reported problems with lack of respite care. According to the 2001 National Survey of CSHCN, about 22% of Maryland families who reported needing respite in the 12 months prior to the survey indicated that they did not receive all of the respite care that was needed. Respite was identified as the 2nd highest area of unmet need in the survey. The limited availability of trained respite providers in certain areas of the state as well as lack of education on the part of families regarding respite services are barriers that have been identified related to accessing respite care.

Comprehensive Health Care Through a Medical Home

Strengths/Assets

- Over 92% of Maryland CYSHCN are reported to have a usual source of care on the 2001 National Survey of CSHCN.
- 90.5% of families feel that their child's health care providers usually or always listen carefully to them, and almost 89% feel that their child's providers spend enough time with them.
- 91% of families reported a personal doctor or nurse who is consistently available when phone advice or urgent care is needed for their child on the 2003 National Survey of Children's Health.

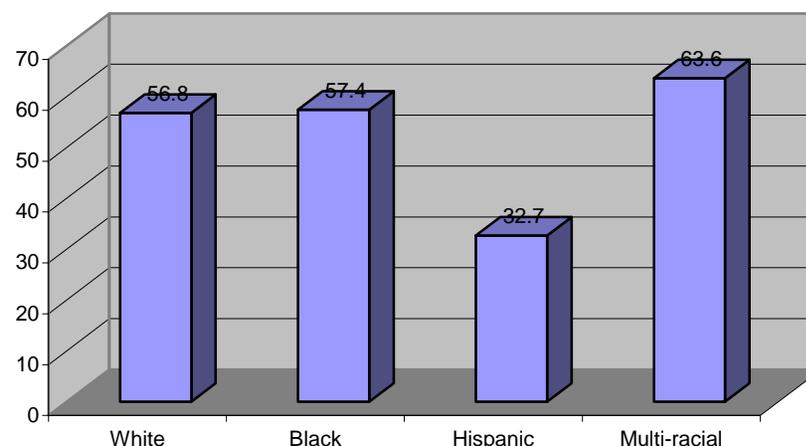
Challenges/Needs

- Just over 56% of Maryland CYSHCN are receiving care that meets all criteria for a medical home according to the 2001 National Survey of CSHCN.
- Only about 35% of families have effective care coordination for their CYSHCN when needed.
- Hispanic CYSHCN, children with functional limitations, and uninsured CYSHCN are the groups least likely to report care consistent with a medical home.

Medical Home Prevalence

While having a medical home is important for all children, CYSHCN in particular need the type of care embodied by this model. According to the 2001 National Survey of CSHCN, just over 56% of Maryland CYSHCN are receiving care that meets criteria for a medical home compared with 52.7% nationally. Hispanic CYSHCN, children with functional limitations, and uninsured CYSHCN are the groups least likely to report care consistent with a medical home (see figure 10). Although the more recent 2003 National Survey of Children's Health measured medical home in a different fashion, similar results were seen for Maryland with just over 51.4% of CYSHCN reporting care consistent with a medical home model. This is compared with 55.8% of children without SHCN reporting care consistent with a medical home.

Figure 10: % of CYSHCN who have medical homes by race/ethnicity



Usual Source of Care

Having a usual source of care is a starting point for a medical home. Over 92% of Maryland CYSHCN are reported to have a usual source of care on the 2001 National Survey of CSHCN. A personal doctor or nurse for their CYSHCN was reported by just over 88% of families on this survey, and almost 94% of families on the 2003 National Survey of Children's Health. This is also reinforced by data from the 2003 Needs Assessment of Individuals with Spina Bifida. This survey found that 94% of respondents reported having a primary care provider. In Maryland, the greater need is to move beyond just having a usual source of care and put a more comprehensive medical home model into practice.

Coordinated Care

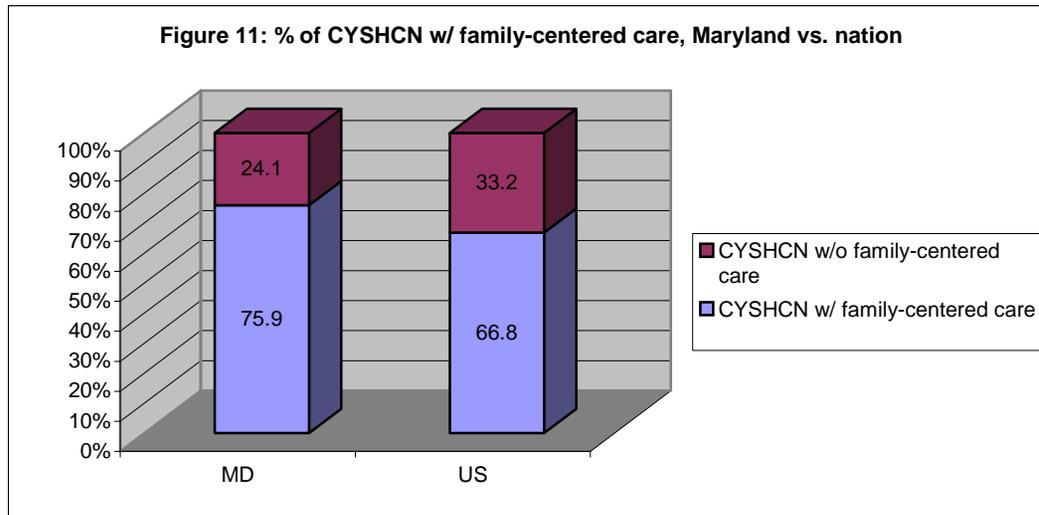
One particular need reported by families is for better coordination of care by health care providers. On the 2001 National Survey of CSHCN, only about 35% of respondents were found to have effective care coordination for their CYSHCN when needed. In a local health department needs assessment in Somerset County (2003), almost all respondents reported that their child's care was sometimes to never coordinated by a professional, and in a series of focus groups conducted by the Maryland Family Access Initiative grant in 2004, families almost unanimously reported that they were receiving no supports with care coordination and none from their primary health caregivers. A key issue in care coordination is communication. On the 2001 National Survey of CSHCN, only 48% of families of CYSHCN who needed care coordination reported that their doctor's communication with other health care providers was excellent or very good, and only 27% reported that their doctor's communication with other programs was excellent or very good. Lack of communication among providers was also a barrier to medical home identified in a series of medical home focus groups held by the Maryland chapter of the American Academy of Pediatrics throughout the state in early 2005. Even providers note that effective communication and collaboration is problematic. For example, in a local health department needs assessment in Talbot County (2003), providers identified a key need for liaisons between parents, schools, agencies, and medical providers.

