

AN ANALYSIS OF MEDICAID PRIVATE DUTY NURSING FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS

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OVERVIEW

Home health care for children with special health care needs (CSHCN) has been called a “medical and social innovation” that has “potential risks and benefits, inevitable uncertainties, and unique ethical considerations.”¹ An estimated 50,000 children use home health care services daily, with 60% of these services for skilled nursing care.² Recent national cost estimates specific to children are not available. However, the Health Care Financing Administration (HCFA) reported overall home health care costs for all ages at \$22.3 billion in 1999. In Florida, costs for the private duty nursing component of home health care is reported to be \$100 million for State Fiscal Year (FY) 2000-2001.

The purpose of this report is to present:

- A summary of the literature on private duty nursing for children and relevant case law on private duty nursing,
- A summary of interviews conducted with staff in five different states about their private duty nursing programs,
- A summary of telephone survey data collected in 1997 with families whose children are enrolled in Children’s Medical Services (CMS), Florida’s Title V CSHCN Program addressing their unmet health care needs and out-of-pocket spending for home health care services; and
- An analysis of current expenditures for home health care and private duty nursing among CMS enrollees and projections of future spending.

REVIEW OF LITERATURE

Over the past 30 years federal legislative action has greatly influenced approaches toward children with special health care needs (CSHCN).³ For example, in 1967 Congress mandated that states must provide Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) services through their Medicaid Programs. EPSDT services encompassed screening of individuals under the age of 21, “to ascertain their physical or mental defects, and such health care, treatment, and other measures to correct

or ameliorate defects and chronic conditions discovered thereby, as may be provided in regulations of the Secretary.” However, in 1989 Congress passed the Omnibus Budget Reconciliation Act of 1989 (OBRA ’89). As part of OBRA ’89, preventive care and disability-related services were addressed. Significantly, as it relates to CSHCN, the law required states to provide all medically necessary services that were eligible for federal financial reimbursement to children whose health care screens revealed problems. These services had to be provided even if they were not otherwise covered under the state’s Medicaid Program.^{4,5} This particular provision is a point of serious contention with some state agencies, which believe that it greatly limits their ability to control Medicaid spending.

The recent literature on issues related to home care, private duty nursing, or personal attendant services for CSHCN is very limited. One has to turn to literature that is 10 to 20 years old to find in-depth discussions of home nursing services. In the 1980’s Lou Ann Aday conducted a national program evaluation to assess the outcomes of care for ventilator-assisted CSHCN who were transferred from the hospital to home.⁶ This evaluation is one of the most comprehensive assessments of pediatric home care, to include private duty nursing, available. As part of the study, Aday and her colleagues reported that home care costs were significantly lower than hospital costs for these children. Hospital care was used as a basis for comparison because this was the only other alternative for the children’s care. Others have noted that home care costs are less expensive than hospital costs only if the parent is assuming part of the caregiving responsibility. If a nurse provides the majority of home care, the home care costs approach and sometime exceed hospital care costs.⁷

Other early work that considered the financial aspects of children’s long-term care needs focused on the inadequacy of most benefits packages for CSHCN and the out-of-pocket spending that families often experience when caring for these children.⁸ Recommendations from this early work focus on ensuring that families and their CSHCN are given appropriate support and services and that benefits packages are structured to best meet their complex needs.

Much of the current literature that might be applicable to understanding issues associated with the provision of private duty nursing for CSHCN fall into the category of long term care (LTC) provision. The majority of this literature focuses on adults and not children. None-the-less the LTC literature documents the rapidly escalating Medicaid expenses for these services, which include the provision of long-term physical, speech and other therapies, long-term institutional care, and long-term home care.

States often use community-based waivers (1915 C waivers) to design programs to provide services for the elderly and persons with physical and developmental disabilities in the home and community.⁹ Home and community-based LTC arrangements continue to be seen as the best environment to deliver care as opposed to institutionalizing Medicaid-eligible individuals. In 1998, Medicaid accounted for 17% of total spending on home health care in the United States. To control these

expenditures, states are increasingly exploring options of providing a range of LTC services, including home health and personal care services, in a managed care setting. Texas and Michigan are providing such services in managed care environments under 1915(b) and 1915(c) waivers, which typically include limiting freedom of choice for the families selecting service providers.¹⁰

In a four state study of children receiving Medicaid and incurring \$10,000 or more in health care charges annually, Kuhlthau et al., documented that LTC expenditures accounted for 10% to 42% of the total health care expenditures for this group of children. LTC expenditures were not well defined, but did include facility charges, such as structured nursing facilities. Home health expenditures, which was not restricted to private duty or skilled nursing, accounted for 4% to <1% of the total expenditures, depending on the state.¹¹ The authors noted that one of the uses of their findings was to help states plan for their expenditures for these very high cost children.

