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December 1, 2008

Representative James W. Crawford, Jr., Co-Chair, Joint Legislative Program Evaluation Oversight Committee
Senator Daniel G. Clodfelter, Co-Chair, Joint Legislative Program Evaluation Oversight Committee
Senator Fletcher L. Hartsell, Jr., Co-Chair, Joint Legislative Program Evaluation Oversight Committee
North Carolina General Assembly
Legislative Building
16 West Jones Street
Raleigh, NC 27601

Honorable Co-Chairs:

The Program Evaluation Division 2007-2008 Work Plan, approved December 5th, 2007, directed the Program Evaluation Division to evaluate the cost of alternatives to the private duty nursing benefit currently provided under the North Carolina Medicaid Program. This study examined how North Carolina and other states structure their private duty nursing benefit and identified options for containing the cost of care for Medicaid recipients who require continuous, complex, and substantial nursing services.

I am pleased to report that the Department of Health and Human Services, Division of Medical Assistance cooperated with us fully and were at all times courteous to our evaluators during the evaluation.

Sincerely,

John W. Turcotte
Director
Controlling the Cost of Medicaid Private Duty Nursing Services

Summary

The Joint Legislative Program Evaluation Oversight Committee directed the Program Evaluation Division to evaluate the cost of alternatives to private duty nursing services currently provided under the North Carolina Medicaid Program. Under the state Medicaid plan, private duty nursing is defined as medically necessary continuous, complex, and substantial nursing services provided by a licensed nurse in a recipient’s home.

Under federal law, private duty nursing for adults is an optional Medicaid service. In Fiscal Year 2006-07, 150 adults received private duty nursing services at a total cost of $23,301,404, or an average cost of $155,343 per recipient. From Fiscal Years 2003-04 to 2006-07, the number of adults receiving private duty nursing grew a total of 33%, at an average annual rate of 10%. The cost of private duty nursing for adults grew 87% between 2004 and 2007, at an average annual rate of 23%. Projections based on monthly data suggest by Fiscal Year 2011-12 there may be 375 adult private duty recipients at a total annual cost of $61,540,786.

Twenty states pay for private duty nursing for adults under their state Medicaid plans. Of those 20 states, North Carolina and North Dakota are the only states that do not set limits on the benefit. Several states limit the number of service hours recipients can receive, require the presence of a willing and capable caregiver, and/or require the patient to be dependent on medical technology.

Fifteen states limit private duty nursing services for adults through Medicaid waivers targeted to certain subgroups (e.g., individuals dependent on medical technology). The remaining 15 states do not pay for private duty nursing services for adults.

Federal law requires all states to provide private duty nursing to Medicaid-eligible children under age 21. In North Carolina, children receive private duty nursing under the state Medicaid plan and continuous skilled nursing under Medicaid’s Community Alternatives Program for Children (CAP/C) waiver, which is tailored to medically fragile children and their families. Continuous skilled nursing under the waiver is subject to budget limits, thereby allowing the state to meet the cost neutrality requirements of the waiver.

The North Carolina General Assembly should direct the Division of Medical Assistance to

- adopt one or more of the cost-containment mechanisms used by other states for its private duty nursing benefit for adults; and
- modify the CAP/C waiver to encourage use of the waiver program by children in need of continuous skilled nursing.
Scope

The North Carolina General Assembly’s Joint Legislative Program Evaluation Oversight Committee directed\(^1\) the Program Evaluation Division to evaluate the cost of alternatives to the private duty nursing benefit currently provided under the North Carolina Medicaid Program. The Division examined how North Carolina and other states structure their private duty nursing benefit and identified options for containing the cost of care for Medicaid recipients who require continuous, complex, and substantial nursing services.

The Program Evaluation Division collected data from several sources including
- the Division of Medical Assistance, the Division of Health Service Regulation, and the Division of Vocation Rehabilitation;
- states that offer private duty nursing under their state Medicaid plans and states that offer private duty nursing through Medicaid waivers;
- interviews of ten private duty nursing recipients and/or their families;
- the North Carolina Health Care Facilities Association and the Association for Home and Hospice Care of North Carolina;
- the United States Center for Medicare and Medicaid Services;
- the Kaiser Family Foundation; and
- the Center for Personal Assistance Services.

Background

The United States Centers for Medicare and Medicaid Services (CMS) defines private duty nursing services as nursing services provided by a registered nurse or a licensed practical nurse under the direction of a physician for recipients who require more individual and continuous care than is available from a visiting nurse or routinely provided by the nursing staff of a hospital or skilled nursing facility.\(^2\) Private duty nursing is an optional\(^3\) Medicaid service for adults; therefore, states do not have to cover it. Thirty-five states, including North Carolina, have chosen to cover private duty nursing. States that choose to cover private duty nursing offer it either under their state Medicaid plan, through 1915(c) Home and Community-Based Services Medicaid waivers, or both.

The North Carolina Medicaid Program began offering private duty nursing services under its state plan in 1988. The benefit covers medically necessary continuous, complex, and substantial nursing services provided by a licensed nurse in a recipient’s home.\(^4\) Recipients choose private duty nursing services over nursing facility services because they prefer to be

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\(^1\) The Joint Legislative Program Evaluation Oversight Committee establishes the Program Evaluation Division’s work plan in accordance with N.C. Gen. Stat. § 120-36.13.