Accessible Care

Accessibility of care is a critical medical home component. On the 2003 National Survey of Children's Health, 91% of families of CYSHCN reported a personal doctor or nurse who is consistently available when phone advice or urgent care is needed for their child. A more problematic issue involving accessibility is referral to specialty care. On the 2001 National Survey of CSHCN, almost 27% of families who reported that their child needed specialty care had problems getting a referral. The medical home focus groups highlighted a tension between parents and providers about what constitutes an "appropriate" referral. Insurance barriers and availability of specialists also play a role in this issue. An additional problem related to referrals was highlighted on the 2003 National Survey of Children's Health, where only 62.5% of families reported having a personal doctor or nurse who consistently follows up with the family after the CYSHCN sees a specialist or gets specialized services/equipment. A lack of follow-up by physicians after referrals was also noted in the medical home focus groups held by the Maryland chapter of the American Academy of Pediatrics.

Family-Centered Care

Another important pillar of the medical home model is family-centered care. This is a relative strength for Maryland according to the 2001 National Survey of CSHCN, where it was estimated that almost 76% of Maryland CYSHCN receive care that is family-centered,



compared with less than 67% nationwide (see figure 11). The survey estimated that 90.5% of families felt that their child's health care providers usually or always listened carefully to them, almost 89% felt that their child's health care providers spent enough time with them, and over 90% felt that their child's health care providers were sensitive to their families' values and customs. On the 2003 National Survey of Children's Health, 79% of families reported that their CYSHCN had a personal doctor or nurse who consistently spent enough time with them and explained things in a way that parents and the child could understand. In Maryland, family-centered care was found to be less accessible to

CYSHCN who had functional limitations, children who were Hispanic, and children without insurance. Not surprisingly, this is similar to the disparities found for having a medical home as noted previously. One emerging issue of importance that was noted in local health department needs assessments by both parents and providers (Caroline County 2004, Frederick County 2000) was the issue of inadequate resources for communicating appropriately with families with limited English proficiency.

Cost of Care/Reimbursement

The greatest barriers to providing medical homes identified by pediatricians in the medical home focus groups conducted by the Maryland chapter of the American Academy of Pediatrics were time and money. Caring for CYSHCN takes more time than caring for a child without special health care needs, and much of this time is either not reimbursed or inadequately reimbursed by insurance companies. Examples included the time needed for extended visits, making referrals, refilling prescriptions, writing letters of medical necessity, communicating with other providers, and generally coordinating care. They also noted the burden of trying to keep up with the various and changing procedures and provider lists among the many insurance companies that they must deal with. This takes so much time and effort that many practices are resorting to use of a dedicated referral coordinator, but this again is an unreimbursed expense for the practice.

Adequate Insurance to Pay for Services

Strengths/Assets

- On the 2001 National Survey of CSHCN, over 97% of Maryland families of CYSHCN reported having insurance at the time of the interview.
- Over 93% reported no gaps in health insurance coverage in the year prior to the survey, compared with 88.4% nationally.

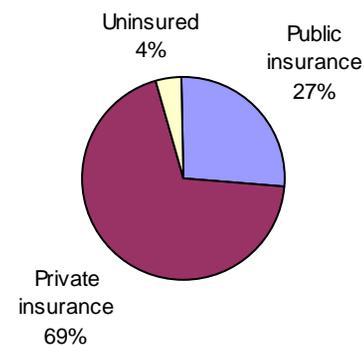
Challenge/Needs

- Almost 1/3 of Maryland CYSHCN do not have adequate insurance, according to the 2001 National Survey of CSHCN.
- CYSHCN from the poorest families are more likely to lack insurance coverage or to have insurance that is not adequate to pay for the services they need.
- Hispanic and multi-racial CYSHCN and those with functional limitations are less likely to have adequate insurance.