In summary, with the exception of considering caring for CSHCN within managed care arrangements, there is little in the current literature about how to address the rising private duty nursing costs for this group of children. Some states have attempted to obtain modifications to OBRA'89 and others are using 1915 waiver programs. Attempts to modify OBRA'89 have failed in the past and the outcomes from states using 1915 waivers to address their LTC costs in Medicaid are not known.

Court cases about LTC issues have involved adults and usually also involve a unique aspect associated with program eligibility. For example, a recent court case involving LTC for adults was heard in Albany, New York (June 2000). The New York Court of Appeals upheld two lower court decisions that the state cannot refuse to provide medical coverage for people needing long-term institutional care in cases where the spouse refuses to turn the ailing person's assets over to the government.

Another recent case (1999) involved Florida's Agency for Health Care Administration (AHCA). AHCA revoked home care nursing services for a five year-old child with autism, esophagitis reflux, and dysphagia on the basis that the services that the child needed were not "skilled nursing services." The family challenged the decision. The judge ruled that skilled nursing was medically necessary for this child because 1) the child's physician ordered the services, 2) there was a medical need for a nurse to supervise the child's feeding to avoid choking, and 3) the child needed nursing services as prescribed by the doctor to combat dysphagia.

STATE INTERVIEWS

To learn more about states' experiences with private duty nursing in their Medicaid Programs, telephone interviews were held with Title V CSHCN Program and Medicaid Program representatives in six states. Table 1 contains a summary of the states selected for interview and the rationale.

Table 1. States Included for Interviews About Private Duty Nursing for CSHCN in Medicaid

States Included	Rationale
Michigan	Michigan has done extensive working assessing health care use and charges for CSHCN. They offer Medicaid fee-for-service (FFS) and capitated managed care programs for their CSHCN. Thus, it was anticipated that analysis of their approaches would provide useful information for Medicaid FFS and capitated environments.
Texas	Texas has a unique program to identify CSHCN for referral to specialized case management services. It also is a large and culturally diverse state with many demographic similarities to Florida. Thus it is a good state for comparison purposes and useful data in CSHCN's health care use and charges are available. Texas has a 1915(b) and 1915(c) waiver.
Oregon	Oregon is well known for their work identifying "medically necessary services". This state tends to take a more restrictive approach to health care services for all its residents, when compared to other states. Oregon provides "home follow-up services" for their CSHCN. More information from a state that has taken a more conservative approach to funding health care was determined to be helpful.
Tennessee	Tennessee is well known for its TennCare Program. This managed care program carefully monitors CSHCN's health care use and charges. Some view this program as a success and others do not. This program is recommended for inclusion because it is highly managed and there are reports that it has resulted in cost savings to the state. However, it is also a controversial program.
Washington State	Washington has conducted detailed analyses of their CSHCN in Medicaid and likely will be able to provide useful information about these children. Moreover, for their CSHCN in Title V, services are provided based on determining available resources and various payer sources.
Arkansas	Arkansas was selected for interview on the recommendation of Florida's Title V CSHCN Program staff. Arkansas recently changed their approach to authorizing and providing private duty nursing services for their CSHCN. Learning more about their reasons for changing their approaches and what types of approaches they were using were determined to be important for this analysis.

In addition, interviews were conducted with state Title V and Medicaid staff in Louisiana based on the recommendations of Title V CSHCN Program staff in Arkansas. The Arkansas staff believed that Louisiana had developed some innovative approaches for caring for these children. Tennessee staff were unable to provide detailed information at this time. CSHCN in that state do receive private duty nursing services if it meets their medical necessity guidelines. All private duty nursing services are provided within managed care.

An interview guide was developed to address the following:

1. Whether the state funds private duty nursing,
2. The benefit package and any limitations such as the number of total days in a year or the number of hours per day that the service can be provided,
3. Eligibility criteria in terms of who receives the services and in terms of the amount that can be received,
4. Who does eligibility determination,
5. The number of children received private duty nursing for the last three fiscal years,
6. Expenditures on private duty nursing for children ages birth through 18 annually for the last three fiscal years,
7. Contracting relationships with agencies providing private duty nursing,
8. The use of selective contracting for private duty nursing services, and
9. Alternatives to private duty nursing that the state has considered.

