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HEALTH INSURANCE COVERAGE OF SPECIAL NEEDS CHILDREN

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Executive Summary of the Comprehensive Final Report

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HEALTH INSURANCE COVERAGE OF SPECIAL NEEDS CHILDREN

Statement of the Problem:

Health insurance coverage plays a critical role in ensuring appropriate access to care for children with special health care needs (CSHCN). Insured CSHCN are much more likely than their uninsured counterparts to have a usual source of care and to obtain needed medical care, dental care, mental health services, and prescription medications. Adequate health insurance coverage for all children, and CSHCN in particular is a major goal of Healthy People 2010. The most recent available national estimates of health insurance for CSHCN, based on data from 1994, suggest relatively high rates of enrollment in Medicaid, and relatively low rates of uninsurance. However, 11 percent of all CSHCN, and 17 percent of poor CSHCN remained without insurance coverage. Since that period, there have been several important federal and state policy initiatives, including welfare reform and the State Children's Health Insurance Program (SCHIP) that likely affect eligibility for, and participation in insurance programs for all children. These policy initiatives may have had unique effects on CSHCN due to differences in their underlying characteristics and possible differences in their families' responses to changing incentives.

In order for child health policy makers to evaluate the effects of initiatives such as SCHIP on insurance coverage for CSHCN, it is necessary to update the estimates of insurance coverage for CSHCN, and analyze the effects of changes in public insurance eligibility and other policy changes over time on insurance coverage. Particular attention must be paid to whether the unique characteristics of CSHCN and their families and/or unique behavioral responses result in different policy impacts for CSHCN.

Research Objectives:

In response to these perceived needs, this project is organized around three specific aims:

1. Update estimates for patterns of insurance coverage for Children with Special Health Care Needs (CSHCN) and their families, and compare them with children who do not have special health needs. A preliminary task is to create an operational definition of CSHCN that is consistent with the Maternal and Child Health Bureau (MCHB) definition and can be applied to the household survey data used in the analysis.
2. Estimate the number and describe characteristics of children eligible for Medicaid or SCHIP in 2000/2001, and compare patterns for CSHCN with other children. Use descriptive and multivariate techniques to analyze take-up of Medicaid and SCHIP among eligible CSHCN, compared with other children. Simulate the effect of

additional eligibility expansions on eligibility patterns and coverage.

3. Estimate the effects of expansions in Medicaid and SCHIP eligibility between 1997 and 2001 on insurance coverage for CSHCN, compared with other children.

During this first year of the two year project, the work for specific aim # 1 has been completed, and much of the work associated with specific aim #2 has been completed as well.

Study Design and Methods

This study encompasses a series of analyses related to insurance coverage and public insurance eligibility for CSHCN compared with other children as described in the specific aims. The National Health Interview Survey (NHIS) from various years between 1997 and 2001 is the principal source of data. Because there is no single indicator for CSHCN, an operational definition was created to identify CSHCN on the NHIS consistent with the content and logic of the CSHCN Screener (Bethell et al. 2002).

Patterns of insurance coverage were described for all CSHCN compared with other children, and for the subgroup of low-income children (with incomes less than 200 percent of FPL). The analysis focused on the type of coverage, the burden on families to provide coverage, and the consistency and adequacy of coverage.

Patterns of eligibility for Medicaid and SCHIP were described for CSHCN compared with other children, and for the subgroups of low-income children and uninsured children. To identify Medicaid and SCHIP eligible children, an algorithm was created that parallels the eligibility determination process. Indicators were created for each child as to whether they were eligible for Medicaid, for a SCHIP Medicaid expansion or a SCHIP freestanding program. Indicators identified those required to pay premiums, and those SCHIP eligible children who faced waiting period requirements. Additional eligibility expansions to either 250 or 300 percent of FPL, consistent with alternative proposals for the Family Opportunity Act were simulated. Once eligible children were identified, take-up rates in Medicaid and SCHIP were calculated for CSHCN compared with other children.

Analyses in the second year of this two year project will focus on determinants of public insurance take-up among eligible children, and whether patterns for CSHCN are distinct from those of other children. Various “what if” policy scenarios will be simulated. The final analyses will estimate the effects of changes in public insurance eligibility between 1997 and 2001 on insurance coverage for CSHCN.

Findings

Despite the policy emphasis on public insurance, 61 percent of CSHCN have private employer sponsored insurance (ESI) and 3 percent have private non-group insurance. Almost 29 percent of CSHCN report Medicaid, SCHIP or some other state

sponsored program. Almost 11 percent of CSHCN are uninsured. Patterns are significantly different for other children, who are more likely to have private insurance, less likely to have public coverage, and more likely to be uninsured. Low-income CSHCN have substantially higher rates of public coverage and are more likely to lack insurance, compared with higher income CSHCN.

Two thirds of families with private insurance share the premium cost with their employer and one fifth pay none of the premium cost. Premium dollar contributions are \$1901 for ESI plans and \$3421 for non-group plans covering the child. Six percent of currently insured CSHCN are uninsured at some point during the year; most (94%) are covered for the entire year. Insured CSHCN are more likely to have unmet needs compared with other insured children, suggesting that insurance may be inadequate to meet their elevated needs. Consistent with inadequate insurance coverage, out-of-pocket spending for health care is much greater for insured CSHCN compared with families of other children.

CSHCN are more likely to be eligible for some form of public insurance compared with other children, and most of the difference is due to children who would have been eligible under rules in place in 1997. Forty-nine percent of CSHCN were eligible for Medicaid or SCHIP, compared with 43 percent of other children. Among CSHCN, 33 percent were eligible based on 1997 rules - 6 percent through reported receipt of SSI, and 27 percent through other mechanisms. However, the SCHIP expansions did not increase eligibility of CSHCN more than of other children: 14 percent of CSHCN became newly eligible through the SCHIP expansions compared with 16 percent of other children. Most of the difference is seen in the proportion eligible through freestanding SCHIP programs. Finally, the eligibility analysis found that the overwhelming majority (74 %) of uninsured CSHCN are eligible for public insurance.

Among all eligible CSHCN, 19 percent face a waiting period. Among the CSHCN who are subject to waiting periods, only 36 percent clearly meet the requirements. Approximately one fifth of all eligible CSHCN children have a premium requirement associated with participation. Because premiums are more common for higher income eligible children, the lower income CSHCN are less likely than other children to face premium requirements.

If eligibility thresholds were raised to 250 percent of FPL, an additional 9 percent of CSHCN would become eligible for public insurance. Raising the thresholds to 300 percent of FPL would extend eligibility to an additional 16 percent of CSHCN. Raising the eligibility thresholds would increase the proportion of uninsured CSHCN who are eligible for public insurance by 13 percent at the 250 percent of FPL threshold, and 18 percent at the 300 percent of FPL threshold.

Overall, we estimate that 55 percent of eligible CSHCN are enrolled in some form of public insurance. The highest participation rates are among those with SSI (82 %), and others eligible according to rules in place in 1997 (65 %). CSHCN made newly eligible through either Medicaid or SCHIP expansions are less likely to participate (29 percent)

than those previously eligible. Among other children, the overall participation rate is 39 percent. Participation is highest among those eligible via rules in place in 1997 (53 percent). Rates for those newly SCHIP eligible (18 percent) are significantly lower than participation rates for CSHCN.

Waiting periods appear to discourage participation. For CSHCN, the take-up rates are 26 and 62 percent respectively when enrollment is conditioned on meeting a period of uninsurance versus unconditional eligibility. Similar to waiting periods, premium requirements appear to discourage enrollment in public insurance, and the effects are greater in other children than in CSHCN. Participation among CSHCN who are required to pay a premium is 35 percent, compared with 60 percent for CSHCN who do not face a premium, and 18 percent for other children required to pay a premium.

We fail to find any significant effects of having a CSHCN on labor force supply for TANF recipients or low-income single parents more generally. However, CSHCN are heterogeneous with respect to type of condition and increased demands on parents. When we examine the dimensions of the definition of CSHCN separately, having an activity limitation does have a significant negative effect on the likelihood of parents' work and work hours.

Discussion and Recommendations

Consistent with expectations, this analysis finds that children with special health care needs have different patterns of insurance coverage than other children. Rates of public insurance coverage are higher, due to higher rates of eligibility – especially for severely disabled children who are recipients of SSI, and higher rates of participation in public insurance, likely due to the incentives associated with expected higher need for services. Rates of private insurance coverage are lower among CSHCN, consistent with lower rates of parent employment, lower incomes, and the difficulty in accessing the non-group insurance market. Higher rates of public coverage more than compensate for lower rates of private insurance, resulting in smaller proportions of CSHCN going uninsured. This scenario implies that the public insurance safety net is working better for CSHCN than it does for other children.

The SCHIP expansions were expected to have a particularly significant impact on insurance coverage for CSHCN because the majority of the uninsured CSHCN were in families with income levels below 200% of poverty. Participation rates among eligible CSHCN are higher than among other children. However, despite the higher rates of coverage, not all CSHCN have coverage. Analyses thus far suggest that both the premium requirements and enrollment waiting periods discourage participation in public insurance. To the extent that these findings are confirmed through multivariate analyses, it may be appropriate to exempt CSHCN from these requirements. The potential dampening effects of premiums and waiting periods on participation also suggest that further expansions of SCHIP or eligibility for a Medicaid buy-in may not be successful in reaching the currently uninsured population of CSHCN.

Final Report

HEALTH INSURANCE COVERAGE OF SPECIAL NEEDS CHILDREN

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I. Introduction

A. Nature of the Research Problem

Health insurance coverage plays a critical role in ensuring appropriate access to care for children with special health care needs (CSHCN). Insured CSHCN are much more likely than their uninsured counterparts to have a usual source of care and to obtain needed medical care, dental care, mental health services, and prescription medications (Aday et al. 1993; Newacheck et al. 2000; Silver and Stein 2001). Adequate health insurance coverage for all children, and CSHCN in particular is a major goal of Healthy People 2010. However, available public and private insurance plans vary dramatically with respect to the scope and extent of covered special services. State Medicaid programs generally cover a broader array of services than do most private policies, however there is variability across states in the level of coverage and in the restrictions on access to special services. Private insurance plans vary tremendously in the scope of covered services and the level of coverage. Persons with chronic illnesses and disabilities with private insurance typically face problems such as high out-of-pocket costs in the form of cost sharing for covered services; exclusion of particular needed benefits; and annual or lifetime limits imposed upon other benefits. Thus for CSHCN, underinsurance may be as much of a problem as uninsurance, and the type of insurance coverage has implications for the likelihood that insurance can adequately meet the needs of the child.