Rate of Insurance Coverage

On the 2001 National Survey of CSHCN, over 97% of Maryland families of CYSHCN reported that their child had public or private health insurance at the time of the interview. The national rate of uninsurance was almost double the Maryland rate. In addition, over 93% of Maryland families of CYSHCN reported that their child had no gaps in health insurance in the year prior to the survey, compared with 88.4% nationally. While the overall rate of insurance coverage for Maryland CYSHCN is high, CYSHCN from the poorest families are more likely to lack insurance coverage, with an uninsurance rate estimated at 2.5 times higher for families living at 0-99% FPL than for Maryland CYSHCN as a whole. Although the numbers are small, this data is similar to the trend at the national level. In addition, from Maryland's experience with the Children's Medical Services Program which serves as payer of last resort for specialty care and related services for uninsured and undersinsured CYSHCN, it is known that a significant portion of the uninsured children in Maryland lack coverage due to their citizenship status. This number

Figure 12: Type of health insurance coverage CYSHCN



will increase as of July 1, 2005, when about 3000 Maryland children who are legal immigrants but have lived in the US for less than 5 years will lose their health insurance through Maryland Medicaid.

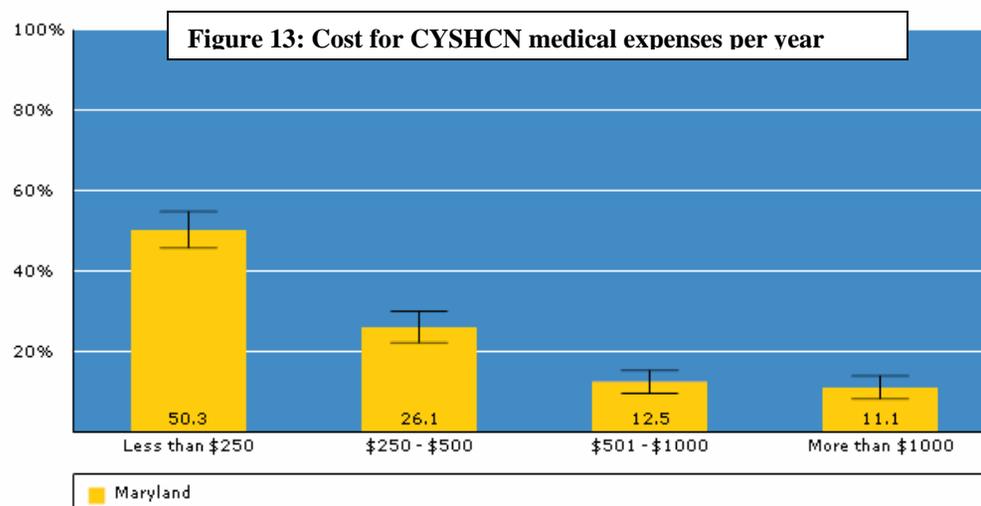
The overall high rate of insurance coverage for CYSHCN in Maryland is supported by more recent data from the 2003 National Survey of Children’s Health, where 95.9% of CYSHCN were insured at the time of the survey. Additionally, this survey indicated that the majority of insured CYSHCN are covered by private insurance (over 69%) with less than 27% covered by public insurance (see figure 12).

Adequacy of Insurance

Adequacy of health insurance is the greater challenge in Maryland. According to the 2001 National Survey of CSHCN, almost 1/3 of Maryland CYSHCN do not have insurance that is adequate to pay for the services they need. On the 2004 Needs Assessment of Individuals with Spina Bifida, over half of respondents indicated that getting health care services covered by their insurance was definitely or somewhat of a problem. Similarly, on the 2005 Hemophilia Foundation Needs Assessment, 43% of respondents were concerned about getting services covered by their health insurance. Adequacy of insurance is a greater problem for CYSHCN from the poorest families, for Hispanic and multi-racial CYSHCN, and for CYSHCN who have functional limitations, according to the 2001 National Survey of CSHCN.

Out-of-Pocket Costs

One issue related to insurance adequacy is out-of-pocket costs. On the 2001 National Survey of CSHCN, over 1/4 of families of CYSHCN reported that costs not covered by insurance were never or only sometimes reasonable. In Maryland, families with private insurance tend to incur more out-of-pocket costs than those with other insurance types. About 1 in 9 families reported costs greater than \$1000 per year on the National Survey of CSHCN (see figure 13); families whose child had private insurance were about 3.5 times more likely to report this than those whose child had Medicaid. Based on 2004 focus group data from the Maryland Family Access Initiative, depending upon the child’s diagnosis, out-of-pocket expenses could reach up to \$10,000 per year.



Access to Needed Providers

Another critical issue is access to needed providers. On the 2001 National Survey of CSHCN, about 1 in 11 families reported that their child's insurance never or only sometimes allowed them to see needed providers. Focus groups on medical home conducted by the Maryland chapter of the American Academy of Pediatrics in early 2005 highlighted the fact that some pediatric providers do not accept Medicaid or limit the number of patients with Medicaid due to lower reimbursement rates. On the 2003 Maryland Medicaid Managed Care Customer Satisfaction Survey, 21% of child members reported having significant problems seeing needed specialists. Difficulty accessing needed specialist services was also reported in Maryland Family Access Initiative focus group findings for both those with Medicaid and those with private insurance, as well as in a number of local health department needs assessments (Talbot County 2003, Somerset County 2003, Caroline County 2004, Frederick County 2000). Issues included no appropriate specialist in network and no appropriate specialist in geographic proximity. The providers most frequently noted were mental health providers and dental providers.