The interviews were conducted in March and April 2001. The participants were sent a copy of the interview guide to review prior to the call and then were interviewed by telephone. One state was required by their state policies to respond in writing and not verbally and to have the responses reviewed by various administrators before the responses could be released to the Institute.

RESULTS OF STATE INTERVIEWS

Table 2 contains a summary of the states responses to the topics listed above. The results are described more fully in the subsections below.

Administration of the Benefit: All of the states participating in the interviews offer private duty nursing services to CSHCN age birth to 21 meeting medical eligibility or other criteria. The states all noted that they are required to do so as part of OBRA'89. For three of the six states, the Medicaid

Program administers the benefit. For one of these states, this is a recent change. In Arkansas, the State Title V CSHCN Program had administered the benefit. However, due to rising costs, the administration was moved to the Medicaid Program. The rationale for the move was that the Title V Program played too much of an advocacy role and that the Medicaid Program would conduct more objective screening before authorizing the service. For three of the six states, the benefit is administered through programs that are specifically devoted to the care of children with special health care needs.

The Benefit Package: Three of the six states report limits to the private duty nursing benefit, whereas three do not. The limitation to the benefit involves the number of hours per day that the family can receive private duty nursing. Typically the family is expected to provide eight hours of care per day. This requirement is most carefully specified in Michigan and the most liberal in Oregon. For example, Michigan specifies that the family's eight-hour obligation cannot be met during a time when the child would normally be at school or in a day care facility. Oregon will reduce their usual eight-hour family care requirement to four hours, if the family is having trouble managing the child's care.

Michigan has specific guidelines that are used to determine the number of private duty nursing hours the child can receive. These guidelines are considered along with social and family factors. A summary of their guidelines is contained in Appendix A.

Similarly, Oregon assesses each task that must be completed when caring for the child and then assigns a score, which is used to determine the number of hours of care the child will receive. For example, a child with a tracheotomy and a 24-hour ventilator requires more care than a child with a tracheotomy and no ventilator. The former child would receive a higher score and therefore more private duty nursing care than the latter child. The child's care needs are reassessed regularly and the private duty nursing hours adjusted to account for any changes in the child's condition (either improvement or deterioration).

Three states indicate that they do not have any limitations. However, the average number of private duty nursing hours reported by one state is eight and another is 12. The third state without benefit limitations did not provide the average number of private duty nursing hours delivered. Interestingly, Louisiana reports no benefit limitation. However, this state uses an outside company, Unisys, to determine the amount of hours that are most effective for the child to receive. Unisys does receive information from a decision team that plans the child's care before authorizing the number of private duty nursing hours.

Program Eligibility: The program eligibility requirements are very similar from state to state. The children all must be Medicaid eligible. Some states also require enrollment in their program for

CSHCN. A physician must order the private duty nursing services and the child must have a documented need for such services. States also require that the child have a designated caregiver. Typically the child must also have equipment needs and the need for ongoing skilled nursing intervention. Appendix B contains a summary of the eligibility criteria provided during the interview or through separate, additional documentation from the states. The eligibility for all of the states were very similar.

Conducting the Eligibility Determination Process: The three states that use programs dedicated to CSHCN to administer the benefit also conduct the eligibility determination process. As previously noted, the Title V CSHCN Program in Arkansas used to conduct the eligibility determination. Arkansas Medicaid now conducts this process. Texas recently established a Private Duty Nursing Benefit Administrator Position. The person in this position works with a contracted authorization and utilization review firm) to conduct eligibility determination, to monitor the benefit after it is implemented, and to conduct ongoing quality assurance for the children's care.

Number of Children Receiving Private Duty Nursing and Expenditures: The typical number of children receiving private duty nursing benefits for those states able to report annual figures was 160 to 250 cases. Texas reported over 1,200 recipients in 2000. Louisiana reported 540 cases over a five-year time frame.

Two states were unable to report their expenditures. One state said they could not accommodate the request and the other state said they would send us the information. For three of the states, it was possible to calculate a per child expenditure, using the number of recipients covered and the total expenditures reported for that year. The results varied dramatically from a high of \$52,963 in Texas to \$25,000 in Oregon to \$8,100 in Washington. It is important to note that these figures are for private duty nursing only and do not reflect home visits provided by nurses on a short-term basis. With the available information, it is very difficult to explain the differences in expenditures per beneficiary by state. It is unknown if this is related to the acuity of the children, the cost of nursing services in the areas, the provision of a higher number of nursing hours per day in some states as compared to others, or to some other factors. Only analyses of claims and encounter files, coupled with more in-depth knowledge of the state's clinical practices would elucidate the findings.