The most recent national estimates of insurance coverage for CSHCN are from the 1994 National Health Interview Survey (NHIS). Changes in policy related to public insurance eligibility and enrollment and private insurance coverage are likely to have had significant effects on insurance options and coverage for CSHCN:

- The passage of the Personal Responsibility and Work Opportunity Act of 1996 (PRWORA) altered the disability definition used in determining eligibility for Supplemental Security Income, making it considerably more restrictive than the definition in use in the early 1990s. Since SSI is an important vehicle for Medicaid eligibility and enrollment for CSHCN, this change is likely to have a negative effect on Medicaid participation rates (Westat/DALTCP 2000).
- The implementation of PRWORA allowed states greater flexibility in determining eligibility for family coverage (section 1931) through the Medicaid program. It was also associated with dramatic declines in Medicaid enrollment for children in general (Ellwood and Ku 1998; Ku and Garrett 2000). Medicaid take-up rates among eligible children declined from 53 percent in 1994 to 45 percent in 1997 (Davidoff, Garrett and Yemane 2001). It is possible that CSHCN were affected to a lesser degree by the

changes in take-up patterns, because their parents had strong incentive to maintain coverage.

- The Balanced Budget Act (BBA) of 1997 created Title XXI – the State Children’s Health Insurance Program (SCHIP) which allows states to extend eligibility for public insurance coverage to 200 percent of the federal poverty line. States were allowed to extend eligibility for existing Medicaid coverage, or to create independent insurance programs that were modeled on private insurance plans. Over the past five years all states have implemented some variety of SCHIP plan, although many states have not extended coverage up to the maximum level. Because the majority of uninsured CSHCN are in families with income levels below 200% of poverty, SCHIP expansions could have a significant impact on reducing uninsurance.
- Recent changes in Medicaid regulations allow states increased flexibility to alter the calculation of spend-down countable income in their Medically Needy program. This will increase the proportion of CSHCN families who qualify for Medicaid coverage, and reduce reliance on child only coverage. Further expansions of eligibility for disabled children up to 300 percent of poverty are being considered by Congress through the Family Opportunity Act (HR 600.IH; S 321.IS).

In order for child health policy makers to evaluate the effects of initiatives such as SCHIP on insurance coverage for CSHCN, it is necessary to update the estimates of insurance coverage for CSHCN, and analyze the effects of changes in public insurance eligibility and other policy changes over time on insurance coverage. Particular attention must be paid to whether the unique characteristics of CSHCN and their families and/or unique behavioral responses result in different policy impacts for CSHCN.

B. Research Objectives

In response to these perceived needs, this project is organized around the following specific aims:

1. Describe patterns of insurance coverage for Children with Special Health Care Needs (CSHCN) and their families, and compare them with children that do not have special health needs. The analysis includes information on type of coverage, patterns of coverage within the family, availability of private insurance through a parent’s employer, premium burdens, and reasons for children being uninsured. CSHCN are defined using the broad Maternal and Child Health Bureau (MCHB) conceptual definition. A preliminary task is to create an operational definition of CSHCN that is consistent with the MCHB definition and can be applied to the household survey data used in the analysis.
2. Identify children eligible for Medicaid or SCHIP in 2000/2001, describe patterns of eligibility for CSHCN, compare those patterns to other children, and describe patterns of change between 1997 and 2001. Simulate the effects of various policy changes on eligibility, such as dropping the requirement that the child be uninsured for a period

of time prior to SCHIP enrollment, and raising the eligibility thresholds to 300 percent of the federal poverty level. Use descriptive and multivariate techniques to analyze take-up of Medicaid and SCHIP among eligible CSHCN, compared with other children.

3. Estimate the effects of expansions in Medicaid and SCHIP eligibility between 1997 and 2001 on insurance coverage for CSHCN, compared with other children. Simulate the effects on insurance coverage that would be associated with the eligibility expansions simulated under specific aim #2.

During the first year of the project, the work for specific aim # 1 has been completed, and much of the work associated with specific aim #2 has been completed as well.

C. Nature of the findings

The findings reported span a broad range of issues related to insurance coverage and eligibility of CSHCN, with comparisons to other children. The operational definition of CSHCN is described in the methods section, and resulting estimates of prevalence are reported in the findings section. Also described are patterns of insurance coverage, including the type of coverage, dual coverage patterns, financial burdens on families to provide insurance, adequacy of existing coverage, and family patterns. The algorithm created to identify children eligible for Medicaid and SCHIP is described in the methods section, and patterns of eligibility, including the prevalence of enrollment waiting periods and premium requirements are described in the findings. We also report rates of participation of eligible CSHCN in public insurance programs, among all eligible children and those without private coverage, and compare them to rates for other children. Finally, the results of the analysis of the effects of having a CSHCN on labor force participation are summarized.

II. Review of the Literature

Prior Estimates of Insurance Coverage for CSHCN and Other Children

The most recent national estimates of insurance coverage for CSHCN, based on the 1994/1995 NHIS, suggest a heavy reliance on private insurance, but a disproportionate enrollment in public coverage. Among CSHCN, 56.2 percent had private insurance alone, 29.1 percent had public health insurance, and 3.5 percent had dual public-private coverage. The remaining 11.2 percent of children had no insurance coverage (Newacheck et al. 2000). Uninsurance rates were particularly high for the poor and near poor, at 16.7 and 18.1 percent respectively, and 80 percent of the uninsured CSHCN had family incomes under 200 percent of the federal poverty line (Scanlon 2000). The low-income uninsured CSHCN were estimated to represent approximately 17 percent of all low-income uninsured children (Newacheck et al. 1998b).

Comparable published estimates of insurance coverage for all children are not available from the 1994 NHIS, but data from the 1994 CPS suggest that relative to all

children, CSHCN are more likely to have public coverage, and less likely to be uninsured. Overall, 22.9 percent of children were enrolled in Medicaid, 60.9 percent had employer sponsored insurance, and 14.2 percent were uninsured.¹ Between 1994 and 2000, estimates from the CPS suggest little movement in the percent of children enrolled in public insurance, but increased coverage of children through employer sponsored plans have decreased rates of uninsurance. Comparable trend information is not available specifically for CSHCN.

Eligibility for Public Insurance

Despite the seeming lack of new net public insurance enrollment for children during the latter part of the 1990s, dramatic expansions of eligibility through the Medicaid and SCHIP programs resulted in a greater proportion of children who had access to public insurance. Estimates from 1994 indicate that approximately 33 percent of children were eligible for Medicaid (Davidoff, Garrett, and Yemane 2001). By 2000, after implementation of SCHIP programs in all states, closer to half of all children were eligible for either Medicaid or SCHIP (Dubay, Haley, and Kenney 2001).²

There are no specific estimates of the proportion of CSHCN who are eligible for public insurance, but it is likely that different institutional issues and different characteristics of CSHCN and their families result in different patterns of eligibility compared with other children. For example, severely disabled children who receive SSI are automatically eligible for Medicaid in most states. Since income eligibility for SSI may be more generous than eligibility through other Medicaid mechanisms, these SSI recipients may be eligible at higher incomes than non-disabled children. Likewise, CSHCN who qualify for Medicaid through the Medically Needy program as a result of elevated medical spending may also have relatively high gross family incomes. Because these higher income CSHCN already qualify for Medicaid eligibility, there may be fewer made newly eligible through SCHIP expansions. In addition to these special eligibility categories, CSHCN may be more likely to meet the categorical and income eligibility requirements for Medicaid, to the extent that they are more likely to be in low-income single parent families.

Estimates of Public Insurance Take-up

Historically, participation in Medicaid has been low, particularly for children ineligible for cash assistance (Selden, Banthin and Cohen 1999; Dubay and Kenney 1996). In addition, the implementation of state and federal welfare reform in the mid-1990s may have further reduced enrollment rates through their effects on the enrollment and retention practices of states (Garrett and Holahan 2000; Families USA 1999;

¹ These estimates are not strictly comparable to the NHIS estimates for CSHCN, because they measure insurance coverage at any point during the year, as opposed to the prior month coverage measured by the NHIS in 1994. CPS data accessed from (www.census.gov/hhes/hlthins).

² This study simulated eligibility for Medicaid and SCHIP using 2000 eligibility rules using characteristics of the population from 1999. Family income continued to grow between 1999 and 2000, thus the estimated 50 percent eligible likely overstates the actual number of eligible children in 2000.

Davidoff, Garrett and Yemane 2001). Take-up rates for all eligible children were estimated at 53 percent in 1994 , but declined to 45 percent by 1997 (Davidoff, Garrett and Yemane 2001). Participation rates among those without private insurance was higher, and was stable - at 72 and 71 percent respectively in 1994 and 1997.

As states expand public insurance eligibility to higher income levels through the SCHIP program, the need to understand effects on participation in public and private coverage is increasingly critical. Early predictions of SCHIP participation suggested that take-up of SCHIP would be even lower than Medicaid take-up due to different child characteristics and the higher prevalence of private coverage in the SCHIP eligible population (Selden et al. 1999). More recent estimates from 1999 indicate that 72 percent of Medicaid eligible children without private insurance and 45 percent of those newly eligible through SCHIP had public coverage (Dubay, Kenney, and Haley 2002).