Other Scope of Benefits

Insurance plans may place limitations on coverage for certain types of services that particularly impact CYSHCN. For instance, some plans limit the number of visits per year to mental health providers or limit visits for specialized therapies such as PT, OT and speech. In addition, plans can restrict how frequently durable medical equipment can be purchased and the types of equipment covered. These restrictions translate into out-of-pocket costs as noted above, or families may do without services. While this information is heard not infrequently when discussing insurance issues with families, there was little data from the needs assessment about these specific issues.

Navigating Health Plans

A final issue is the complexity of using health plans and difficulty getting or understanding information about how to use the plan or how to appeal adverse decisions. On the 2003 Maryland Medicaid Managed Care Customer Satisfaction Survey, between 23-38% of respondents with a child with special health care needs reported difficulties with customer service in their plans, compared with 13-25% of child members with no special health care need. Based on statistics tracking family calls to Parents' Place of Maryland through the Maryland Family Access Initiative in 2004 for assistance with insurance issues, the number one concern of callers with either Medicaid or private insurance was lack of information about how to navigate their plans.

Community-Based Services Organized for Easy Use

Strengths/Assets

- Over 70% of Maryland families of CYSHCN report that services are usually or always organized for easy use on the 2001 National Survey of CSHCN.

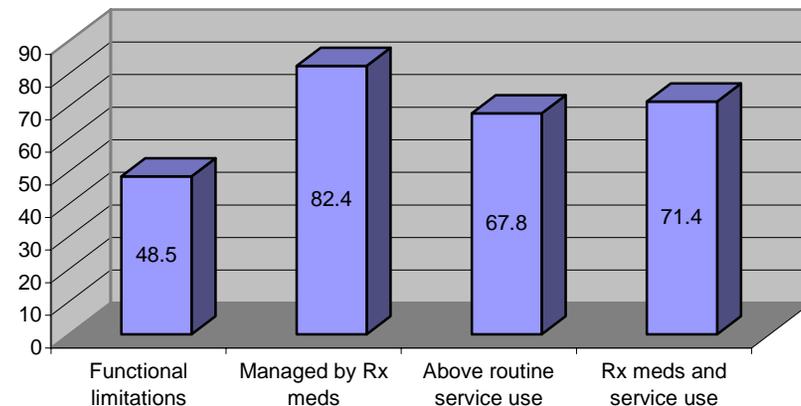
Challenges/Needs

- Less than half of families whose CYSHCN have functional limitations report that services are organized for easy use.
- Only 43% of families of uninsured CYSHCN report that services are organized for easy use.
- Hispanic and multi-racial families of CYSHCN are less likely to report that services are easy to use.

Organization for Easy Use

CYSHCN and their families must often access a number of health-related and family support services to meet their needs. Ideally, all of the services that a child and family require would be easily available and accessible within that child's community. On the 2001 National Survey of CSHCN, over 70% of families of CYSHCN reported that services were usually or always organized for easy use. While this represents the majority of CYSHCN and their families, there is still a significant number who feel that there are problems with how community-based service systems are organized. In particular, a little less than half (48.5%) of families whose CYSHCN have functional limitations report that services are organized for easy use (see figure 14). The survey data suggest that these children are those with more severe health conditions or disabilities, and it is likely that they may require more extensive services than other children with special health care needs. In addition, families whose CYSHCN are uninsured are also much less likely to report that services are organized for easy use. It is not surprising that lack of health insurance presents a barrier to using needed services within the community. Hispanic and multi-racial families of CYSHCN are also less likely to report that services are easy to use. This may in part reflect issues with limited English proficiency and lack of culturally competent service systems.

Figure 14: % of CYSHCN reporting community services organized for easy use, by SHCN type



Navigating the System

Other available data beyond the 2001 National Survey of CSHCN highlight a number of different problems that are perceived by families and providers related to community-based systems of care. A persistent problem is the issue of “navigating the system” or finding out about available services within the community and gaining access to them. On the 2003 Needs Assessment of Individuals with Spina Bifida, 60% of respondents reported a lack of information about available services. Tracking calls to Parents’ Place of Maryland as part of the Maryland Family Access Initiative in 2004, one of the top 3 needs of families was information about health care and non-medical services and how to access them. In addition, multiple local health department needs assessments (Caroline County 2005, Talbot County 2003, Frederick County 2000) indicated a need for information and referral mechanisms, resource coordinators, and “helping families know about services.”

Of note, in the medical home focus groups held by the Maryland chapter of the American Academy of Pediatrics in early 2005, parents did not feel that pediatrician’s offices were a good source of information on accessing community resources. Even pediatricians admitted that they don’t typically have this type of information in their offices, and some had never even thought about this. Most thought that it was a good idea to have information about community resources available to families, but they didn’t feel like they had the time or personnel to put this together for their practice.

Local Access to Services and Transportation

Another barrier to community-based systems of care, particularly in the outlying areas of the state such as the Eastern Shore and Western Maryland, is the limited availability of specialty providers (especially mental health) and dentists within the community. Even when providers are available locally, there may be other problems such as long waiting lists or insurance issues (especially not accepting Medicaid). When providers are not available or accessible within the community, families are forced to travel, sometimes several hours to the large specialty centers, in order to get the care that their child needs. Transportation remains a major barrier for many families, as noted in virtually every local health department needs assessment. Lack of providers for CYSHCN within the community also extends to specialized therapies such as PT, OT and speech/language services in some areas of the state as well as respite, child care, and other family support services. Once again, this forces families to look for these services outside their community or to go without them.