Alternatives: All of the states reported considering alternatives. Arkansas indicated that their new approach to private duty nursing benefit management and eligibility determination was "the alternative." As previously described, staff in Arkansas are hoping that the Medicaid Program will be better able to control costs than the Title V CSHCN Program. However, there is some concern that

families' needs are not adequately considered now that the Medicaid Program is making the decisions about private duty nursing.

Michigan is changing its private duty nursing program. In their current program, they authorize hourly nursing services and in addition, provide a certain number of skilled nursing visits per month to add additional oversight to the in-home staff. Under the new program, the additional visits will no longer be authorized.

Staff in Texas indicated that their primary concern is meeting the social and psychological needs of families. They believe the current benefit is inadequate and only addresses the physical needs of the child, leaving many other needs unmet. Texas wants to provide additional resources for families. Similarly, staff in Washington said the goal is to have the resources to support families together and to avoid institutionalizing the children.

Oregon is not pursuing other alternatives but indicated that better "exit points" need to be developed. Staff participating in the interview believed that some children were receiving private duty nursing benefits when they were no longer necessary. Finally, staff in Louisiana indicated that they were exploring the use of personal care attendants to provide some of the care that skilled nurses are currently providing.

Table 2. Summary of Interview Responses

Item	Michigan	Texas	Oregon	Washington	Arkansas	Louisiana
Does state provide private duty nursing services as part of the benefits available to CSHCN?	Yes	Yes	Yes	Yes	Yes	Yes
Who administers the benefit?	The Children with Special Health Care Services Program (CSHCS) administers the program	The Medicaid Comprehensive Care Program.	The Medically Fragile Children’s Unit (MFCU) of the Children’s Intensive In-Home Services (CIIS) is the main administrator of the benefit.	The Department of Health and Social Services, Division of Developmental Disabilities, Medical Assistance Administration.	As of January 1, 2001, the Medicaid Screening and Utilization Review Program. The Title V CSHCN Program used to make the determination. This was changed to keep the costs down. Concern was raised that this has reduced the level of advocacy and family oriented services.	Medicaid administers the Extended Home Health Services Program.
Are there limitations to the benefit?	Yes	Yes	Yes	No	No	No
Benefit limitations	A caregiver must reside with those under 18 years and must provide 8 hours of care/day. The 8 hours may not occur when the child would normally be out of the home (i.e., school). For those 18 to 21, there must be an alternate caregiver for 8 hours per day but this person does not need to reside there.	There are no caps, no time limits and no cost limits. However, 24-hour care is not an option unless a special circumstance for care is authorized for a short period of time.	A child may go home from the hospital with 24-hour care but within 4 to 8 weeks, it is expected that the family will do one 8-hour shift daily with one to two weekends off per month if they can get the coverage. If the family cannot care for the child, the expectation of 8 hours is adjusted but never to less than 4 hours.	The average hour per day provided is 9 hours. The average hours per month are 290. RNs are paid \$30 per hour, which is cheaper than institutional care.	Some parents sign a form stating that they are aware that private duty nursing services will decrease over time and their level of care responsibility will increase. However most cases are so complex that this is not an issue.	The average amount is 12 hours per day. RNs and LPNs are paid \$24.50 per hour and personal attendants are also used at \$8 to \$12 per hour.

Item	Michigan	Texas	Oregon	Washington	Arkansas	Louisiana
Eligibility	Must be Medicaid eligible and require skilled nursing care. ¹	Eligibility requirements specify that the child must require skilled nursing care that is continuous.	Eligibility based on medical criteria.	Home care must cost less than institutional care and the child must be enrolled in Medicaid. A treating physician must order home care.	Not currently available.	The current guidelines focus on the child being “medically fragile.” This is defined as a child who has a medically complex condition characterized by multiple and significant medical problems.
Who conducts the eligibility determination process?	The CSHCS program makes all decisions.	There is a Private Duty Nursing benefit administrator. Any child under 21 who is on Medicaid has a right to the benefit, if they meet eligibility criteria.	The MFCU makes all decisions about coverage based on medical criteria. All assessments are conducted by RNs.	The program coordinator gives final approval.	The Medicaid Program gives final approval.	A decision team is used to determine receipt of services. The physician prescribes home health and an external company approves the amount of hours the family can receive.
		There is a contracted authorization and utilization review (UR) company and the Private Duty Nursing Administrator is a new position that is assigned to administer the benefit and will conduct more in-depth quality assurance.				