\(^2\) CMS allows states to determine whether private duty nursing services are provided in a recipient’s home, a hospital, and/or a skilled nursing facility.

\(^3\) Federal law (42 CFR §§ 440.210, 440.220) requires state Medicaid programs to cover mandatory services, including nursing home care and home health care for recipients entitled to nursing home care. States may elect to cover any of the optional services listed in 42 CFR § 440.80, and then they must provide the service statewide to all beneficiaries.

\(^4\) Recipients must live in private residences to receive private duty nursing services. A nurse may accompany the recipient outside of the home when the recipient’s normal life activities take the recipient away from the home during the day. For example, a private duty nurse can accompany a child to school.
cared for at home, and they need to supplement the care their family is providing or they do not have family members willing and capable of providing the care they need. Exhibit 1 shows the number of adults and children who have received private duty nursing services and the cost of those services for Fiscal Years 2003-04 to 2006-07.

Exhibit 1: Private Duty Nursing (PDN) Recipients, FY 2003-04 to 2006-07

<table>
<thead>
<tr>
<th>Fiscal Year</th>
<th>Number of Recipients</th>
<th>Hours of PDN</th>
<th>Cost of PDN</th>
<th>Number of Recipients</th>
<th>Hours of PDN</th>
<th>Cost of PDN</th>
</tr>
</thead>
<tbody>
<tr>
<td>2003-04</td>
<td>117</td>
<td>214,805</td>
<td>$7,647,975</td>
<td>113</td>
<td>351,609</td>
<td>$12,491,066</td>
</tr>
<tr>
<td>2004-05</td>
<td>129</td>
<td>303,317</td>
<td>10,922,016</td>
<td>122</td>
<td>417,514</td>
<td>15,201,171</td>
</tr>
<tr>
<td>2005-06</td>
<td>158</td>
<td>363,328</td>
<td>13,061,395</td>
<td>134</td>
<td>513,689</td>
<td>18,773,448</td>
</tr>
<tr>
<td>2006-07</td>
<td>187</td>
<td>473,033</td>
<td>17,139,329</td>
<td>150</td>
<td>626,293</td>
<td>23,301,404</td>
</tr>
</tbody>
</table>

Notes: Across the fiscal years, the federal share of the Cost of PDN ranged from 63-66%, and North Carolina’s share ranged from 34-37%. The number of 2006-07 recipients in this exhibit is based on fiscal year data and, consequently, does not match the number of recipients in Exhibit 2, which relies on data from Calendar Year 2007.

Source: Program Evaluation Division based on Division of Medical Assistance claims data.

Private Duty Nursing Policies and Procedures

Most patients learn of private duty nursing services when they are being discharged from a hospital; others are referred by home care agencies or nursing facilities. To receive private duty nursing services in North Carolina, an individual’s attending physician must determine if the individual requires care that can be provided only by a licensed nurse and care that is needed continuously. The amount of private duty nursing services an individual can receive is restricted to that which is medically necessary and has received prior approval from the Division of Medical Assistance’s Private Duty Nursing Team. The Private Duty Nursing Team (1.5 nurse consultants) is responsible for determining whether Medicaid recipients meet the coverage criteria for services and for approving the number of hours of skilled nursing care recipients can receive.

The ability to safely care for patients at home has increased over the last 20 years due to advances in technology such as ventilators, oxygen saturation monitors, and total parenteral nutrition. Private duty nursing recipients usually depend on some type of medical technology that requires licensed nursing care (i.e., care by a registered nurse or a licensed practical nurse). A nursing license is required to make the professional judgments necessary to implement any treatment or pharmaceutical regimen that is likely to produce side effects, toxic effects, allergic reactions, or other unusual effects or any treatment or pharmaceutical regimen that may rapidly endanger a client’s life or well-being. For example, a nursing license is required to care for a tracheostomy tube whenever frequent suctioning and assessment is required. There are no restrictions on the care family members can provide to each other. However, if a nurse is delegating the task, the nurse must ensure family members are well trained and competent before turning care over to them.
In Calendar Year 2007, 88 home care agencies licensed by the Division of Health Service Regulation provided private duty nursing services. Agencies may offer a variety of home care services, including skilled nursing, personal care, therapy, and rehabilitation, and may employ a variety of professionals, including nurses and nurse aides. In North Carolina, private duty nursing services cannot be billed during the same time a recipient is receiving hospice care, personal care services, skilled nursing visits, home health aide visits, or home drug infusion therapy. Furthermore, private duty nursing is not covered when a recipient is receiving medical care in an inpatient facility, outpatient facility, hospital, or physician's office.

Private Duty Nursing Recipients

To gain a better understanding of who receives private duty nursing, the Program Evaluation Division requested information on individuals who received the service in Calendar Year 2007. In Calendar Year 2007, 346 Medicaid recipients received private duty nursing services. The 155 adults receiving private duty nursing services had been approved for services for 4.6 years on average and 25 years at most. The 191 children receiving private duty nursing services had been approved for services for 2.4 years on average and 12 years at most. Private duty nursing services may terminate for several reasons: the recipient’s condition improves (e.g., decanulation of tracheostomy tube, removal of ventilator); the recipient passes away; the recipient moves to a facility or to another state; or the recipient loses his or her Medicaid eligibility.