Family-Professional Partnerships and Satisfaction with Services

Strengths/Assets

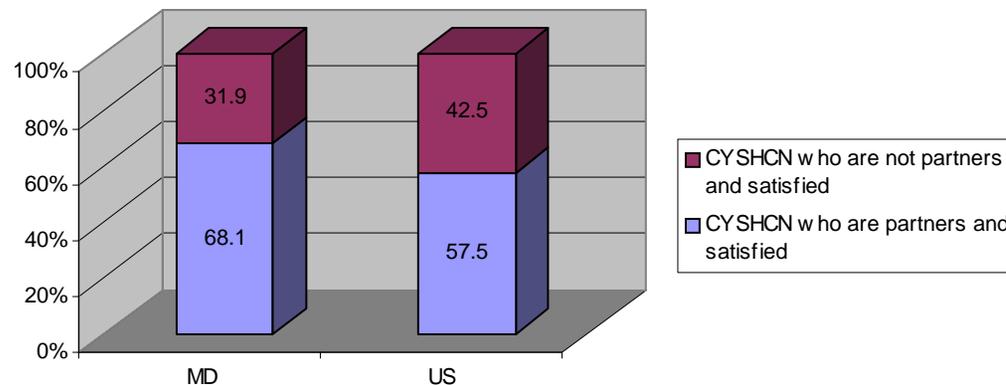
- According to the 2001 National Survey of CSHCN, over 88% of families of Maryland CYSHCN report that their child’s health care providers help them feel like a partner in care.
- Over 70% of Maryland families report that they are very satisfied with services compared with 60% nationally.
- Almost 76% of families of CYSHCN are estimated to receive family-centered care, compared with less than 67% nationwide.

Challenges/Needs

- Hispanic families, uninsured families, and those whose child has a functional limitation are less likely to report feeling like partners and satisfaction with care.
- These same families are also less likely to receive care that is family-centered.

Family-professional partnerships and satisfaction with care are a relative strength for Maryland. According to the 2001 National Survey of CSHCN, over 68% of families of CYSHCN report that they are partners in decision-making and are satisfied with the services they receive, compared with 57.5% nationally (see figure 15).

Figure 15: % of CYSHCN who are partners in care and satisfied w/ services, Maryland vs. nation



Family-Professional Partnerships

Over 88% of families of Maryland CYSHCN report that their child’s health care providers help them feel like a partner in care on the 2001 National Survey of CSHCN. This finding is supported by data from the 2003 Needs Assessment of Individuals with Spina Bifida which found that over 82% of respondents felt that medical personnel have kept them informed and involved in health care decisions.

Satisfaction with Care

Over 70% of Maryland families report that they are very satisfied with services on the 2001

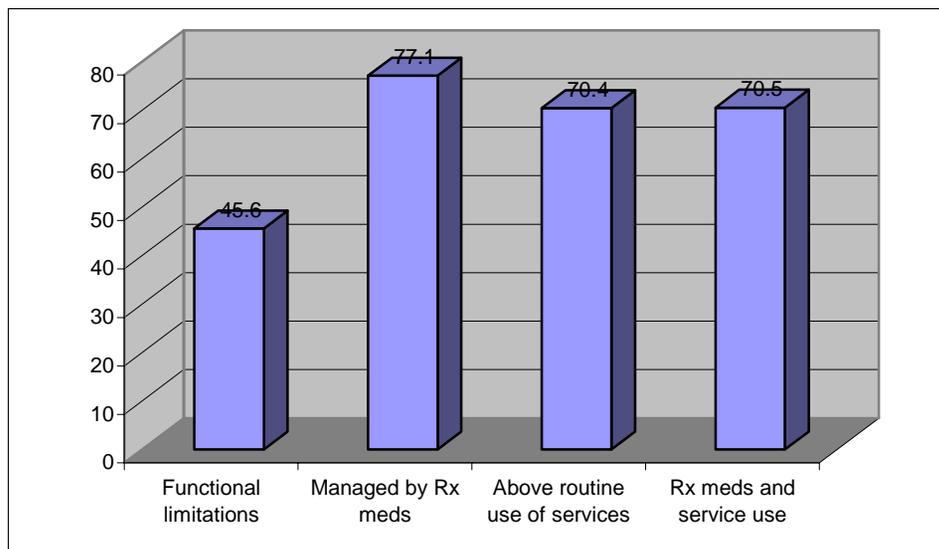
National Survey of CSHCN, compared with only 60.1% nationally. Satisfaction with health care services in Maryland is also indicated by the 2003 Medicaid Managed Care Customer Satisfaction Survey where families of CSHCN members gave their child's overall health care an average rating of 8.6-8.8 out of 10 and gave their child's personal doctor or nurse average ratings of 8.8-9.2 out of 10. In addition, on the 2005 Hemophilia Foundation Needs Assessment, 91% of respondents were satisfied with the quality of their health care services.

Family-Centered Care

According to the 2001 National Survey of CSHCN, almost 76% of Maryland families of CYSHCN receive care that is family-centered, compared with less than 67% of families of CYSHCN nationwide. Family-centered care is discussed in detail under the domain "Comprehensive Health Care Through a Medical Home."

While Maryland does appear to do somewhat better than the nation in regards to family-professional partnerships, satisfaction with services, and family-centered care, there is certainly a good deal of room for improvement. The 2001 National Survey of CSHCN does indicate some areas of disparity, including Hispanic families, uninsured families, and families whose child has functional limitations (see figure 16).