¹ See narrative for more detailed discussion of eligibility criteria.

Item	Michigan	Texas	Oregon	Washington	Arkansas	Louisiana
The number of children receiving private duty nursing.	200-250 children are receiving these services at any given time.	1,230 recipients in 2000 1,157 recipients in 1999 1,254 recipients in 1998	There are 120 recipients.	159 cases – 2001 158 cases- 2000 163 cases- 1999 167 cases - 1998	250 children receive private duty nursing.	Since 1996, 540 children have received services. Annual breakdowns are not available.
Expenditures for private duty nursing services.	The state does not have this information readily available and cannot accommodate the request due to the amount of staff work required to produce a report.	\$65,145,296 in 2000 \$60,273,304 in 1999 \$64,751,919 in 1998	\$3 million in 2000 \$2.5 million in 1997 and 1998	\$1,287,900 – 2001 \$1,279,800 – 2000 \$1,320,300 – 1999 \$1,352,700 – 1998	Not currently available.	Over the past 3 years, \$6 million dollars has been spent. Although the total Medicaid budget has decreased, this area has increased and is expected to continue to do so.
Contractual relationships with agencies providing the service.	The services are provided under the auspices of a Medicaid Home Health benefit. Thus the state reports they are technically limited to authorize Medicare-certified home health care agencies that also are enrolled as Medicaid providers.	There are 3 providers: the Texas licensed Medicaid certified Home Health Agencies, independently enrolled registered nurses (RNs), and independently enrolled licensed practical nurses (LPNs).	They contract with home health nursing agencies, particularly those specializing in children’s care. The parents may hire nursing aides themselves if the doctor and the family feel this is safe. MFCU then pays for professional nursing oversight.	28 home health agencies are regularly used. The primary quality assurance for the program is conducted by the Department of Health. In addition, the Medicaid Fraud Office is used as needed.	Medicaid certified home health agencies are used.	Medicaid certified home health agencies are used. Currently there are 323 different agencies that are used.

Item	Michigan	Texas	Oregon	Washington	Arkansas	Louisiana
	<p>On a case-by-case basis some non-Medicare and non-Medicaid agencies have been used due to significant access problems. Under their proposed plan, they will no longer be limited to Medicare-certified agencies. The plan is to enroll both agencies and independent nurses meeting proposed requirements.</p>					
<p>Have you used selective contracting?</p>	<p>No, but the state is planning to contract with independent nurses in the future for private duty nursing. .</p>	<p>No, some agencies are used more because they specialize in children and others do not. However this is not considered selective contracting.</p>	<p>No</p>	<p>No mainly because of freedom of choice issues. The private duty nursing is a non-waiver benefit.</p>	<p>No, there are not enough providers.</p>	<p>No.</p>
<p>Have you considered other alternatives?</p>	<p>Michigan currently authorizes hourly nursing services. These will no longer be authorized in the future and only private duty nursing will be used.</p>	<p>Alternatives have been considered ever since OBRA'89 was established. The primary concern in Texas is getting additional resources to families. Nursing is not sufficient and families have social and psychological needs that are not being met with the current system of care.</p>	<p>Better exit points need to be defined for the program. There are instances reported of children playing basketball with a nurse on the sidelines, which is not perceived to be good for the state or the child.</p>	<p>Any alternative to keep the family together is considered. The mission is to prevent children from being institutionalized. If families are not able to stay together, then foster care is sought for the child.</p>	<p>The alternative was the newly implemented program. The state moved the private duty nursing program from Title V to Medicaid to control costs. They also are considering using less costly providers such as personal care attendants to provide some of the services that RNs provided.</p>	<p>The state currently is examining the role of personal care attendants and seeing if there is more that they can do.</p>

NUMBER OF CHILDREN RECEIVING SKILLED NURSING THROUGH CHILDREN'S MEDICAL SERVICES (CMS)

Children receiving skilled nursing services were identified using claims and encounter data provided by CMS for 1997-1998, 1998-1999, and 1999-2000 (July 1 to June 30). In 1997-1998, 1,214 children were identified, 496 in 1998-1999, and 602 in 1999-2000. On average, these children were 5.8 years of age (standard deviation of 5.07). In terms of diagnoses, 18.7% of the children had various congenital anomalies listed as their primary diagnoses, 31% had nervous system disorders, 10% had diseases occurring in the perinatal period, 9% had respiratory conditions, and 6% had injuries. Other conditions occurred with much less frequency. For example, 2% of the children had neoplasms, 2% had digestive disorders, 2% had infectious diseases, 2% had endocrine or other metabolic disorders, and 1% had musculoskeletal conditions.