Public Insurance Take-up and CSHCN

Given the potentially broad scope of coverage under SCHIP, and the program's limited cost sharing, families with income eligible CSHCN who currently have costly and/or limited private coverage might view SCHIP as a very attractive alternative and desire to enroll their children in the program. However, the federal statute forbids children with existing creditable insurance from being made eligible for SCHIP, and the emphasis placed on preventing crowd out of private insurance has led to the imposition in many states of three, six, and even 12 month waiting periods during which a previously insured child must be uninsured before enrolling in SCHIP. Faced with such an eligibility rule, a family with an underinsured CSHCN is not likely to view dropping their coverage, even temporarily, as a viable option.

Studies that have examined the effect of child health status on take-up of Medicaid among eligible children, find mixed results. Davidoff, Garrett, and Yemane (2001) found that being in fair or poor health had a significant negative effect on the likelihood of having private coverage, while having a limitation in major activity increased the likelihood of Medicaid coverage. However, SSI recipients were excluded from the analysis. Dubay, Kenney, and Haley (2002) found that having poor health increased the likelihood of enrollment among SCHIP but not Medicaid eligible children, whereas having an activity limitation had a positive effect on take-up overall and particularly among those also eligible for TANF. These findings suggest that CSHCN would be more likely to participate in Medicaid or SCHIP relative to other children.

Preliminary qualitative studies suggest that enrollment of CSHCN in special SCHIP programs is quite low relative to expectation (Hill et al. 2001). Relatively few states have special programs for CSHCN. Policy makers at the level of the states are trying to determine whether the failure to enroll CSHCN into SCHIP is a function of the restrictions on enrollment for those with private coverage. Alternatively, concerns have been raised that the estimates of the SCHIP eligible CSHCN population might have been overstated or that the screening mechanisms to identify SCHIP eligible CSHCN are inadequate.

The confusion concerning patterns of SCHIP enrollment and frustration over lack of information on SCHIP eligible and uninsured children underscore the need for improved measurement and analysis. This project fills an important gap by providing updated estimates of insurance coverage for CSHCN, and by providing brand new information on eligibility for public health insurance programs that is based on detailed state policies, rather than gross poverty measures. In the second year of the project, econometric techniques will be used to estimate the behavioral response of CSHCN to changes in public insurance eligibility and the effects on public and private insurance coverage.

III. Study Design and Methods

A. Study Design

This study encompasses a series of analyses related to insurance coverage and public insurance eligibility for CSHCN compared with other children as described in the specific aims. As a precursor to the analyses, an operational definition was created to identify CSHCN on the NHIS. Survey items were selected from the NHIS and thresholds designated to replicate the content and logic of the CSHCN Screener (Bethell et al. 2002). The Screener asks explicit questions concerning an elevated need for and use of health care services and about limitations in activity, both caused by a chronic health condition. The algorithm created was applied to the pooled 1999/2000 NHIS to generate national prevalence estimates. Multivariate logistic regression was estimated to determine the effect of having particular demographic characteristics on the likelihood of being identified as CSCHN. Log odds ratios were compared to those from earlier NHIS based estimates and from a pre-test of the CSHCN Screener.

In the first phase of the analysis, patterns of insurance coverage were described for all CSHCN compared with other children, and for the subgroup of low-income children (with incomes less than 200 percent of FPL). The analysis was based on pooled data from 1999 and 2000. The measures of insurance include the type of insurance, whether the child was covered by more than one insurance plan, what private insurance premium payments were made for insurance that covers the child, whether coverage was consistent over the year, and for uninsured children, the length of the uninsured spell and the reason the child was uninsured. The analysis also examined whether CSHCN were more likely to be in families with fragmented coverage – where the child had different coverage or a different coverage status than other family members. Sensitivity analyses were conducted using alternative definitions of children with chronic conditions.

In the second phase of the study, patterns of eligibility for Medicaid and SCHIP were described for CSHCN compared with other children, and for the subgroups of low-income children and uninsured children. To identify Medicaid and SCHIP eligible children, an algorithm was created that parallels the eligibility determination process. Indicators were created for each child as to whether they were eligible for Medicaid according to rules in place in 1997, were eligible for Medicaid through expansions that occurred between 1997 and 2000 or 2001, were eligible for a SCHIP Medicaid expansion

or a SCHIP freestanding program. For all eligible children, indicators were created to identify those required to pay a premium to participate, and those who faced SCHIP waiting periods. Using information on current insurance and length of time uninsured, indicators were created for whether children who were subject to waiting periods met the waiting period requirements. In addition to estimating current eligibility, the analysis simulated additional eligibility expansions to either 250 or 300 percent of FPL, consistent with alternative proposals for the Family Opportunity Act.

Once eligible children were identified, take-up rates in Medicaid and SCHIP were calculated for CSHCN and compared with other children. Initial analyses were unadjusted for other characteristics.

In the second year of this two year project, multivariate analyses will be used to estimate determinants of public insurance take-up among eligible children, determine whether patterns for CSHCN are distinct from those of other children, and simulate take-up of Medicaid and SCHIP if the requirements for uninsured waiting periods and premiums were dropped. Analyses will simulate take-up among those who would be made newly eligible by additional expansions through the Family Opportunity Act. The final analyses in the second year will estimate the effects of changes in public insurance eligibility between 1997 and 2001 on insurance coverage for CSHCN.

In response to a request from Dr. Paul Wise, MD (at Boston University Medical Center) and Wendy Chavkin, MD (at Columbia University) estimates were developed of the proportion of children with parents receiving TANF who had disabling chronic conditions. These estimates were incorporated into a memorandum and letter directed to the Senate Finance Committee, as they considered TANF reauthorization measures. As an outgrowth of this request, additional analyses have been undertaken to examine the effects of having a CSHCN on labor force participation among parents who are TANF recipients and more generally, among low-income parents. Characteristics of children and parents in those two subgroups were described, and multivariate regression techniques were used to estimate the effects of having a CSHCN on both the likelihood of working and hours worked. This analysis used pooled NHIS data from 1999 and 2000.

B. Source of Data

The primary source of data is the National Health Interview Survey (NHIS). The NHIS is an ongoing household survey that collects data on demographics, labor force participation, income, offers of insurance from employers, current insurance coverage, health status, and use of healthcare services for a sample of approximately 45,000 households annually (Botman et al. 2000) More detailed information on medical conditions, additional questions on access to care, and specifics of labor force participation, such as a firm size and industry, are asked concerning a sample adult and child in each family. An adult knowledgeable about the children in each family serves as the respondent for them. We analyze data for children age 0 to 17 years, pooling data from either the 1999 and 2000 NHIS, or the 2000 and 2001 NHIS.

The content and design of the revised NHIS make it a particularly useful source of data for analyzing public insurance eligibility and coverage for CSHCN because it includes the data necessary to identify CSHCN. To identify CSHCN in a manner consistent with the MCHB definition, information is needed on the presence of chronic medical conditions, limitations of activity, and need for health care services. Starting in 1997, the NHIS underwent a major redesign, changing the focus of the survey from the prevalence of specific medical conditions and detailed utilization of health care services, to the prevalence of functional limitations and disabilities. Information is still collected on the presence of a subset of the most common chronic conditions and acute ailments. In addition to the change in focus, there was a shift in the survey design. Previously, all persons responded to questions in the core survey, except that the list of medical conditions was split into six sub-lists, and each family was asked about only one sixth of the conditions. This design made it impossible to ascertain the presence of a range of chronic conditions for any one person. With the redesign, a series of questions on the presence of specific medical conditions is asked of a sample adult and child in each family, while information on demographics, disability, disabling conditions, access to care and use of services, health insurance and income are asked of all respondents.

The analyses concerning prevalence, characteristics and patterns of insurance coverage for CSHCN all used public use NHIS files available from the NCHS website (www.cdc.gov/nchs/). The analyses concerning eligibility for Medicaid and SCHIP require that we link information on state specific eligibility policy to the observations in the NHIS. Access to the state identifiers is available only through the Research Data Center at NCHS, which is where we conducted this latter group of analyses.

Sources of Data on Federal and State Eligibility Policies for Medicaid and SCHIP

The analysis requires detailed information about federal and state eligibility policy for Medicaid and SCHIP. The information required includes age and family structure requirements, income and resource (asset) eligibility thresholds, rules concerning allowed expenses and income disregards. Federal standards are available from various government publications such as the Federal Register, and are available on the CMS website. The state specific data are available from the state TANF, Medicaid and/or SCHIP plans, or through special surveys of state officials. As part of its work under the Assessing the New Federalism Initiative, the Urban Institute regularly abstracts data from the state TANF plans, and works in conjunction with other policy groups, such as the Center on Budget and Policy Priorities to collect data concerning Medicaid and SCHIP program eligibility (e.g. Bruen et al. 1999; Ku et al. 1999; Malloy et al. 2001).

C. Sample Selection: Identifying Children with Special Health Care Needs

Children with special health care needs are defined in a manner consistent with the federal Maternal and Child Health Bureau definition: “Children with special health care needs are those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and

related services of a type or amount beyond that required by children generally.” (McPherson et al. 1998). Consistent with the work of other researchers, those *at risk* of developing a condition are excluded, due to difficulties in operationalizing this portion of the definition; the analysis is limited to children with reported conditions.

An operational definition of CSCHN is created for the NHIS that replicates the CSHCN Screener (Bethell et al. 2002). This screening instrument is modeled after the questionnaire for identifying children with chronic conditions (Stein et al. 1997), and focuses on identifying children who experience consequences associated with having a chronic condition in the form of elevated service need or functional limitations. The Screener asks explicit questions about whether a child needs or uses prescription medications, needs or uses more medical care or educational services than is usual for most children of the same age, is limited or prevented in his/her ability to do the things most children the same age can do, needs or receives special therapy, and needs mental health treatment or counseling, all associated with a health problem that has lasted or is expected to last 12 months or longer. A child that meets any of the five criteria is identified as having a special health need.

Following the organizational structure of CSHCN Screener, survey items and responses from the NHIS designate children meeting each of the five screening criteria. For example, an NHIS question concerning the presence of a condition that requires use of prescription medications is used, as well as questions about outpatient health provider visits, hospitalizations and home health service use. The full methodology is described in Davidoff (2002).