Figure 16:
% of CYSHCN who are partners in care and satisfied w/ services by SHCN type



Early and Continuous Screening

Strengths/Assets

- In Maryland, almost 100% of newborns who are screened and confirmed with conditions receive appropriate follow-up as defined by the State.
- According to FY04 data, 91.2% of newborns were screened for hearing before leaving the hospital.
- Screening of children though EPSDT has been increasing.

Challenges/Needs

- Available data indicate that loss to follow-up at a number of levels is problematic for the UNHS Program.
- The 2003 National Survey of Children's Health estimated that almost 1 in 4 Maryland children is at moderate or high risk for developmental delay
- This survey documented that almost 47% of families of children ages 0-5 reported that they were not asked by their providers if they had concerns about their child's learning, development, or behavior in the past year.

Newborn Metabolic Screening

Screening is an important mechanism for the early identification of special health care needs in children. Institution of early treatment for children identified with certain disorders may prevent serious health and developmental consequences. Through the newborn metabolic screening and follow-up program in Maryland, almost 100% of babies identified with disorders are linked with appropriate medical care and other needed services. In the past several years, only one baby (a child with sickle cell disease) has been lost to follow-up as defined by the State. In FY04, 133 babies with metabolic and hematologic disorders were detected through the newborn metabolic screening and follow-up program.

In Maryland, the most important problem over the past 2-3 years has been the increasing difficulty in maintaining a comprehensive newborn screening program with 2 laboratories in the state licensed to provide newborn screening: the State public health laboratory and a private lab, Pediatrix. There have been a number of obstacles to providing what the OGCSHCN considers appropriate follow-up, particularly related to data sharing with Pediatrix and with comparing the results from several specimens on the same baby when some go to Pediatrix and some go to the State lab (Maryland has a routine 2nd specimen). The problems encountered are becoming increasingly significant as the fraction of Maryland hospitals using Pediatrix increases.

Maryland currently screens for all of the disorders recommended by the American College of Medical Genetics and the March of Dimes except for cystic fibrosis. However, cystic fibrosis will be added in the near future. The recent national attention brought to

newborn screening has created some tension between advocates and the newborn screening program. While new technology continues to make it possible to screen for increasing numbers of disorders, there does not appear to be awareness in the general public that not all conditions may be appropriate for screening. In addition, the resources required to create and support the infrastructure that would be needed for adequately following up individuals identified through a further expanded screening process are lacking.

Shortly after Maryland expanded its newborn screening panel to include disorders detectable through tandem mass spectrometry, focus groups on communication around newborn screening were conducted separately with new mothers of healthy infants and with pediatricians. Most mothers indicated that they had very little information about newborn screening. This is despite the fact that all mothers are given a brochure about newborn screening in the hospital and asked to sign a consent form prior to the heel stick. Many mothers remembered seeing the newborn screening brochure in their packet of information, but most reported receiving little information about it and did not read it. Mothers and pediatricians felt it was important that parents should have some basic information about newborn screening presented in a simple format, and both mothers and pediatricians indicated they would like to have information presented prenatally as well as after the baby is born.

Newborn Hearing Screening

In Maryland's Universal Newborn Hearing Screening (UNHS) Program, most newborns are screened for hearing prior to hospital discharge. This was 91.2% of infants in FY04, down slightly from 93.7% in FY03. Historically, between 180-210 infants are diagnosed with hearing loss each year in Maryland, with the average age at diagnosis 93.7 days in FY03. Nearing the end of its 5th year, the UNHS Program has made great strides in screening Maryland babies, but still experiences loss to follow-up at a number of levels. Recent evaluation of program data identified a number of problem areas. First, there are a disproportionate number of NICU babies lost to follow-up, which is particularly concerning because many of these infants are at a greater risk for hearing loss. In addition, the UNHS Program has noted that the number of infants failing the initial hearing screen who do not receive a rescreen by 6 weeks of age is relatively high. Follow-up specialists in the UNHS Program continue to meet resistance from parents and medical personnel when calling to suggest rescreening. Lastly, there is a lag between rescreen failure and diagnostic evaluation, which it seems may be at least partly due to failure of the audiology community to report diagnostic evaluations to the UNHS Program.

Another identified need of the Program is to raise awareness of the importance of early intervention services for children who are diagnosed with hearing loss. The Chapter Champion of the Maryland chapter of the American Academy of Pediatrics surveyed pediatricians in 2004. While 61.5% of respondents claimed familiarity with early intervention services in their area (i.e. the Infants and Toddlers Program), less than half referred to early intervention. In a survey of licensed audiologists also conducted in 2004 by Towson University Department of Audiology, only 64% of audiologists reported that they refer to the Maryland Infants and Toddlers Program. The UNHS Program also currently lacks the ability to track children's entry into early intervention services as well as the outcomes of intervention over time.