Total health care use rates were calculated for the children. On average, the children had 5.25 health care encounters per month (standard deviation of 5.0). Thus there was great variability in the children's health care use patterns.

There does not seem to be any clear trend in the number of children receiving skilled nursing. The numbers fluctuated greatly throughout the three years of claims data. The types of conditions the children had, their average age, and the average number of their health care encounters was relatively stable across the study period.

UNMET HEALTH CARE NEEDS RELATED TO SKILLED NURSING CARE

In 1997, the Institute for Child Health Policy conducted telephone surveys with parents of participants in CMS who were receiving supplemental security income (SSI) about their unmet health care need and family out-of-pocket spending for health care services. Fifty-three families out of 353 CMS enrollees who were receiving SSI reported that their children received skilled nursing care in the home. There were no unmet needs reported in this area.

SUMMARY

The focus in the literature on LTC expenses in Medicaid is largely related to adults. Little information is available about children, except from an advocacy perspective. States seem to have very similar practices regarding their management of the benefit. The most stringent controls appear to be in those states that require an outside group to determine eligibility and do not allow the entity providing services to make the eligibility determination. Some states are also trying to substitute more personal

attendant care for skilled nursing care. This is occurring in part due to expenses, but also in part due to the national nursing shortage.

A small number of children in the CMS Program are receiving skilled nursing care and as expected the health care use of these children is very high. Their monthly health care use is in excess of the annual health care use for most children (i.e., 5 encounters per month compared to about 2.5 encounters per year). Families report no unmet need related to obtaining skilled nursing care for their children.

It is well beyond the scope of this report to assess appropriateness of services for the children determined to be eligible for skilled nursing care. Because of OBRA '89, there are few alternatives related to limiting this particular benefit. Children must receive those services determined to be medically necessary. The state of Florida should review its eligibility determination process and consider using a separate vendor to determine eligibility apart from the group delivering or coordinating services (if this is not already the practice). Substituting less costly staff can be problematic from a quality of care perspective and should only be undertaken if determined appropriate and safe by the health care providers who best know the child.

Appendix A – A Summary of Michigan’s Guidelines to Determine the Number of Private Duty Nursing Hours a Child May Receive

- Beneficiaries with tracheotomies receiving CPAP, BiPAP, or other positive pressure mechanical ventilation: 12 to 16 hours per day;
- Beneficiaries with tracheotomies but not receiving CPAP, BiPAP, or mechanical ventilation: 8 to 12 hours per day;
- Beneficiaries with parenteral nutrition: 8 to 12 hours per day (Note: the medical fragility of the child, especially regarding their fluid and nutrition status, and the age of the child are important determinants in this category.);
- Beneficiaries receiving mechanical ventilation but without tracheotomies, including children with CPAP or BiPAP administered by face mask; and beneficiaries receiving negative pressure mechanical ventilation: 8 to 12 hours per day; and
- Beneficiaries with severe respiratory disorders who are receiving home oxygen therapy, continuous pulse oximetry, and who require frequent adjustments of their oxygen therapy and frequent assessments of their respiratory status: 4 to 12 hours per day.

The actual number of hours authorized requires a clinical judgment which considers both the categories described above, and the following factors:

- Medical fragility - including, but not limited to, severity and lability of the condition, diagnosis, and age;
- Skilled nursing needs and the frequency of such needs - including, but not limited to, suctioning of the airway, tracheotomy care, injections, assessment of the beneficiary’s condition, indwelling central venous catheter care, initiation and discontinuation of parenteral nutrition solutions;
- Social and family conditions - including, but not limited to, the number of parents and /or adult care givers in the home, the number of other children in the home, the number of children in the home with special needs, competency of the parents and care givers, and support of the family from extended family, friends, and organizations; and
- The time a beneficiary is under the care or supervision of another party (e.g., in school or day care) - generally, the number of hours the beneficiary is under the care and supervision of another party is subtracted (in whole or in part) from the number of hours that would otherwise have been authorized for the beneficiary.