The most common diagnoses of private duty nursing recipients are neuromuscular diseases, tracheomalacia, and respiratory failure. As shown in Exhibit 2, the majority of private duty nursing recipients needed tracheostomy tubes and/or ventilators to help them breathe. The remaining recipients required private duty nursing for other complicated medical conditions, such as seizures.

\footnote{In some cases, the Private Duty Nursing Team approves recipients for services before Medicaid begins paying for services to ensure a smooth transition from private health insurance to Medicaid.}
Exhibit 2
Approved Hours and Medical Condition of 346 Private Duty Nursing Recipients in Calendar Year 2007

<table>
<thead>
<tr>
<th>Approved Hours</th>
<th>Children (under 21)</th>
<th>Adults (21 and over)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Tracheostomy Dependent</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16 hours or less</td>
<td>110</td>
<td>40</td>
</tr>
<tr>
<td>More than 16 hours</td>
<td>13</td>
<td>15</td>
</tr>
<tr>
<td>Subtotal</td>
<td>123</td>
<td>55</td>
</tr>
<tr>
<td><strong>Ventilator Dependent</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16 hours or less</td>
<td>27</td>
<td>51</td>
</tr>
<tr>
<td>More than 16 hours</td>
<td>13</td>
<td>38</td>
</tr>
<tr>
<td>Subtotal</td>
<td>40</td>
<td>89</td>
</tr>
<tr>
<td><strong>Other</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16 hours or less</td>
<td>27</td>
<td>10</td>
</tr>
<tr>
<td>More than 16 hours</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Subtotal</td>
<td>28</td>
<td>11</td>
</tr>
<tr>
<td><strong>Grand Total</strong></td>
<td>191</td>
<td>155</td>
</tr>
</tbody>
</table>

Note: The number of recipients in this exhibit is based on data from Calendar Year 2007 and, consequently, does not match the number of 2006-07 recipients in Exhibit 1, which relies on fiscal year data.

Source: Program Evaluation Division based on Private Duty Nursing Team data.

To gain a better understanding of why individuals choose to receive private duty nursing services, the Program Evaluation Division interviewed 10 private duty nursing recipients and/or their family members. Recipients were selected based upon several factors: age, geographic location, approved hours of service, medical technology needs, and caregiver situation. The interviews revealed that recipients and their families choose private duty nursing care over institutional care for two main reasons.

- **Recipients and family members believe patients have a higher quality of life at home than at an institution.** Patients have more freedom and independence at home, patients are more comfortable at home, and families are able to remain intact.

- **Recipients and family members believe patients receive a higher quality of care from private duty nurses than they would receive in nursing facilities.** In their opinion, patients experience fewer acute episodes—avoiding hospitalization entirely or extended hospital stays; patients are closely monitored so complications can be caught earlier; and patients are exposed to fewer germs by avoiding hospitals and nursing facilities.

Indeed, private duty nursing services may offer Medicaid recipients more constant care than a nursing facility is able to staff.\(^6\) Furthermore, nursing facilities may not be appropriate for non-elderly Medicaid recipients because they cater to the elderly.\(^7\) Other concerns about nursing facilities as compared to home care include increased risks of depression, malnutrition, dehydration, and bacterial infections.

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\(^6\) In North Carolina, facility licensure rules only require that nursing facilities have 2.1 nursing hours per patient per day.

\(^7\) In North Carolina, 88% of nursing facility residents are 65 and older.
Private Duty Nursing for Children

Federal law, through the Early Periodic Screening, Diagnosis, and Treatment (EPSDT) Program, requires state Medicaid programs to provide private duty nursing to Medicaid-eligible recipients under 21 years of age, whether or not the service is covered under their state Medicaid plans. EPSDT aims to improve the health of low-income children by financing appropriate and necessary pediatric services. It requires state Medicaid programs to provide the services listed in section 1905(a) of the Social Security Act that are medically necessary to correct, ameliorate, or prevent the worsening of a recipient’s condition. Private duty nursing is one of the health care services listed.

The services covered under EPSDT are not subject to many of the restrictions Medicaid imposes for services under a waiver or services provided to adults. For example, there is no waiting list for EPSDT services, and there are no limits on total cost or number of hours or visits. However, state plan services that require prior authorization, as private duty nursing does in North Carolina, still require prior authorization under EPSDT.

Because private duty nursing is an EPSDT service, Medicaid programs must provide the service to Medicaid-eligible recipients under 21 years of age regardless of limits on how much the service costs or how many hours are covered.

In North Carolina, children receive continuous skilled nursing in two ways:

- **Private duty nursing under the state Medicaid plan.** In Fiscal Year 2006-07, 187 Medicaid recipients under 21 years of age received private duty nursing services under the state Medicaid plan, at a total cost of $17,139,329 or an average cost of $91,654 per recipient.

- **Continuous skilled nursing under the Community Alternatives Program for Children (CAP/C) Medicaid waiver.** In Fiscal Year 2006-07, 259 children age 18 and under received continuous skilled nursing through CAP/C, at a total cost of $22,636,346 or an average cost of $87,399 per recipient.