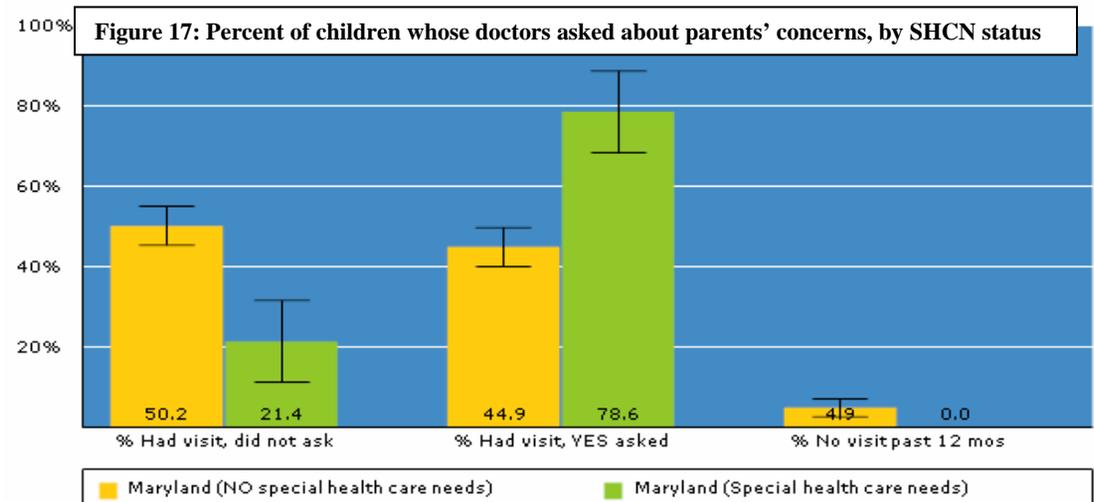
Birth Defects Surveillance

While not a screening program, the Birth Defects Reporting and Information System (BDRIS) seeks to identify children with birth defects as early as possible after birth and link their families with services. Maryland law currently mandates reporting of only 12 sentinel birth defects, with voluntary reporting of others. BDRIS is a passive surveillance system, and must rely upon the reports from providers in addition to reviewing vital records for case ascertainment. This creates a time lag in the program’s ability to accurately report data. The most recent complete statistics are from CY02, during which there were 536 sentinel defects in 491 Maryland babies and 1,034 non-sentinel defects. The rate of defects has been relatively stable over the past few years.

Since the adoption of HIPAA regulations, BDRIS has encountered significant difficulty in obtaining the medical information critical to fulfilling its role. This is due to concerns from health care providers about the extent to which the release of information is legally authorized under HIPAA. A need in Maryland is to pass legislation that will allow BDRIS to collect data on all birth defects, and to give the program clear-cut authority to access medical records for the purpose of identification and characterization of birth defects cases, investigation of birth defects clusters or potentially hazardous trends in the prevalence of birth defects, and investigation of environmental hazards. A bill to this effect was introduced in the 2005 legislative session, but ultimately failed due to unresolved concerns about informed consent issues.

Screening for Developmental and Behavioral Problems

The 2003 National Survey of Children’s Health estimated that almost 1 in 4 Maryland children is at moderate or high risk for developmental delay. However, in terms of screening for developmental and behavioral problems, this survey documented that almost 47% of families of children ages 0-5 reported that they were not asked by their providers if they had concerns about their child’s learning, development, or behavior in the past year. While almost 80% of families with CSHCN were asked about these concerns, less than 45% of families whose children did not have a special health care need were asked (see figure 17). In medical home focus groups held by the Maryland chapter of the American Academy of Pediatrics in



2005, many parent and professional participants felt that pediatric health care providers are not performing thorough screening for developmental problems. Issues raised were inappropriate or incomplete use of screening tests, amount of time required to administer tests, and lack of reimbursement.

Even when screening is accomplished and concerns are identified, there may be barriers to following up on these concerns. Of those families who reported that they were highly concerned about their child's learning, development, or behavior, over 45% reported that they did not get specific information from their doctors to address their concerns. Families with CSHCN were much more likely to report getting specific info than families who had children without special health care needs, almost 74% versus about 41%. In the medical home focus groups, families reported that some pediatricians seem to be reluctant to diagnose certain developmental and mental health problems and may recommend taking a "wait and see" approach rather than refer for specialist evaluation.

EPSDT

The Maryland Medicaid program tracks screening under EPSDT. On the 2003 Annual EPSDT Participation Report, an improvement from the previous year was reported in overall child screening ratio from 72% to 74%. Ratios were .96 for children under age 1 year, 1.13 for children ages 1-2, and .78 for children ages 3-5. Older children were screened at a ratio of .51 or less, which emphasizes the need for "continuous" screening as children get older.

Lead Screening

Elevated blood lead levels remain a serious problem for Maryland. Lead screening will be discussed elsewhere in the Maryland needs assessment report.

Transition to Adult Life

Strengths/Assets

- Available data indicates that some of the important components necessary for successful transition to adult life are occurring for some Maryland CYSHCN.