Appendix B – A Summary of Eligibility Criteria

Michigan

To be eligible for the CSHCS Hourly Nursing benefit the person must be determined by CSHCS to meet **all** of the following criteria:

- Be enrolled in CSHCS;
- Be eligible for Medicaid in the home/community setting (i.e., in the non-institutional setting);
- Be dependent daily on medical equipment or medical technologies to sustain life, and require frequent skilled nursing care on a daily basis. **Both** of the following criteria must be met:
 - The beneficiary is dependent daily on technologically sophisticated or technology-based medical equipment to sustain life. “Technologically sophisticated” medical equipment includes: 1) mechanical ventilation four or more hours per day or assisted respiration (BI-PAP or CPAP); and 2) receiving total parenteral nutrition in association with complex medical problems and extreme medical fragility. “Technology-based” medical equipment includes 1) oral or tracheotomy suctioning an average of eight or more times in a 24-hour period (i.e., at least every 3 hours); 2) nasogastric tube feedings or medications when removal and insertion of the nasogastric tube is required, when associated with complex medical problems or medical fragility; 3) parenteral nutrition and a central line associated with complex medical problems or medical fragility; 4) continuous oxygen administration, in association with a pulse oximeter and a documented need for observations and adjustments in the rate of oxygen administration; and 5) a history of complex medical problems and medical fragility with a recent history of an unstable course at home resulting in at least two hospital admissions during the past 6 months.
 - The beneficiary requires frequent skilled nursing care on a daily basis, during the time when the licensed nurse is paid to provide services. Frequent means at least once every three hours throughout a 24-hour period, and/or when delayed interventions may result in further deterioration of health status, in loss of function or death, in acceleration of the chronic condition, or in a preventable acute episode. Equipment needs alone do not create the need for skilled nursing services. Skilled nursing means assessments, judgments, interventions, and evaluations of interventions requiring the education, training, and experience of a licensed nurse. Skilled nursing care includes, but is not limited to: performing assessments to determine the basis for acting or a need for action; monitoring fluid and electrolyte balance; suctioning of the airway;

injections; indwelling central venous catheter care; oxygen administration and evaluation; and tracheotomy care.

- The beneficiary's need for licensed nursing care is of sufficient severity and/or frequency to warrant hourly nursing;
- Hourly nursing services are appropriate, considering the beneficiary's health and medical care needs and other services or programs for which he/she is eligible;
- Hourly nursing can safely be provided in the home setting;
- An Hourly Nursing Service IHCP/Assessment is developed in collaboration with the beneficiary, the beneficiary's family or guardian, relevant service providers and community agencies. The HNS IHCP/Assessment identifies and addresses the beneficiary's need for hourly nursing, and is signed and dated by the beneficiary's attending physician and family; and
- The beneficiary is not receiving services under any of the following publicly funded programs which provide home and community-based service supports: the Children's Waiver, Habilitation/Support Services Waiver, Specialized Support Services For Persons With Developmental Disabilities, or the Home and Community Based Waiver for the Elderly and Disabled (also known as the MIChoice Waiver).

Washington State

Home care activities must cost less than institutionalized care. The recipient:

- Must be enrolled in Medicaid;
- Must have Medicaid paying for the institutional care – no third party insurance can be involved; and
- Must have the treating MD at the hospital or institution prescribe home care as a necessary need to even be able to discharge the patient.

Texas

Clients must meet all of the following conditions to be considered eligible for private duty nursing services. A client must:

- Be under 21 years of age and eligible for THSteps-CCP,
- Meet medical necessity criteria for PDN, and
- Have a primary physician who:

1. establishes a plan of care (POC),
2. provides a statement that PDN services are medically necessary,
3. provides continuing medical care and supervision of the child, including, but not limited to: examination or treatment within 30 days (for initial requests of PDN services), or examination or treatment which must either comply with the American Academy of Pediatrics (AAP) recommended periodicity schedule; or be within 6 months of the PDN extension start-of-care date, whichever is more frequent (for extensions of PDN services). (This requirement may be waived based upon review of the child's specific circumstances.), and
4. provides specific written, dated orders for the child.
5. require care beyond the level of services provided under Texas Medicaid home health services, skilled nursing visits, and
6. has an identified primary care-giver residing in the child's residence and an identified alternate care-giver who is or can be trained to provide part of the child's care; or if no alternate care-giver is identified,
7. have a plan to enable the child to receive care in an alternate setting or situation if the primary care-giver is unable to fulfill his or her role.