CAP/C provides home care for medically fragile children (through age 18) at risk of institutionalization. The program aims to improve the quality of life for children and their families, while providing home care that is cost-effective in comparison to the cost of institutional care. To receive nursing through CAP/C, a child’s attending physician must determine if the child requires care that can be provided only by a licensed nurse and care that is needed continuously.

Through the CAP/C waiver, North Carolina provides continuous skilled nursing to children age 18 and under whose parental income makes them ineligible for traditional Medicaid. Once these children are enrolled in Medicaid through the CAP/C waiver, they may be eligible for any Medicaid and/or EPSDT service, but the cost of their care cannot exceed the monthly budget of $2,730 for an intermediate level of care, $3,537 for a skilled level of care, or $28,729 for a hospital level of care. In addition to nursing services, CAP/C recipients receive case management services.

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8 The CAP/C waiver refers to continuous skilled nursing as CAP/C nursing.
and may be eligible for nurse aide services, respite care (which includes additional continuous skilled nursing and nurse aide hours), waiver supplies such as reusable diapers and oral nutritional supplements, and home modifications.

Findings

Finding 1. Unlike other states, North Carolina has not set limits on Medicaid’s coverage of private duty nursing for adults.

The majority of the 20 states that cover private duty nursing for adults under their state Medicaid plans limit the benefit. Twenty states, including North Carolina, offer private duty nursing services under their state Medicaid plans. As compared to other states, only North Carolina and North Dakota have no limits on their private duty nursing coverage. For all Medicaid services, states have the authority to establish reasonable and appropriate limits on the amount, duration, and scope of the service. States use a variety of cost-containment mechanisms to limit their private duty nursing coverage for adults under their state Medicaid plans (see Exhibit 3). It is not possible to determine how much money states save by imposing these limits because the United States Centers for Medicare and Medicaid Services (CMS) does not require them to track their private duty nursing expenditures separately from their home health expenditures.

- **Other states limit the number of service hours available.** The private duty nursing policy in North Carolina does not limit the number of hours of care that will be approved. Five states covering private duty nursing under their state Medicaid plans limit the number of hours of care that will be approved. For example, Colorado and Massachusetts cover up to 16 hours of private duty nursing a day. Delaware, Massachusetts, and Ohio’s policies allow some flexibility, stating additional hours may be approved for short periods under certain circumstances (e.g., to adjust to hospital discharge, to avoid hospitalization).

- **Other states require a willing and capable caregiver.** In North Carolina, private duty nursing is not intended to replace care from willing and capable unpaid caregivers, but there is no requirement that recipients have a willing caregiver. In contrast, four states require recipients to have a caregiver available to meet a portion of their care needs.

- **Other states require dependence on medical technology.** North Carolina does not limit private duty nursing services based on technology dependency. Of the 20 states offering private duty nursing services through their state Medicaid plans, 9 limit the service to technology-dependent recipients. Some of these states further restrict services to recipients on ventilators and/or recipients with tracheostomy tubes.

9 CMS defines technology dependence as needing both a medical device to compensate for the loss of a vital body function and substantial and ongoing nursing care to avert death or further disability.
Exhibit 3: Most State Medicaid Plans Impose Some Limits on Private Duty Nursing (PDN)

<table>
<thead>
<tr>
<th>State</th>
<th>Hours</th>
<th>Family Situation</th>
<th>Medical Device</th>
<th>Medical Need</th>
<th>Reimbursement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Arizona</td>
<td></td>
<td></td>
<td>Ventilator dependent</td>
<td>More than 2 hours of skilled nursing care at a time</td>
<td></td>
</tr>
<tr>
<td>Arkansas</td>
<td></td>
<td></td>
<td>Ventilator or tracheostomy dependent</td>
<td>Require constant supervision, visual assessment, and monitoring</td>
<td>For ventilator dependent, cost must not exceed the cost for acute inpatient hospital care</td>
</tr>
<tr>
<td>Colorado</td>
<td>Up to 16 hours/day</td>
<td>Technology dependent</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Delaware</td>
<td>Up to 8 hours/day</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Indiana</td>
<td></td>
<td></td>
<td>Ventilator dependent</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Maine</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Recipients must meet a specified level of care</td>
</tr>
<tr>
<td>Massachusetts</td>
<td>Up to 16 hours/day</td>
<td></td>
<td></td>
<td>More than 2 hours of skilled nursing care at a time</td>
<td>Must be least costly form of comparable care available in community and no more costly than institution</td>
</tr>
<tr>
<td>Minnesota</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Different reimbursement for complex and regular PDN</td>
</tr>
<tr>
<td>Nebraska</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Per diem reimbursement cannot exceed average cost of care in a nursing facility</td>
</tr>
<tr>
<td>Nevada</td>
<td></td>
<td></td>
<td>Technology dependent</td>
<td></td>
<td></td>
</tr>
<tr>
<td>New Hampshire</td>
<td>PDN cannot provide all the care that a recipient requires to live at home</td>
<td></td>
<td></td>
<td>More than 2 hours of skilled nursing care at a time</td>
<td></td>
</tr>
<tr>
<td>New York</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Services provided by licensed practical nurses unless demonstrate need for registered nurses</td>
</tr>
<tr>
<td>North Carolina</td>
<td>NO LIMIT ON PRIVATE DUTY NURSING BENEFIT</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>North Dakota</td>
<td>No limit on private duty nursing benefit</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ohio</td>
<td>Up to 12 hours/day</td>
<td></td>
<td>At least 4 continuous hours/day of skilled nursing care</td>
<td>Different rules for on-going maintenance and post-hospital PDN</td>
<td></td>
</tr>
<tr>
<td>Tennessee</td>
<td>Must have trained, competent, and willing caregiver</td>
<td>Ventilator or tracheostomy dependent</td>
<td>At least 8 hours/day of skilled nursing care</td>
<td>Reimbursed up to the cost of nursing home care</td>
<td></td>
</tr>
<tr>
<td>Utah</td>
<td></td>
<td></td>
<td>Technology dependent</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vermont</td>
<td>Not provided 24 hours a day</td>
<td>Must have trained primary and backup caregivers with ability to take on care responsibilities in anticipation of decreased level of supportive nursing</td>
<td>Technology dependent</td>
<td>Not reimbursed if requested to accommodate caregiver employment, illness, or absence</td>
<td></td>
</tr>
<tr>
<td>Washington</td>
<td>Families must assume a portion of care</td>
<td>Technology dependent</td>
<td>At least 4 continuous hours/day of skilled nursing care</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wisconsin</td>
<td></td>
<td></td>
<td>At least 8 hours/day of skilled nursing care</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Source: Program Evaluation Division based on state Medicaid plan policies and personal communication.
• **Other states require that recipients need a certain number of skilled nursing hours.** The private duty nursing policy in North Carolina does not define continuous skilled nursing. In some states, recipients must need at least two hours of skilled nursing care at a time to be eligible for private duty nursing; in other states, recipients must need at least eight hours a day of skilled nursing care. Washington’s policy states nursing home care should be considered for clients that need more than 16 hours a day of skilled nursing care.