D. Measurement of Key Variables

1. Defining Families

The concept of an insurance family (i.e., health insurance unit) is used in this analysis to identify children eligible for coverage through a parent’s employer-sponsored insurance (ESI) and to identify those adults whose income would be considered in determining whether a child is eligible for public insurance. This insurance family generally includes the parents (married and cohabiting) and dependent children (biologic, step or adopted) through age 18, in addition to full time students up to age 23. Information from the NHIS on family structure, child age, and student status are used to identify insurance families.

2. Health Insurance

The NHIS collects information concerning current health insurance coverage for each member of the household. The sequence of questions begins with whether anyone is covered by health insurance or some other health care plan, and then proceeds to identify who has coverage, and the kind of health insurance covering each person. Included in the list of insurance options are Medicaid, SCHIP, other state sponsored plans, Medicare, Military coverage, other government plans, employer sponsored insurance, non-group insurance, and single service plans. For those who report any type of private health insurance, the NHIS collects the plan name, which family members are covered, the

policy holder, who pays for the plan (employer, family, public source), the premium contribution, and the type of plan. Depending on the analysis, we generally include children with all types of coverage. Where specified, we exclude those who report Medicare or other government coverage. We create coverage groups for some analyses, combining Medicaid, SCHIP and other state sponsored coverage; and employer sponsored, individual private insurance and military coverage.³ The uninsured are defined as a residual group, including those who do not report any type of insurance coverage (other than single service plans or Indian Health Service).

3. Earned and Total Family Income

Different components of the analysis require different measures of income. In characterizing income available to a family to purchase insurance or other goods and services, total family income is the appropriate measure. Total family income includes earnings, and unearned income from financial and property assets, pension income, and transfers from various public assistance programs. In determining public insurance eligibility, transfer income should be excluded. However, the total family income measured by the NHIS does not distinguish transfer income from other sources of income received by family members. Instead we use an alternative measure that captures only earned income as the basis for the eligibility determination process.

The NHIS collects total prior year earnings for each working adult, and total family income for the legal family. Indicators for other sources of income, but not amounts, are collected for each person. A substantial proportion of observations in the NHIS (26 percent in 1999) do not report total family income at all, or only report that income is above or below \$20,000.⁴ Furthermore, reported prior year earnings and income may not be consistent with current labor force participation of adults in the family, or with the insurance family concept we use. Instead of dropping the observations with invalid earnings or income data, an imputation process is employed that updates sources of income based on current labor force participation. Earnings are assigned to adults currently working. Total income is assigned for insurance families that are part of larger legal families, as well as for families for whom total income is not reported at all.

We impute both earnings and total family income using a hot-deck imputation method known as predictive mean matching (Kalton and Kasprzyk 1986). The method for imputing earnings starts by estimating a detailed regression model of individual earnings using the observations with valid earnings data. Predictions are generated using the results of the regression for all observations, and then the observations (missing earnings or not) are sorted by the earnings prediction. Missing earnings values are filled with actual earnings values of people who have the same or approximately the same value for predicted earnings. After the imputation process, earnings for adults in the insurance family are summed and assigned back to all members of the family. A similar process is used for total family income, except that the donor group in the imputation

³ Although qualitatively different in some ways from private insurance, military coverage for child dependents is grouped with employer sponsored plans because it derives from a parent's employment situation.

⁴ Non-reporting is somewhat less prevalent for data on earnings.

process includes only those observations where the insurance family is identical to the legal family.

The public use NHIS files only report total family income and earnings in ranges. The midpoint for each range is selected and converted to a percentage of the federal poverty level. Low-income children are defined as those with total family income below 200 percent of the federal poverty level.⁵ Files available at the Research Data Center include continuous measures of total income and earnings, so we use these for all analyses related to eligibility and participation among eligible children.

4. Measuring Medicaid and SCHIP Eligibility Using the NHIS

To identify Medicaid and SCHIP eligible children in 2000 and 2001 we create a complex algorithm that mimics the eligibility determination process, modeled on the Urban Institute's TRIM (Giannarelli 1992). Although there are several pathways through which children could be eligible for Medicaid, we are principally concerned with the broader distinction of Medicaid versus SCHIP eligibility. Therefore, we only model those Medicaid eligibility pathways that capture the upper bound of eligibility for the various age groups.

The algorithm determines whether children were eligible for Medicaid based on 1997 rules, whether they became newly eligible for Medicaid based on expansions that occurred after 1997, or whether they were eligible for a SCHIP program. If they were eligible for SCHIP, we create indicators for whether they were subject to an uninsured waiting period prior to enrollment, and the duration of that waiting period. For both Medicaid 1115 waiver programs and SCHIP programs, we create indicators if a premium is required for participation. For the indicator that a child was eligible according to 1997 rules, we model eligibility through Section 1931 rules (but using TANF income and resource thresholds in place at that time), poverty-related expansions for infants and children, section 1115 waiver programs, and Transitional Medicaid Assistance (TMA), using the rules in place in 1997. Medicaid expansions that occurred after 1997 include expansions to Section 1931 eligibility through relaxed categorical rules and more generous income and asset disregards and expanded 1115 eligibility. In addition, older children aged into eligibility for the child poverty expansions.

Eligibility Criteria

For each of the Medicaid and SCHIP eligibility mechanisms there may be categorical, income and resource tests used by the states. Categorical requirements may include family structure requirements, such as requiring that an adult have dependent children, or that a child lack insurance. Income tests may be based on gross income or income less disregards for work expense, childcare expense, child support and some

⁵By having to use the midpoint of an income range to calculate percent of poverty, some error is introduced in the assignment of low-income children. Based on comparison of the categorical to continuous family income data from the NHIS available through the Research Data Center, we estimate that 83 percent of NHIS observations are correctly assigned as having income above or below 200 percent of FPL when we use the income ranges available on the public use NHIS data.

portion of earned income. Income thresholds may be family size specific dollar amounts or a percent of the federal poverty level (FPL). Depending on the eligibility mechanism, states may have more or less flexibility to choose which requirements to apply, and to set the thresholds for income and assets.

We identify the key state and year specific categorical, income, and resource rules for each eligibility mechanism. We use data from the NHIS to create family level measures for each relevant eligibility test, and compare the measures to the categorical requirements or income thresholds. We determine whether the family passes the relevant asset tests. Wherever feasible, we model all key categorical and income eligibility requirements. Special requirements and measurement issues are discussed below.

Section 1931. Section 1931 eligibility is the mechanism for family coverage that replaced AFDC-related Medicaid eligibility. Section 1931 eligible units include parents with dependent children. In two parent families, states may require that the primary earner parent is disabled or underemployed – working no more than 100 hours per month. Since we do not have information on who is the current primary earner of the household (earnings information on the NHIS is for past-year earnings), we require that all working adults in a two-parent family meet the 100 hour rule.

To determine eligibility through Section 1931, we determine gross income, compute net income according to the formula adopted by the state, and determine whether the family had financial assets. We compare the categorical eligibility requirements for the state to the observed family structure and work status of parents. We compare computed gross and net income to the applicable state standards. Families that meet all the relevant state requirements are deemed to be eligible through Section 1931.

For the 2000 and 2001 rules, there were states that still had not established an explicit Section 1931 category for families. For these states, we used the rules for the defacto family coverage category that existed in the state, which was either the state's Medically Needy program or a state's Section 1115 poverty expansion.

Medically Needy Coverage. States may opt to provide Medicaid coverage through a medically needy program. If states choose to have a medically needy program, they are required to cover children under age 18 and elderly, blind, or disabled adults who meet the income and asset tests. At the state's option, they may extend medically needy coverage to parents and older dependent children. Income thresholds for medically needy programs are generally higher than the AFDC related eligibility programs on which the medically needy coverage was originally based. In addition, children and families with large out-of-pocket expenses may subtract them from net income, "spending down" to meet the income eligibility thresholds. To determine Medicaid eligibility under the Medically Needy program, we identify children and adults who were categorically eligible in each state with a medically needy program. We determine

whether those individuals meet the income and asset standards for their state, but we do not model medically needy eligibility through spend-down.⁶

Section 1115 Waivers. Some states replaced their family coverage programs with Section 1115 waivers, which allowed the states to expand coverage to persons at higher income thresholds or different categorical groups, such as childless adults. These programs have their own categorical rules, and income and resource formulas and thresholds. To determine eligibility, we compare the relevant family structure, parent employment, income and assets to the relevant state rules and thresholds.

Poverty Expansions. To model poverty-related expansion eligibility, we compared the age of the child at the time of the survey to the age relevant rules in effect that calendar year. If the person was age eligible, we compared the percent poverty (based on family size and state specific formulas) and to the state standards, and applied the asset test in states where it was relevant.

Transitional Medicaid Assistance (TMA). TMA is a program designed to extend Medicaid eligibility to families who lose Section 1931 eligibility for Medicaid because they increase their earnings or receive higher levels of child support. States must make families eligible for TMA if they were previously eligible and participated in Medicaid for three out of six months prior to losing eligibility. Eligibility is extended for six months regardless of the new income levels. Eligibility is extended for an additional six months if gross income is less than 185 percent of the federal poverty level. The NHIS does not allow us to measure past participation in Medicaid. Instead we make use of an indicator that the family received TANF during the prior calendar year as an indicator of likely prior Medicaid participation. The family is designated as TMA eligible if any family member reports prior year TANF receipt, if the family is not currently eligible for Medicaid coverage, and if family gross income is less than 185 percent of FPL. TMA eligibility is not modeled for six states that do not have Section 1931 family coverage programs.

State Children's Health Insurance Programs (SCHIP). To model SCHIP expansion eligibility, we compare the age of the child at the time of the survey to the age relevant rules in effect that calendar year. If the child was age eligible for SCHIP, we compare the calculated percent poverty (based on family size and state specific net income formulas) to the state standards, and apply the asset test in states where it was relevant. We also link to the child's record information on whether the SCHIP program for which they are eligible is a freestanding program or a Medicaid extension, whether a premium payment is required and whether the child must be uninsured for a period of time prior to enrolling.