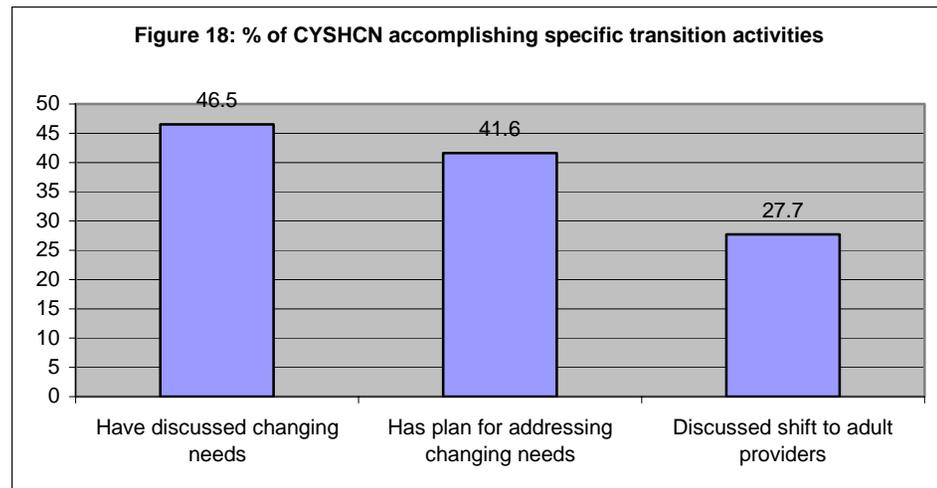
Challenges/Needs

- The 2001 National Survey of CSHCN estimates that the number of Maryland CYSHCN ages 13-17 who receive all the services necessary to make the transition to all aspects of adult life is only 2.7%.
- For the majority of CYSHCN, the data suggest that there is no cohesive plan to assist with transition to adult life and/or there are significant barriers within the current system to address transition needs.

Transition to adult life has emerged as an important issue as more CYSHCN are surviving into adulthood. The 2001 National Survey of CSHCN estimated that the number of Maryland CYSHCN ages 13-17 who receive the services necessary to make the transition to all aspects of adult life is only 2.7%; this is compared with an estimate of 5.8% for the nation as a whole.

Health Care Transition Process

Transition must take place in a number of different arenas. Health care transition is helping young people with special health care needs plan their move from the child-centered health care system to the adult-centered health care system. On the 2001 National Survey of CSHCN, about 47% of families of CYSHCN reported that they had providers who have talked with them about changing needs as an adult, and almost 42% had providers who have developed a plan with the child/youth to address changing needs (see figure 18). The 2005 Hemophilila Foundation Needs Assessment found that for individuals who had already transitioned, only 40% reported that someone had spoken to them about their transition to adult care. In transition focus groups held



with parents and their youth ages 13-21 across the state, very few families reported that their doctors had discussed health care transition with them, and very few had begun the process on their own. In fact, in the youth discussion, youth under age 18 expressed little knowledge and interest regarding health care transition.

Change to Adult Providers

One aspect of health care transition is the change to adult health care providers. On the 2001 National Survey of CSHCN, less than 28% of families of CYSHCN had providers who have discussed the eventual shift to adult providers (see figure 18). The 2004 Needs Assessment of Individuals with Spina Bifida found that a little over 50% of respondents over age 13 had talked with their primary care provider about seeing adult providers. In the transition focus groups, families and youth expressed a number of concerns related to finding a new doctor that takes care of adults. One concern was whether there would be a doctor willing to take on their youth with special health care needs. In medically underserved areas of the state, parents felt it was difficult enough to find good doctors for “normal, healthy adults.” A second concern was finding providers who were knowledgeable about the youth’s particular health condition or disability. Parents expressed that they were uneasy with the thought of their child being treated by doctors who did not have knowledge or experience with their child’s medical condition or disability, even if the doctor was willing to learn. They also expressed frustration at potentially having to educate a new doctor about their child’s condition. Youth generally expressed similar views. Lastly, families had concerns about the nature of the adult health care environment including differences in bedside manner and how individuals are treated, and less accommodating scheduling, office hours, etc.

Assuming Responsibility for Care

Another important component of health care transition is for CYSHCN to learn to take responsibility for their care as developmentally appropriate. In the 2004 Needs Assessment of Individuals with Spina Bifida, over 63% of respondents over age 13 reported that they knew how to manage their health care. In the 2005 Hemophilia Foundation Needs Assessment, parents reported that children as young as 6 years of age were assisting with some aspects of their health care. While some parents in the transition focus groups had already taken a few steps toward encouraging their children to play a more active role in their health care, they reported that it is often difficult to get their children to take on more responsibility. In families where the youth had a condition that significantly interferes with decision-making, a number of parents were wrestling with the issue of obtaining some form of guardianship. However, there was a general lack of information about how and when to obtain guardianship, the benefits and risks involved, and the cost of getting legal help.

Health Insurance

Health insurance was a significant area of concern in the transition focus groups. Families did not understand the various insurance options available to them, many did not understand Medicaid eligibility rules, families reported having to negotiate a number of

different agencies and receiving conflicting information, etc. For youths, most who participated knew very little about their health care coverage and had given little thought to how health insurance would be obtained in the future.

The preceding data on transition suggests that while some of the important components necessary for successful health care transition are occurring for some CYSHCN, for the overwhelming majority, there is no cohesive plan to assist with transition to adult life and/or there are significant barriers (real or perceived) within the current system to address transition needs.

Other Transitions

Transition in other aspects of life also presents challenges for CYSHCN. According to the 2001 National Survey of CSHCN, only about 28% of CYSHCN ages 13-17 had received any vocational or career training. Of respondents ages 14-21 on the 2004 Needs Assessment of Individuals with Spina Bifida, only 36% reported having an Individualized Transition Plan. The result is that of those respondents over 18, only 20% were employed full time and 40% reported being involved in neither work nor school. Several local health department needs assessments (Caroline 2004, Talbot 2003, Somerset 2000) also indicated the need for job training/placement for CYSHCN. In the transition focus groups, parents were divided as to whether they felt medical providers should play a role in transition in other areas of life such as job training, employment, and finding a place to live, but most agreed that it was probably unrealistic to expect physicians to play an active role in these due to lack of time and knowledge in these areas.