• **Other states limit how the service is reimbursed.** North Carolina pays a single rate for private duty nursing services and does not limit how much it will reimburse for the service. In contrast, Massachusetts, Nebraska, and Tennessee will not pay more for private duty nursing services than they would pay for institutional care. In New York, only licensed practical nurses provide private duty nursing services, unless recipients can demonstrate a registered nurse needs to provide the service. Some states offer different levels of private duty nursing. Minnesota has different reimbursement rates for "regular" private duty nursing for non-ventilator-dependent and non-intensive recipients and "complex" private duty nursing for ventilator-dependent and intensive recipients. In Ohio, recipients who are no longer making significant improvements in their medical conditions can receive “on-going maintenance" private duty nursing services indefinitely, but recipients can only receive “post-hospital” private duty nursing for up to 56 hours per week for up to 60 days after discharge.

**North Carolina is the only southern state without any limits on private duty nursing since Tennessee restructured its private duty nursing benefit.** Tennessee, which offers private duty nursing under the 1115 Demonstration TennCare II, recently modified its private duty nursing benefit. Similar to North Carolina, Tennessee did not place any limits on its private duty nursing service for adults. Tennessee attempted to eliminate the service completely in 2005 but instead was able to achieve budget cuts through changes in its pharmacy program. However, after seeing the cost of private duty nursing services continue to grow over the past three years, Tennessee decided to restructure its private duty nursing benefit. CMS advised Tennessee to use limits that resemble the benefit structures used by other states.

In May 2008, Tennessee proposed the limits discussed below to its private duty nursing benefit for adults. CMS approved Tennessee’s request, and the new limits went into effect in September 2008. Private duty nursing services are now covered when medically necessary for two groups of adults: those who are ventilator dependent at least 12 hours of the day and those who have a functioning tracheostomy and require a significant amount of other specified nursing services.

Tennessee’s definition of medical necessity requires that a service must be the least costly alternative course of treatment adequate for the medical condition. Thus, private duty nursing care will only be approved in an amount up to the cost of nursing home care if a nursing home is available and able to treat a recipient at a cost less than the cost of 24/7 private
duty nursing. In essence, recipients have a choice between two covered benefits: nursing home care or an amount of private duty nursing that does not exceed the cost of nursing home care. To receive private duty nursing services, the recipient must have family members or other caregivers who are competent, trained, and willing to meet the recipient’s needs during the hours when a private duty nurse is not present.

**Fifteen states control the number of private duty recipients and their cost by offering the benefit through Medicaid waivers.** Instead of covering private duty nursing under their state Medicaid plans, 15 states cover private duty nursing through 1915(c) Home and Community-Based Services Medicaid waivers. These states cover private duty nursing for at least one of the following targeted groups: disabled, mental retardation/developmental disabilities, aged, human immunodeficiency virus (HIV)/acquired immunodeficiency syndrome (AIDS), and technology dependent. For example,

- South Carolina offers private duty nursing services to adults under their HIV, head and spinal injuries, mental retardation/developmental disabilities, and ventilator dependent waivers, but adults only receive private duty nursing services under the ventilator dependent waiver. To be eligible for the ventilator dependent waiver, adults have to be dependent on a ventilator six or more hours a day. In Fiscal Year 2005-06, 38 adults received private duty nursing at a total cost of $770,218 or an average cost of $20,269 per recipient. No one under the waiver receives 24 hours per day of private duty nursing services.