Medical necessity of private duty nursing services is based on consideration of whether a child requires the following:

- Continuous, skillful observation and judgment to maintain or improve health status
- Ongoing and frequent skilled interventions to maintain or improve health status, and delayed skilled intervention is expected to result in at least one of the following:
 1. Deterioration of a chronic condition,
 2. Loss of function,
 3. Imminent risk to health status, and
 4. Risk of death.
- Technology to sustain life.
- Determination of medical necessity is based on submitted documentation, which describes the following elements:
 1. Complexity and intensity of care,
 2. Stability and predictability of the child's condition, and
 3. Frequency of the child's need for skilled nursing intervention.

Louisiana

The Bureau of Health Services Financing provides reimbursement for approved home health services for Medicaid recipients based upon the certification of a licensed physician that the recipient is homebound and upon the determination of the Medicaid program that the recipient meets the bureau's homebound criteria under the Medicaid program.

Homebound Criteria for Medicaid Recipients

Homebound status is determined by the recipient's illness and functional limitations. A recipient is considered to be homebound if the individual:

- 1) experiences a normal inability to leave home; or
- 2) is unable to leave home without expending a considerable and taxing effort; and
- 3) whose absences from the home are infrequent, of short duration, or to receive medical services which may be unavailable in the home setting, such as ongoing treatment of outpatient kidney dialysis or outpatient chemotherapy or radiation therapy.

The bureau allows an exception to the third requirement of being unable to leave home for EPSDT recipients, up to age 21, who attend school. However, the services may only be provided in the home. These recipients may be considered to meet the homebound criteria while attending school if prior authorization has approved the individual for multiple daily home visits and/or extended skilled nursing visits in accordance with the certifying physician's orders which must document and meet the following criteria:

- 1) the medical condition of the child meets the medical necessity requirement for the skilled nursing services in the home and that the provision of these services in the home is the most appropriate level of medical care;
- 2) that the failure to receive skilled nursing services in the home would place the recipient at risk of developing additional medical problems or could cause further debilitation; and
- 3) that the recipient/student requires skilled nursing services on a regular basis and that these services cannot be obtained in an outpatient setting before or after normal school hours.

In addition, the following conditions must be met.

- 1) The recipient/student is determined to be medically fragile. A medically fragile individual is one who has a medically complex condition characterized by multiple, significant medical problems, which require extended care. Examples of medically fragile patients are patients whose care requires most or all of the following services/aides: use of home monitoring

equipment, IV therapy, ventilator or tracheotomy care, feeding tube and nutritional support, frequent respiratory care or medication administration, catheter care, frequent positioning needs, etc.

- 2) Special accommodations such as specially equipped vehicles or medical devices and/or personal care attendants are needed to accompany the patient/student to and from school and/or to assist the patient/student at school.

The responsibilities of the home health agency: The home health agency must provide to the bureau upon request the supporting documentation used to determine the recipient's homebound status.

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- ¹Lantos JD, Kohrman AF. Ethical aspects of pediatric home care. *Pediatrics*. 1992; 89:920-924.
- ²Clemans CJ, Davis RL, Novack AH, Connell FA. Pediatric home health care in King County, Washington. *Pediatrics*. 1997;99:581-924.
- ³Stein REK. *Caring for Children with Chronic Conditions: Issues and Strategies*. New York, Springer Publishing Company; 1989.
- ⁴Gullota TP, Hampton RL, Adams GR, Ryan BA, Weissberg RP. *Children's Health Care: Issues for Year 2000 and Beyond*. Thousand Oaks, California: Sage Publications, 1999.
- ⁵Gavin NI, Adams EK, Herz EJ. The use of EPSDT and other health care services by children enrolled in Medicaid: The Impact of OBRA'89. *The Milbank Quarterly*. 1998;76:207-250.
- ⁶Aday LA, Aitken MJ, Wegener DH. *Pediatric Home Care: Results of a National Evaluation of Programs for Ventilator Assisted Children*. Chicago, Illinois: Pluribus Press; 1988.
- ⁷Lantos JD, Kohrman AF. Ethical aspects of pediatric home care. *Pediatrics*. 1992; 89:920-924.
- ⁸Kohrman A. Facing the Financing of Care. In: Stein REK (Ed). *Caring for Children with Chronic Conditions: Issues and Strategies*. New York, Springer Publishing Company; 1989.
- ⁹Provost C, Hughes P. Medicaid: 35 years of service. *Health Care Financing Review*. 2000; 22:141-174.
- ¹⁰Provost C, Hughes P. Medicaid: 35 years of service. *Health Care Financing Review*. 2000; 22:141-174.
- ¹¹Kuhlthau K, Perrin JM, Ettner SL, McLaughlin TJ, Gortmaker S. High expenditure children with supplemental security income. *Pediatrics*. 1998;102:610-615.