⁶ Most people who qualify for the Medically Needy program through this spend-down mechanism have acutely elevated spending over a several month period. The annual health care utilization and out-of-pocket spending measures available on the NHIS essentially spread out the observed spending over the course of the year. Average monthly measures do not allow us to identify a major acute elevation in spending that would be sufficient to bring net income below eligibility thresholds.

Hierarchy of Eligibility Group Assignment

With the exception of TMA eligibility, the algorithm tests eligibility for each mechanism regardless of whether the child has already been determined to be eligible through a previous mechanism. We use a hierarchy to assign a unique eligibility path for each child. We do this because some children are eligible through multiple mechanisms, and we only want to assign children to the SCHIP expansions who would not otherwise have been eligible for public insurance. The hierarchy we implement starts with eligibility through any Medicaid mechanisms and rules in place as of 1997, Medicaid eligible in 2000 or 2001, SCHIP Medicaid expansion eligible, and SCHIP freestanding program eligible.

Key Measurement Issues for the Eligibility Algorithm

To create the measures of family structure, income, and assets required to determine eligibility, it is necessary to manipulate and supplement the data collected on the NHIS. We use nuclear families as our unit of eligibility for family coverage and as the basis for computing earnings and assets. To evaluate eligibility, members of the family that report receiving SSI are excluded from the income and family size determinations.

Income. Current average gross monthly income was calculated by summing prior year annual earnings for the adults in the family, dividing by twelve and multiplying by an adjustment factor based on the Employment Cost Index . Eligibility determinations are actually based on earned and unearned income from pensions and financial and property assets, but not transfer income from public programs (e.g. SSI, SSDI, TANF, and general assistance). Since the NHIS does not report amounts of unearned income by type we based the income measure solely on earnings. This simplification biases the algorithm to identify too many children as income eligible for public insurance. Based on evidence from a study using data from 1994 – where we were able to compare estimates of the number of children identified as Medicaid eligible when alternatively including and excluding unearned income, we believe that this simplification increases the proportion of children identified as eligible by approximately three percent.

Income disregards. Net income generally disregards some child support, child care and work expenses. Child support payments are not reported on the NHIS. Data from the CPS indicate that only a small portion of families below 200 percent of poverty report any child support income, thus we do not attempt to impute child support amounts. We compute the allowable work expense and deduct it from income in each family with a non-SSI working parent. Historically, work expense deductions were capped at \$90 per worker, but increasingly states have taken advantage of the flexibility to expand coverage to working families through increasing disregards and have either raised the fixed dollar amount deduction or turned this disregard into a percentage of income. By increasing the

work expense deduction, states can continue to provide this important social support to families transitioning from welfare-to-work.⁷

Childcare expenses are imputed for families with children under age 14 with a parent who works at least part time. We use model estimates prepared by Sharon Long at the Urban Institute using data from the 1993 Survey of Income and Program Participation to predict average childcare expenses for the families included in the NHIS. Unless otherwise specified by a state, predicted values were capped at \$200 monthly for children under two and \$175 for children two through 14. To calculate countable income, we subtract earnings disregards in addition to the childcare and work expense, based on state specific formulas. As with the work expense deductions, states have instituted earnings disregards that go beyond the typical \$30 and one-third of gross income net of other disregards so as to expand coverage to working families.

Assets. The NHIS does not allow us to measure the level of financial assets, only the presence of interest and dividend income associated with those assets. As a result, we cannot compare the value of assets to a state specific asset threshold. Instead we create a dichotomous indicator for whether the family reports dividend and/or interest income. If the state has an asset test, families with these assets are deemed to fail. This simplification biases the algorithm against families that have non-zero but low levels of assets. To correct partially for this limitation, families that report Medicaid but are ineligible when the full complement of tests are applied, are deemed eligible if they pass all categorical and income tests.

E. Statistical Analysis

Bivariate analyses test whether there are differences in sample means and proportions for CSHCN and other children, and between low-income and higher income children in both categories. In the analyses on the effects of having a CSHCN on parent labor supply, we use multivariate techniques. All standard errors are adjusted for the complex survey design used by the NHIS. All estimates are weighted to reflect national population totals. All analyses were conducted using Stata software.

II. Presentation of Findings

A. Prevalence of CSHCN

Overall, we estimate that 12 percent of children in 1999-2000 have special health care needs. This translates into a weighted annual average of 7.85 million children. The unweighted sample over the two years of pooled data consists of 2,740 CSHCN and 20,963 other children.

⁷ This is particularly relevant to the Section 1931 program where states can only increase income eligibility thresholds at a rate that does not exceed the rate of increase in the CPI but have broader flexibility to establish income disregards.

Across the five main criteria measured by the CSHCN screener, elevated service use consistently captures the largest group of children (14 percent). The next largest group is prescription drug use (11 percent), followed by activity limitations (7 percent), mental health service use (5 percent) and use of special therapies (5 percent). Overall, almost one quarter of children meet at least one of the five criteria. A smaller percentage of children meet the criteria for both elevated service use or activity limitation *and* a chronic health condition. For example, only 8 percent of children report elevated or unusual service use and report a chronic medical condition. Most of the children who have limitations of activity also report a chronic condition, whereas only 60 percent of children using prescription drugs and a similar percent of children for whom a mental health visit is reported have chronic conditions. Sensitivity analyses concluded that the prevalence estimates are higher when a broader group of measured medical conditions is included.

B. Patterns of Health Insurance for CSHCN

Despite the policy emphasis on the importance of public insurance for CSHCN, the majority of these children have some form of private insurance. Sixty one percent of CSHCN have employer sponsored insurance (ESI) and 4 percent have private non-group insurance. Almost 29 percent of CSHCN have some form of publicly sponsored insurance, with 25 percent enrolled in Medicaid, and an additional 3 percent enrolled in SCHIP or some other state sponsored program. Almost 11 percent of CSHCN are uninsured.

Patterns of insurance for CSHCN are different from other children, who are more likely to have private insurance – both ESI (67 percent) and non-group (3 percent), and less likely to have public insurance. Only 14 percent of other children are enrolled in Medicaid and 17 percent are in Medicaid, SCHIP or other state sponsored programs. The higher rates of private coverage do not compensate for the lower rates of public coverage, thus the uninsurance rate for other children is higher than for CSHCN at 13 percent.

Patterns of coverage are quite different for low-income compared with higher income children overall, for special needs children, and for other children. As would be expected, the role of public insurance is dramatically reduced for higher income children. Only 9 percent of CSHCN report Medicaid, SCHIP or other state sponsored programs, compared with 50 percent among lower income CSHCN. Among other children, the relative gap in public coverage is even greater (4 percent among higher income versus 37 percent among low-income) due to the lack of special coverage provisions for children without special needs. Uninsurance rates are more than twice as high for low-income CSHCN (15 percent) compared with higher income CSHCN (7 percent). These higher rates of uninsurance suggest that the public insurance safety net does not support all low-income CSHCN during the period represented by these data. However, if only data from 2000 were examined, it is likely that even greater proportions of low-income children would have public coverage due to continued SCHIP expansions.

There are few differences in the burden on families with respect to premium share and dollar amount across children with and without special needs and across income groups. Among all children with private insurance, the largest group of families (65 percent) share the premium costs with an employer or public payer. There is no family contribution for 23 percent, and for 14 percent, the family pays all. The proportion of CSHCN families who pay none of the premium cost is slightly lower at 21 percent (versus 24 percent for other children), and the proportion sharing premium costs is slightly higher (67 percent versus 64 percent for other children). These small shifts may suggest that families of CSHCN are more willing to pay some of the cost of insurance, or that the options available to them are more likely to require some cost sharing.

Premium dollar contributions for all children were \$1901 for ESI plans covering the child and \$3421 for non-group plans covering the child. There were no significant differences across any of the groups in the amount contributed by the families for ESI plans.

One of the main concerns is whether insurance coverage for CSHCN is consistent over time and adequate to meet the needs of the child. Although the NHIS does not include access measures that relate to the special areas of concern for CSHCN (e.g. the need for specialized equipment), data are collected to determine whether the child is insured for the full year; whether there is unmet need due to cost for medical, prescription drug, dental, mental health and vision care services; and the burden on the family with respect to out-of-pocket spending. The results suggest that currently insured CSHCN are slightly more likely than other children to be uninsured at some point during the year, although the magnitude of the difference (6 versus 5 percent) is small. Moreover, insured CSHCN are more likely to have unmet needs compared with other children. For example, 4 percent of CSHCN report unmet need for prescription drugs compared with 1 percent of other children. The most common type of unmet need for all children is for dental care, due to the lack of dental coverage by most private plans and the difficulty in finding providers willing to accept Medicaid. Almost 8 percent of CSHCN report unmet dental care needs, whereas 4 percent of other children face similar needs. Finally, the distribution of out-of-pocket spending for health care is much greater for CSHCN compared with families of other children. Although slightly more CSHCN families report no out-of-pocket costs, many fewer (36 percent versus 46 percent among other children) report costs between \$1 and \$500, and more CSHCN families report spending in the highest dollar ranges.

To better understand the gaps in the insurance safety net, it is useful to examine the experience of the uninsured. Among children who are uninsured, 21 percent have been uninsured for six months or less, whereas 26 percent have never had insurance. Among uninsured CSHCN, the current spell of insurance tends to be less, with 34 percent reporting that they have been uninsured for less than 6 months, and less than 10 percent reporting that they have never had insurance. Slightly more than half (51 percent) of uninsured CSHCN have access to ESI through a parent's employer, but this is not significantly different from other children.

The most common reason reported for being uninsured across all groups is that the cost of insurance is too high. Forty-five percent of CSHCN and half of other children cited this explanation. Other commonly cited reasons are that the family member with insurance lost or changed jobs (25 percent among all children – no significant difference between CSHCN and other children), and that the child lost Medicaid because the parents increased their earnings (14 percent among CSHCN compared with 8 percent among other children). Analyses stratified by income reveal that lower income children were more likely to cite loss of Medicaid coverage, while higher income children were more likely to cite that a parent lost or changed jobs, as the reasons for being uninsured.