- Virginia also covers private duty nursing under a technology-assisted waiver. The waiver serves up to 320 people. It covers up to 16 hours per day of private duty nursing services, and the recipient’s family must undergo training and assume responsibility for 8 hours of care per day.

**Fifteen states do not cover private duty nursing for adults.** Medicaid-eligible adults in need of continuous, complex, and substantial nursing services in states that do not cover private duty nursing are cared for in the home by their family members, nurse aides, and/or nurses on an intermittent basis. Otherwise, they are cared for in institutions, such as nursing facilities or hospitals. For example,

- Georgia covers private duty nursing for children under its state Medicaid plan and through Medicaid waivers, but it only covers intermittent nursing for adults under various waiver programs.

- Florida covers private duty nursing for children under its state Medicaid plan and through its developmentally disabled waiver. Although adults can be on the developmentally disabled waiver, they are not eligible for nursing care under it.

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10 Colorado and New Hampshire cover private duty nursing for adults under their state Medicaid plans and through Medicaid waivers.
Finding 2. The structure of North Carolina's private duty nursing benefit limits the ability of the Private Duty Nursing Team to make independent and objective determinations of recipient need.

The Private Duty Nursing Team's decisions are dependent on the information it receives from a recipient's attending physician. The Private Duty Nursing Team must approve the amount of private duty nursing services an individual can receive prior to service delivery. An individual’s attending physician determines if continuous, complex, and substantial nursing services are medically necessary and specifies the number of hours and length of service time the recipient needs. Due to their role as advocates for patients, physicians may be inclined to request licensed nursing services as opposed to care from unlicensed personnel, and they may request more hours of care than are necessary. There is no independent assessment of a recipient's initial need for private duty nursing.

If the Private Duty Nursing Team does not agree with the number of hours an individual's attending physician specifies, the Private Duty Nursing Team tries to negotiate with the physician. The team generally tries to start recently hospitalized or recipients with new technology requirements with 24 hours of skilled nursing care a day for 2 weeks, then reduce their coverage to 20 hours a day for 2 weeks, then 16 hours a day for 2 weeks, and finally 12 hours a day thereafter. This incremental design helps families know what to expect and gives them time to be trained and to become comfortable and proficient in providing care.

The Private Duty Nursing Team's decisions are dependent on the information it receives from a recipient’s home care agency. The Private Duty Nursing Team reviews recipient need approximately every 60 days based on documents it receives from the recipient’s home care agency. Because an agency is being paid to take care of a recipient, it has a financial incentive to seek renewal for services even when continuous skilled nursing care is no longer necessary or to seek the same amount of hours of care when less is necessary. There is no independent assessment of a recipient's continued need for private duty nursing.

The current private duty nursing policy does not include clear and objective criteria for evaluating recipient need. The Division of Medical Assistance recognizes its current private duty nursing policy does not allow the Private Duty Nursing Team to make defensible determinations of recipient need. The policy defines private duty nursing as medically necessary continuous, substantial, and complex nursing services without defining these criteria.

In September 2006, the Division of Medical Assistance sought consultation from the Physician Advisory Group regarding some proposed changes to the private duty nursing policy. The Physician Advisory Group recommended the Division of Medical Assistance seek external validation of an acuity tool included in the revised policy. Thereafter, the Division of Medical Assistance began piloting the acuity tool and has made further revisions to the draft policy. The Division of Medical Assistance plans to

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present the latest version of the policy to the Physician Advisory Group for official consideration in early 2009.

The Division of Medical Assistance is considering the following changes to its private duty nursing policy in an effort to control costs and to establish more objective and clear criteria for evaluating recipient need for continuous, complex, and substantial nursing care:

- **Requiring that recipients need more individual and continuous care than is available from a visiting nurse or is routinely provided by the nursing staff of a hospital or skilled nursing facility.** This requirement is consistent with the United States Centers for Medicare and Medicaid Services (CMS) definition of private duty nursing, but it is not stated explicitly in the current private duty nursing policy.

- **Requiring that there is no equally effective and more conservative or less costly treatment available statewide.** This requirement would help ensure private duty nursing is not provided primarily for the convenience of a recipient, a recipient’s caretaker, or a provider. These requirements would be consistent with Medicaid’s mission of structuring benefits in a manner that promotes access to medically necessary and cost-effective care. It would allow the Private Duty Nursing Team to deny services when a recipient’s needs could be met by a less expensive service (e.g., intermittent nursing, home health care, and/or personal care) and/or by a less expensive health care provider, such as a nurse aide.

- **Requiring the use of an acuity tool for approval and renewal of services.** In an effort to make medical necessity determinations more objective, the team—along with the Association for Home and Hospice Care of North Carolina and representatives of home care providers—has developed an Hourly Nursing Review Criteria form. For skilled nursing needs to be considered substantial, a recipient’s technology needs must meet a minimum threshold.

- **Requiring multiple, interrelated nursing assessments.** For skilled nursing needs to be considered complex, a recipient must need multiple, interrelated nursing assessments requiring interventions that can only be performed by a licensed nurse.

- **Requiring recipients to need hourly nursing assessments and interventions every two to three hours.** For skilled nursing needs to be considered continuous, a recipient must need hourly nursing assessments and interventions every two to three hours during the time period when private duty nursing services are provided. This requirement would allow the Private Duty Nursing Team to deny approval of continuous skilled nursing when recipients’ needs could be met by intermittent skilled nursing or care by nurse aides.

- **Requiring that recipients must have a trained caregiver available at least eight hours per day.** The Private Duty Nursing Team bases its decisions on the medical needs of recipients rather than the convenience of caregivers. However, caregiver availability
frequently impacts the number of private duty nursing hours a recipient is authorized to receive. For potentially adverse decisions, the Medical Director of the Division of Medical Assistance reviews and makes a final recommendation for authorized hours. Because the Division of Medical Assistance is responsible for ensuring home care providers do not endanger the safety of recipients, it is concerned when a private duty nurse becomes a recipient’s sole or main source of clinical and social support with little or no available caregiver backup.

- **Limiting private duty nursing to 16 hours per day.** This limitation would work in conjunction with the requirement that recipients must have a trained caregiver available at least eight hours a day. Two additional hours would be available for caregiver commute time to and from work.

Finding 3. The number of adult private duty nursing recipients and the cost of their care is growing and will continue to do so if left unchecked.

The cost of private duty nursing services for adult recipients in Fiscal Year 2006-07 totaled $23,301,404, with North Carolina’s share being $8,327,339. Because private duty nursing recipients require complex care, they commonly receive other home-based services as well (e.g., durable medical equipment, personal care services, home health services, community support, home infusion therapy, other therapies, case management). Exhibit 4 shows the total costs and average costs per private duty nursing recipient for their private duty nursing care and their other Medicaid services.

<table>
<thead>
<tr>
<th>Continuous Skilled Nursing Costs for PDN Recipients</th>
<th>Total Annual Cost</th>
<th>Average Annual Cost per Recipient</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>$ 23,301,404</td>
<td>$ 155,343</td>
</tr>
<tr>
<td>Other Costs for PDN Recipients</td>
<td>4,738,030</td>
<td>31,587</td>
</tr>
<tr>
<td><strong>Total Medicaid Costs for PDN Recipients</strong></td>
<td><strong>$ 28,039,434</strong></td>
<td><strong>$ 186,930</strong></td>
</tr>
</tbody>
</table>

Note: Other Costs includes Medicaid benefits such as durable medical equipment, prescription medications, and hospitalizations.

Source: Program Evaluation Division based on Division of Medical Assistance claims data.

Adult private duty nursing recipients are an expensive population within Medicaid. Whereas Medicaid spent an average of $186,930 on each adult recipient of private duty nursing in Fiscal Year 2006-07, it spent an average of $14,524 on each disabled enrollee in Fiscal Year 2006-07. It may be more appropriate to compare the amount Medicaid spends on private duty nursing to the amount it spends on nursing facilities. Whereas Medicaid spent an average of $155,343 per recipient on private duty nursing services in Fiscal Year 2006-07, it spent an average of $24,697 per resident on nursing facility services in Fiscal Year 2006-07.

Effective September 1, 2008, private duty nursing services are billed at a rate of $9.74 per 15 minutes, or $38.96 per hour. The rates for nursing
facilities vary based on the medical complexity of their residents, but the average daily rate is $156.58 for a non-ventilator bed and $405.97 for a ventilator bed. Whereas the hourly rate for private duty nursing only covers continuous skilled nursing care, nursing facility rates include several other services. The daily rate for nursing facilities includes room and board; rehabilitative, diagnostic, social, activity, routine, and ancillary services; supplies, appliances, and equipment; nonprescription drugs; and transportation. As shown in Exhibit 5, 8 hours of private duty nursing is more expensive than the daily rate for a non-ventilator bed in a nursing facility and 12 hours of private duty nursing is more expensive than the daily rate for a ventilator bed in a nursing facility.

Exhibit 5

Twelve Hours of Private Duty Nursing Costs More Than the Daily Rate for Nursing Facilities

<table>
<thead>
<tr>
<th>Hourly Costs of Private Duty Nursing (PDN)</th>
<th>Daily Costs of Nursing Facilities</th>
</tr>
</thead>
<tbody>
<tr>
<td>24 hrs of PDN ($935.04)</td>
<td>Ventilator Bed ($405.97)</td>
</tr>
<tr>
<td>20 hrs of PDN ($779.20)</td>
<td></td>
</tr>
<tr>
<td>16 hrs of PDN ($623.36)</td>
<td>Non-Ventilator Bed ($156.58)</td>
</tr>
<tr>
<td>12 hrs of PDN ($467.52)</td>
<td></td>
</tr>
<tr>
<td>8 hrs of PDN ($311.68)</td>
<td></td>
</tr>
</tbody>
</table>

Note: The hourly costs for private duty nursing are based upon the service billing rate of $9.74 per 15 minutes, or $38.96 per hour. The daily costs of nursing facilities are based upon the average daily rate for ventilator and non-ventilator beds across 406 facilities.

Source: Program Evaluation Division based on Division of Medical Assistance rates setting information.