The final analysis examined the extent to which having a child with special health care needs might affect insurance coverage within the family. Most children (90 percent) with insurance are part of families in which the entire family has the same coverage as the child, but 2 percent are in families where the rest of the family is insured but with a different type of insurance, and 4.5 percent are in families where all other family members are uninsured. Among CSHCN, a slightly smaller percentage (87 percent) are in families with the same coverage and slightly more (3 percent) are in families where everyone has different coverage.

Among children who are uninsured, most (75 percent) are in families where all members are uninsured. Some but not all family members are insured for 17 percent of children, and all other family members are insured for 8 percent of children. For CSHCN, point estimates of the percent where some or all family members are insured are higher than for other children (29 percent versus 24 percent), but the differences are not significant.

C. Eligibility of CSHCN for Medicaid and SCHIP

CSHCN are more likely to be eligible for some form of public insurance compared with other children, and most of the difference is due to children who would have been eligible under rules in place in 1997. Forty-nine percent of CSHCN were eligible for Medicaid or SCHIP overall, compared with 43 percent of other children. Based on 1997 rules, 33 percent of CSHCN would have been eligible - six percent of CSHCN were eligible through reported receipt of SSI, and an additional 27 percent of CSHCN were eligible through other mechanisms. Among other children, almost none reported receipt of SSI, and 25 percent of other children were eligible through other mechanisms available in 1997.

In contrast to the situation with Medicaid, CSHCN were somewhat less likely to be made newly eligible through the SCHIP expansions. Overall, 14 percent of CSHCN were eligible through SCHIP, compared with 16 percent of other children. Most of the difference is seen in the proportion eligible through freestanding SCHIP expansions – 11 percent among CSHCN compared with 13 percent among other children.

Similar patterns prevail when examining low-income children, except that the proportions of low-income children eligible are much greater than among all children. An

estimated 97 percent of low-income CSHCN are eligible for public insurance, while only 94 percent of other children are eligible. Eleven percent of low-income CSHCN are eligible as a result of SSI receipt, with an additional 59 percent already eligible based on 1997 rules, 10 percent newly eligible for Medicaid and 21 percent newly eligible through a SCHIP program. Among other low-income children, fewer were eligible according to rules in place in 1997, primarily due to the small number of SSI recipients. A larger percent of other children were made newly eligible through SCHIP expansions.

The overwhelming majority (74 %) of uninsured CSHCN are eligible for public insurance. Most (44 %) are eligible according to the rules in place in 1997, 12 percent are newly eligible for Medicaid, and 23 percent are newly SCHIP eligible. A larger percentage of uninsured CSHCN are eligible according to 1997 rules compared with other children, and a smaller percent of uninsured CSHCN are eligible through SCHIP expansions. Due to the small sample of uninsured CSHCN, the power to detect differences is limited and most of them are not significant.

Prevalence of Waiting Period Requirements for SCHIP Enrollment

As a result of the disproportionate eligibility of CSHCN through SSI and other Medicaid programs, relatively few CSHCN eligible for public insurance are subject to uninsured waiting periods. Among all eligible CSHCN, 19 percent face a waiting period. Waiting periods range from one to six months, with three to four months the most common length. Other children are more likely to face a waiting period (25 percent). When we examine the sub-group of SCHIP eligible children, 66 percent of CSHCN are subject to waiting periods. Although there is no significant difference between CSHCN and other children in whether they face a waiting period, the distribution of waiting periods is different.

Waiting Periods as Potential Barriers to Enrollment

The question of whether waiting periods are more onerous to CSHCN than other children is addressed in part by examining whether eligible children who face waiting periods meet the requirements – either because they report public insurance or because they have been uninsured longer than the waiting period. Among the CSHCN who are subject to waiting periods, only 36 percent clearly meet the requirements. Twenty six percent are already enrolled in public insurance and 10 percent have been uninsured for greater than six months. Sixty percent do not pass the requirement because they are enrolled in private insurance, and we cannot determine whether an additional four percent meet the requirement because both the waiting period and the time uninsured are less than six months. Waiting periods likely present less of a barrier to CSHCN compared with other children because CSHCN are more likely to have public insurance, although they are less likely to have been uninsured for greater than six months.

Premium Requirements for Medicaid or SCHIP Participation

Approximately one fifth of all eligible CSHCN children have a premium requirement associated with participation. Because premiums are more common for eligible children with higher incomes, the lower income CSHCN are less likely to have to contribute, whereas 26 percent of other children face premium requirements. Premium requirements are concentrated in children eligible for freestanding SCHIP programs. Seventy percent of CSHCN eligible through that mechanism are required to pay a premium.

Simulated Expansions of Eligibility Consistent with Family Opportunity Act

Various versions of the Family Opportunity Act would allow states to permit families of children with chronic conditions to buy-in to either Medicaid or SCHIP coverage at higher income levels. Alternative thresholds have been proposed at 250 or 300 percent of FPL. If eligibility thresholds were raised to 250 percent of FPL, an additional 9 percent of CSHCN would become eligible for public insurance. Raising the thresholds to 300 percent of FPL would extend eligibility to an additional 16 percent of CSHCN. At the 250 percent threshold, 13 percent of currently uninsured CSHCN would be made eligible; 18 percent of uninsured would become newly eligible if the threshold were raised to 300 percent.

Expansions of eligibility associated with the Family Opportunity Act could have limited effects on coverage if the expansions were in the context of SCHIP programs and the waiting period requirement were maintained. Among those who would be made newly eligible by further extending the thresholds, 51 percent of CSHCN would face waiting period requirements at the 250 percent threshold, yet only 11 percent would meet those requirements. At the 300 percent threshold, 56 percent of CSHCN would face waiting periods, and only 10 percent would meet those requirements. Advocates for the Family Opportunity Act should consider the potential effects of extensions made through SCHIP compared with Medicaid programs. It may be appropriate to exempt CSHCN from waiting periods and even permit dual private/public coverage for these children.

D. Participation of CSHCN in Public Insurance

Participation or take-up of public insurance is hypothesized to be higher among children eligible for Medicaid compared with SCHIP, and higher for CSHCN compared with other children. The higher rates of participation among CSHCN are expected to be due, in part, to the presence of SSI recipients in the CSHCN group, who are automatically enrolled in Medicaid in some states. However, beyond that mechanical relationship, CSHCN are expected to be more likely to participate due to higher demand for insurance coverage generally.

Our findings strongly support the hypotheses of higher participation rates for CSHCN overall, and for all major sub-categories of eligible children. Overall, we estimate that 55 percent of eligible CSHCN are enrolled in some form of public insurance. The highest

participation rates are among those with SSI (82 %), and others eligible according to rules in place in 1997 (65 %). This latter group likely reflects a lower income population, with fewer private insurance options or resources to purchase it.

CSHCN made newly eligible through either Medicaid or SCHIP expansions are less likely to participate than those previously eligible, with participation rates of 28 percent among those newly eligible for Medicaid, and 29 percent among those eligible through SCHIP expansions. Among other children, the overall participation rate is 39 percent. Participation is highest among those eligible via rules in place in 1997 (53 percent). Rates for those newly SCHIP eligible (18 percent) are significantly lower than participation rates for CSHCN.

Since children with private insurance are not immediately eligible for SCHIP programs with waiting periods, we also examine participation rates among children without private or other public insurance such as Medicare. Participation rates are much higher for this subgroup, but the pattern of higher participation rates among CSHCN persists. The overall participation rate for CSHCN without private insurance is 81 percent. Among those CSHCN eligible according to rules in 1997, 85 percent participate. Those newly eligible are less likely to participate; 59 percent of those newly eligible for Medicaid, and 67 percent of SCHIP eligibles participate. Among other children, participation rates are lower. The overall rate of participation is 66 percent. Among those eligible according to the rules in 1997, 72 percent participate. Only 47 percent of those newly eligible via SCHIP expansions are enrolled in public insurance.

Participation in SCHIP and Waiting Periods

Among SCHIP eligible children, waiting periods appear to discourage participation. For CSHCN, the take-up rates are 26 and 62 percent respectively when enrollment is conditioned on meeting a period of uninsurance versus unconditional eligibility. For other children, the effects are equally dramatic, with rates of 16 percent when a waiting period is imposed, compared with 47 percent otherwise. The higher rates of participation for CSHCN faced with a waiting period do not support the alternative hypothesis – that waiting periods would be more onerous for CSHCN.

Participation and Premium Requirements

Similar to waiting periods, premium requirements appear to discourage enrollment in public insurance, and the effects are greater in other children than in CSHCN. Participation among CSHCN who are required to pay a premium is 35 percent, compared with 60 percent for CSHCN who do not face a premium, and 18 percent for other children required to pay a premium. Premiums are generally charged at higher incomes only, so differences in participation among those who face premiums and those who don't may be related more to income differences than the premium requirement itself. However, differences in participation rates for CSHCN compared with other children who are required to pay premiums suggest that CSHCN are less sensitive to the premium requirements.

E. CSHCN and Parent Labor Force Participation

Characteristics of Low-Income and TANF Recipient Families with CSHCN

Our first set of findings addresses the question of whether TANF recipient and low-income families with CSHCN differ from other families with children in employment, financial resources, and barriers to work. We find that the characteristics of children with special health care needs in TANF and low-income families differ from those who do not have these needs. A significantly higher percentage of CSHCN are older, male, white, non-Hispanic, and U.S. citizens than other children. This is true for both TANF families and low-income families. In our low-income sample, CSHCN are more likely to live in single-parent families, 55 percent compared to 43 percent. However, there is no difference in among TANF families. We do not observe significant differences in the family size of CSHCN in either sample.

Among families receiving TANF, we find no significant differences in work or hours of work between families with CSHCN and other families. In both groups about a third have a parent working full-time (35 hours per week or more) and about half do not have a working parent. Even when we examine single-parent and two-parent families separately, we do not find significant differences. In single-parent families less than a quarter of children's parents are working full-time and 61 percent of children are in TANF single-parent families where the parent is not working.

Given that this sample is defined using receipt of government-provided benefits, it is not surprising the rates of employment are relatively low. We find that among the broader low-income population, employment is significantly higher and there are significant differences in work across families with and without CSHCN. A little more than a quarter of low-income families with a CSHCN have no working parent compared to only 18 percent of families without a CSHCN. This significant difference is found among single-parent low-income families and two-parent low-income families, although employment rates are higher in two-parent families.

Families with CSHCN also differ in their sources of income. For all families, earnings from work are one of the most important sources of income. Almost half of TANF families and two-thirds of all low-income families had some earnings in the previous year, with no significant differences by having a CSHCN. We do find significant differences in receipt of government cash benefits, in particular, disability benefits. Families with a CSHCN are significantly more likely to receive child Supplemental Security Income (SSI) benefits, 18 percent compared to 1 percent among TANF families, and 12 percent compared to 1 percent for low-income families. But families with a CSHCN are also more likely to receive adult SSI benefits (14 percent compared to 9 percent for TANF families) and Social security benefits (11 percent compared to 5 percent for TANF families).

Despite these differences in sources, we find relatively little difference in the level of income or poverty across these families. A large percentage of TANF families, with and without a CSHCN, have very low-incomes. More than a third had annual incomes the previous year of less than \$10,000 and a similar percent of families had income below 50% of the poverty line. However, there is no significant difference in income across families with and without a CSHCN. For the broader group of low-income families there is some evidence that families with CSHCN have lower incomes. Only 33 percent of these families had income above \$25,000 and 39 percent of families without a CSHCN had income in this range. However, after adjusting for family size, we do not find significant differences in the percentages below the poverty line. So incomes vary only a small amount, even while the sources of income are significantly different.

In addition to having a CSHCN, other barriers such as low educational levels, little past work experience, a large number of children, a very young child to care for, or poor health (of the adult) may impede work. We find significant differences across families with and without a CSHCN on the presence of these other factors. A high percentage of mothers who receive TANF and low-income mothers generally have not finished high school. But significantly fewer mothers with a CSHCN fall into this category, 33 percent compared to 45 percent of TANF recipients. This is also true for low-income families, 25 percent compared to 31 percent. About a fifth of TANF and low-income families have four or more children. TANF families with a CSHCN tend to be smaller, with 22 percent having 4 or more children compared to 30 percent of TANF families without a CSHCN. These families also are less likely to have a very young child, under age 1, 21 percent compared to 36 percent. This is consistent with our earlier finding that CSHCN are generally older. The same pattern holds for low-income families.

Poor parental health can also limit work. Using four different measures (whether a parent is limited in usual activities, is in fair or poor health, receives SSI disability benefits, or any of the above), we find a high percentage of families have an adult with at least one of these health problems. In addition, a significantly greater percentage of families with a CSHCN report adult health problems. Among TANF families, 48 percent with a CSHCN report an adult with at least one of these health problems. This is significantly higher than the 31 percent of families without a CSHCN. Among low-income families the difference is 35 percent compared to 18 percent. Clearly, a large number of low-income adults and TANF recipients have health problems that might impede their ability to work.

Relating CSHCN and employment

We use multivariate statistical techniques to better understand the relationship between having a CSHCN and employment, controlling for other barriers to work and demographic characteristics. The dependent variable used is whether a single-parent worked any number of hours in the week prior to the interview.

For both the TANF recipient and low-income samples, we estimate a negative but insignificant relationship between having a child with a special health care need and the likelihood of work. For low-income families the level of the coefficient suggests a 2 percentage point decrease in work associated with having a CSHCN with the overall employment rate for this sample of 65 percent.⁸ However, we cannot confidently say this change is different from zero.

Other factors in these regressions are found to have significant negative relationships to work. For the sample of low-income single-parent families, the age of the youngest child is positively related to employment. Those who have completed high school or received a GED are significantly more likely to be working than those who have not, by 12 percentage points. The likelihood of work is relatively higher again for those who have some college or graduated from college or more. Adults with an activity limitation or in fair or poor health are significantly less likely to work. The associated decline in work is 34 percentage points, nearly a 50 percent decrease in the average employment probability. For comparison, this percent change is 17 times greater than that estimated for a CSHCN (which was not significant). This shows the huge impact of adult health on work.

Results on other barriers for the sample of single-parent families on TANF in the previous year are similar. Both education levels and parental health are significantly related to the probability of work, and with similar magnitude. In addition, black and Hispanic TANF recipients are significantly less likely to be working, which could reflect labor market discrimination or unmeasured differences in geographic areas, or unmeasured differences in human capital.

We also estimated the connection between having a CSHCN and hours of work, using tobit regression. We find no significant relationship between having a CSHCN and hours of work, although the point estimates are negative and small. Similarly, the connection between other children in the family having a limitation and work is also insignificant.

Other factors are associated with lower average hours of work in both samples. Low-income single parents with young children work fewer hours. A decrease of two years in the age of the youngest child is associated with an additional hour of work per week. Single-parents who are black, Hispanic, or other (not white and not Hispanic) work significantly fewer hours than white, non-Hispanic single-parents. Male low-income single parents work on average almost 8 hours more per week than females. Higher levels of education are also associated with significantly greater hours of work. Those with a high school diploma or GED work on average 6 hours more per week than those who have not finished high school. Similar to our findings on the probability of work, parents with activity limitations or fair/poor health work significantly fewer hours per week, almost 16 hours. Our estimates suggest that adult health issues have a many-fold greater affect on hours worked than having a CSHCN.

⁸ Percent change indicates the simulated change in predicted probability of work associated with a change from 0 to 1 in the value of the independent variable.

Results for the sample of single parents on TANF are largely similar with a few exceptions. Black and Hispanic TANF recipients work even fewer hours relative to white, non-Hispanic recipients than in the broader low-income sample. Poor parental health is associated with significantly lower hours of work, but the magnitude is smaller than in the low-income sample, a reduction of about 9 hours compare to almost 16 hours.

The lack of significant relationship between having a CSHCN and employment or hours of work indicates that CSHCN's parents work behavior does not differ appreciably from work among other low-income single parents. However, it is clear that children identified as CSHCN are a heterogeneous group. It includes children with a variety of chronic conditions who have different levels and types of service use. This in turn means the families of these children have varying levels of needs that could impact work decisions, such as associated out-of-pocket costs, elevated time requirements for parental care or visits to medical professionals, need for specialized child care. If the variation in these needs within the group of CSHCN is high, and a fraction of these children do not have health needs that would substantially interfere with work, then our result may be masking significant impacts on work for a subset of CSHCN.

To understand whether subgroups of CSHCN might have a significant relationship to employment, we estimated the same regression models substituting measures of chronic conditions, elevated service use and activity limitations. We find that measures that are based on medical conditions alone or based on elevated or special service use do not have a significant relationship to work for low-income single-parent families. However, families with children identified by the measure of activity limitation or the measure of chronic conditions that lead to activity limitations do have significantly lower probabilities of work. Having a child with an activity limitation is associated with a 6 percentage point lower probability of work. A similar reduction is found for the chronic medical conditions that limit activities.

We also estimated the relationship between these different measures of child health and disability on the number of hours worked last week. These estimates also show a significant negative relationship among low-income single-parent families between the measures of activity limitations or chronic medical conditions that limit activities and hours of work. The estimated marginal effect suggests that having a child in one of these categories is associated with working about two and a half fewer hours per week. Estimates for elevated service use and chronic conditions more generally are not significant.

IV. Discussion of Findings

A. Conclusions

Consistent with expectations, this analysis finds that children with special health care needs have different patterns of insurance coverage than other children. Rates of public insurance coverage are higher, due to higher rates of eligibility – especially for

severely disabled children who are recipients of SSI, and higher rates of participation in public insurance, likely due to the incentives associated with expected higher need for services. Rates of private insurance coverage are lower among CSHCN, consistent with lower rates of parent employment, lower incomes, and the difficulty in accessing the non-group insurance market. Higher rates of public coverage more than compensate for lower rates of private insurance, resulting in smaller proportions of CSHCN going uninsured. This scenario implies that the insurance safety net provided by public coverage is working better for CSHCN than it does for other children.

The analysis does not find major differences in the burden faced by families with CSHCN in terms of private insurance premiums paid. However, the data available on the NHIS do not permit us to incorporate information on the premiums that families of uninsured or publicly insured children would have had to pay to purchase insurance for their child. Moreover, the data do not permit us to compare the comprehensiveness of the policies being purchased. It is likely that policies covering CSHCN, particularly for non-group coverage, will have more cost sharing, or may exclude the specific conditions affecting the CSHCN. Providing care for a CSHCN does place a greater burden on the family with respect to out-of-pocket spending, and CSHCN are more likely to forego various types of care due to cost. Patterns of coverage within families suggest some additional fragmentation in coverage associated with having a CSHCN, but the magnitude of these effects is small.

We find differences between CSHCN and other children in the overall percent of children eligible for public insurance, and in the distribution across public insurance program characteristics. These differences are due to both institutional differences – such as Medicaid eligibility for SSI recipients, as well as differences in the characteristics of CSHCN that determine eligibility. Our bivariate analyses of participation suggest that participation rates are higher for CSHCN. Multivariate analyses to be completed in the next year of the project will help discern what programmatic factors, such as premiums or waiting periods, affect participation decisions, and whether CSHCN have different behavioral responses.

B. Limitations

The principal limitations to the analyses in the project to date are related to potential errors in measurement of eligibility for Medicaid and SCHIP, and limitations in the measurement of CSHCN. The success of the algorithm in identifying Medicaid and SCHIP eligible children is dependent on the accuracy of self reported income, the manner in which the data are made available in the data files, and the extent to which we can model specific rules employed in the determination process. In general, respondents to all household surveys tend to under-report income. To the extent that this is true for the NHIS, then the measured income used in the eligibility algorithm will be understated, and some children will be identified as eligible when they are not truly eligible. This in turn will bias participation rates downward, as ineligible children are included in the take-up denominator. However, the presence of a CSHCN would not particularly bias a family's reporting of income relative to other families, so that the relative patterns of eligibility

should not be affected. Likewise, limitations in the way the data can be accessed in the data files, for example the lack of information on asset levels on the NHIS, may bias the estimates of eligible children, but should not affect CSHCN differently from other children. One limitation that is particularly salient for CSHCN is that the algorithm does not model eligibility for Medicaid through spend-down to the Medically Needy program thresholds. Thus some CSHCN who report Medicaid coverage will not be identified as being eligible for Medicaid, and will not be included in analyses of take-up. This may understate the participation rate for CSHCN relative to other children. Thus the differences we find can be considered to be lower bound estimates.

In the various analyses we identify CSHCN by constructing an algorithm that mimics the CSHCN screener. There are limitations in the variables on the NHIS, that may cause us to both include children who do not truly meet the MCH criteria, and to incorrectly exclude children who do. One of the most significant issues is that most of the measures of unusual or elevated use of services are not linked explicitly to the presence of a chronic condition. Unlike the CSHCN screener, which first asks about elevated service use or need and then asks if it is related to a chronic medical condition, the algorithm created on the NHIS requires that the child report both elevated service need and a chronic condition, but there is no mechanism to link them causally.

The use of household survey data in general presents issues in measuring the presence of chronic conditions. The NHIS collects information on medical conditions by asking the respondent whether the child has ever been diagnosed by a physician as having any of a battery of medical conditions. Uninsured children are less likely to have access to a physician and therefore are more likely to have undiagnosed conditions. Thus uninsured children may be disproportionately excluded from the pool of CSHCN. This may bias estimates of insurance coverage upwards for CSHCN relative to other children. It also means that certain groups with higher rates of uninsurance (e.g. Hispanics) are less likely to be identified as CSHCN. The inclusion of the CSHCN screener within the body of a household survey may ameliorate this bias to some extent, because the respondent must report on the presence of a chronic condition, which is not conditioned on a doctor's diagnosis.

C. Comparisons to Other Studies

The distribution of insurance coverage for CSHCN is similar qualitatively to previous estimates from 1994. This analysis finds a higher proportion of children with private insurance than either Newacheck (2000) or Heck and Makuc (2000). The difference may stem from differences in the population of CSHCN identified. The 1994 NHIS disability supplement contained a very different set of questions that were used to identify children with activity limitations, elevated service need, and chronic health conditions, compared with the current NHIS. The Heck and Makuc definition was much more restrictive, identifying only 7.5 percent of children as having special health care needs, whereas the definition of Newacheck et al. (1998) identified 18 percent of children. Although there are likely to be broad overlaps in the types of children identified, there may also be differences that explain the lower rates of private coverage. Unfortunately it is not

possible to compare the two definitions using one dataset. Alternatively, differences in estimates of insurance coverage may be due to the significant changes in the environment for cash assistance and health insurance in 1999-2000 compared with 1994-1995.

Estimates of the proportion of children overall who are eligible for Medicaid and SCHIP are consistent with the estimates of Dubay et al. (2001) using the 1999 National Survey of America's Families. Given that the general approach to identifying eligible children is similar in both studies, and the data on federal and state specific policies nearly identical, this is not a surprising result. However, Dubay et al. do not stratify eligibility rates by child health status, so it is impossible to compare estimates for CSHCN. Estimates from LoSasso and Buchmueller (2002) using the CPS find similar percentages of children eligible overall. Likewise, overall estimates of participation in Medicaid and SCHIP among eligible children are similar to those of Dubay et al. (2002). Again, participation rates were not stratified by health status, so there is not a good basis for comparison.

There are a number of studies that examine the effects of child health on labor force participation of parents, so there are more meaningful comparisons of the results from this study with previous work. The results from this study suggest that after controlling for other factors, employment rates of single parents who have a CSHCN do not differ from those of other parents. These results stand in contrast to studies that have found significant negative impacts of child health or disability on single-parents' (or single mothers') employment (Bednarek and Hudson 2002; Smith, Hatcher, and Wertheimer 2002; Powers 2001; Powers 2000) or exits from welfare (Brandon and Hogan 2001; Meyers, Brady, and Seto 2000).⁹ There are two important ways this study differs from these others. First, most of the other studies have not limited their focus to low-income families, the exception being Meyers et al (2000) which focuses on poor children in California. Low-income single-parent families may have less ability to adjust labor supply in response to child health needs, especially those that are not eligible for government benefits.

The second major difference in this study is the use of the CSCHN indicator, defined using the MCH definition, to measure child health problems. Prior studies have used a variety of different definitions of child health or child disability, including measures of activity limitations, specific conditions, specific impairments, SSI benefit receipt, and measures of service use, with differing results. The CSCHN indicator used here combines a number of these dimensions of child health problems.

Several previous studies find a negative relationship to work when using a definition based on activity limitations (Bednarek and Hudson 2002; Powers 2001; Powers 2000). Results using services or conditions have been more mixed, and seem to depend on the specific definition. Our results are consistent with these previous findings, since we find a significant association between employment and hours of work and having a child with activity limitations or presence of a chronic limiting condition. These results suggest that different subgroups of CSCHN or different dimensions of the

⁹ A few other studies have found more inconclusive results (Kimmel 1997; Acs and Loprest 1999).

CSHCN definition more likely embody the factors that make work difficult for low-income parents.

D. Policy Implications

These new data indicate that 3.85 million CSHCN were eligible for public insurance in 2001, with almost one-third of them becoming eligible as a result of changes in eligibility rules that occurred between 1997 and 2001. Among the eligible CSHCN, 87 percent have some form of insurance; only 13 percent are uninsured. These uninsured eligible CSHCN represent three quarters of all CSHCN who lack insurance. These results suggest that expansions in eligibility have extended access to public insurance to most CSHCN without other sources of insurance, and that the overwhelming majority of those who are eligible either participate in the public coverage or find alternative sources of coverage. To complete the task of covering all CSHCN, efforts must be undertaken to understand the barriers to enrollment of the small number of CSHCN who are eligible but uninsured. The bivariate results in this analysis suggest that premium requirements discourage participation. If this result is confirmed through multivariate analysis, then policy makers may want to consider waiving or at least subsidizing premiums for CSHCN. Research on children in general suggests that families of uninsured eligible children are not familiar with Medicaid and SCHIP (Dubay, Kenney, and Haley 2002), or that enrollment processes are onerous. It is likely that more families with CSHCN are familiar with the public insurance programs, although they may not realize that their child is eligible. Enhanced outreach efforts and simplification of the enrollment and re-enrollment processes are prescribed generally, and are likely to assist in increasing enrollment of CSHCN further.

The results of the analysis suggest that the existing insurance coverage is adequate for most CSHCN, but there are some areas of unmet need, and out-of-pocket costs to some families are substantial. The burden associated with high out-of-pocket costs can be resolved by encouraging families with private insurance who have Medicaid eligible children to get dual coverage, where the Medicaid coverage pays the cost-sharing for any covered service. This option is not currently available for SCHIP eligible children – but perhaps should be reevaluated by policy makers, at least for CSHCN.

Incremental expansions of eligibility will cover even more of the currently uninsured CSHCN however, it is not clear whether programmatic constraints would limit participation. The simulated further expansions of SCHIP programs reveal that a large number of any newly eligible children would face enrollment waiting periods, and that many would not meet the waiting period requirements because they have pre-existing private coverage.

E. Suggestions for Future Research

The failure to find dramatic differences in the burden associated with providing insurance, in the adequacy of the coverage, and in family patterns may be due to heterogeneity within the population of CSHCN itself. Only a portion of the CSHCN

identified have serious medical problems that require ongoing medical monitoring and/or interventions. These children may be even more likely to be enrolled in Medicaid when eligible, and may face greater barriers to private coverage. Likewise, children with greater requirements are more likely to experience unmet needs and other access problems. In preliminary work, analyses of insurance coverage have been stratified by whether the child's condition is physical as opposed to a mental health or behavioral condition. These results suggest increased enrollment in Medicaid among those with physical conditions. Future research is needed to explore other ways to identify more severely affected CSCHN.

As mentioned previously, the second phase of this research will use multivariate techniques to address the effect of having special health care needs and other child and program characteristics on insurance choices among eligible children. The effects of public insurance eligibility expansions on coverage for CSCHN will be estimated. These analyses have previously been identified as areas of important research. Completion of these steps will likely lead to identification of additional areas for future research.

V. List of Products

A. Working Papers

Davidoff, A. Children with Special Health Care Needs: New Prevalence Estimates from the National Health Interview Survey. Under review by *Health Services Research*. Copy attached.

Davidoff, A. Patterns of Health Insurance Coverage for Children with Special Health Care Needs. Working paper, presented at the Annual Meeting of the American Economic Association in January 2003. Copy attached.

Loprest, P. and Davidoff, A. Facilitating Work Among TANF Recipients with Children with Special Health Care Needs. Draft in progress, not attached.

Davidoff, A., and Yemane, A. Eligibility and Participation of Children in Medicaid and SCHIP: A snapshot from 2001. Draft in progress, not attached.

Davidoff, A., Yemane, A., and Hill, I. Did the SCHIP Expansions Meet Expectations for Covering Children with Special Health Care Needs? Draft in progress, not attached.

Davidoff, A., and Yemane, A. Patterns of Participation in Public Insurance for Children with Special Health Care Needs. Draft in progress, not attached.

B. Conference Presentations

The paper on Patterns of Health Insurance Coverage for CSCHN was presented at the American Economic Association Annual Meeting in January 2003. The paper has also been accepted for presentation at the Annual Academy Health Meeting in June 2003.

A poster concerning eligibility expansions and participation for CSHCN will be presented at the Academy Health meeting as well. Abstracts have been submitted to the American Public Health Association for its meeting in November 2003 and the American Economic Association meetings in January 2004.

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