Growth in the number of adult private duty nursing recipients and the cost of their care has outpaced the growth of Medicaid. Between Fiscal Years 2003-04 and 2006-07, the number of adult private duty nursing recipients has grown 33%, at an average annual rate of 10%. The number of Medicaid recipients, in contrast, has grown 8%, at an average annual rate of 3%. Similarly, the cost of private duty nursing for adults has grown 87%, at an average annual rate of 23%, whereas the cost of Medicaid has grown 22%, at an average annual rate of 7%. Exhibit 6 projects the monthly growth in adult private duty nursing recipients and their costs through June 2012. There were 136 adults receiving private duty nursing in June 2007 at a total monthly cost of $2,040,976. At the current rate of growth, there may be 375 adult private duty recipients at a total monthly cost of $5,617,025 by June 2012. According to these projections, the total annual cost of private duty nursing for adults in Fiscal Year 2011-12 would be $61,540,786.
Exhibit 6: Private Duty Nursing Costs for Adults Will Continue to Grow if Left Unchecked

Note: Dashed lines indicate projections. Monthly data from Fiscal Years 2003-04 to 2006-07 were used to project growth through Fiscal Year 2011-12.

Source: Program Evaluation Division based on Division of Medical Assistance claims data.
In addition to the growth projected based on past trends, more Medicaid recipients in North Carolina may request private duty nursing in the future. The Division of Medical Assistance has been working on a Medicaid Uniform Screening Tool. The Medicaid Uniform Screening Tool is an internet-based screening and assessment tool that will evaluate an individual’s medical, functional, and psycho-social needs for long term care services and support programs. The purpose of the Medicaid Uniform Screening Tool is to inform individuals if they qualify for certain Medicaid long term care programs, including private duty nursing and nursing facilities. The Medicaid Uniform Screening Tool will identify individuals with continuous, complex, and substantial nursing needs and will indicate to them that private duty nursing services, along with nursing facility services, might be an option. An individual's Medicaid eligibility will still need to be established, and eligible individuals will need to be approved for the service option they pursue. However, because Medicaid is a federal entitlement program, Medicaid-eligible individuals have a legal right to receive all services covered by the state Medicaid plan. Therefore, a Medicaid-eligible individual for whom private duty nursing is medically necessary is entitled to the service.

**Finding 4. The Division of Medical Assistance has less control over the continuous skilled nursing service when children receive it under the state Medicaid plan than when they receive it under the Community Alternatives Program for Children.**

Because the Community Alternatives Program for Children (CAP/C) is a waiver program, the Division of Medical Assistance has control over the number of recipients enrolled and their costs. CAP/C, like all 1915(c) Home and Community-Based Services waivers, must demonstrate that waiver services will be no more costly than covering the same services in institutions. The Division of Medical Assistance forecasts program needs and cannot exceed the cost estimates approved by the United States Centers for Medicare and Medicaid Services.

To remain on the CAP/C waiver, recipients must not exceed their individual monthly budgets of $2,730 for an intermediate level of care, $3,537 for a skilled level of care, or $28,729 for a hospital level of care. In contrast, there are no budget limits on the cost of private duty nursing under the state Medicaid plan.

Under the state Medicaid plan, there also is no limit on the number of hours of private duty nursing care that will be approved. The CAP/C program is not meant to replace parents’ caretaking responsibilities. In general, CAP/C recipients with working parents are approved for up to 18 hours of continuous skilled nursing on weekdays and 10 hours on weekends; recipients with non-working parents are generally approved for up to 10 hours a day.
Recommendations

Recommendation 1. North Carolina should adopt one or more of the cost-containment mechanisms used by other states for its private duty nursing benefit for adults.

1-A. The North Carolina General Assembly should direct the Division of Medical Assistance to present its revised private duty nursing policy to the North Carolina Physician Advisory Group and adopt the revised policy by October 1, 2009. The Private Duty Nursing Team has been working toward a clearer and more objective policy for the last five years. The revised policy, which is discussed in more detail in Finding 2, imposes limits and requirements similar to those used by other states that cover private duty nursing under their state Medicaid plans.

The following requirements are programmatic and individual data is not available; therefore, cost savings cannot be directly attributed to them:

- requiring that recipients need more individual and continuous care than is available from a visiting nurse or is routinely provided by the nursing staff of a hospital or skilled nursing facility;
- requiring that there is no equally effective and more conservative or less costly treatment available statewide;
- requiring multiple, interrelated nursing assessments; and
- requiring recipients to need hourly nursing assessments and interventions every two to three hours.

Cost savings can be directly attributed to the following limits and requirements under consideration:

- limiting private duty nursing to 16 hours a day;
- requiring that recipients must have a trained caregiver available at least eight hours a day; and
- requiring the use of an acuity tool for approval and renewal of services.

Exhibit 7 demonstrates potential cost savings had North Carolina imposed the limits discussed above in Calendar Year 2007.
## Exhibit 7: Cost-Containment Mechanisms for Private Duty Nursing (PDN) for Adults—A Snapshot Based on Calendar Year 2007

<table>
<thead>
<tr>
<th>Cost-Containment Mechanism</th>
<th>Number of 2007 PDN Recipients Still Covered Under the Mechanism</th>
<th>Number of 2007 PDN Recipients Not Covered Due to the Mechanism</th>
<th>Potential Cost Savings(^1) Due to the Mechanism</th>
<th>DMA Proposes the Mechanism in the Revised PDN Policy (see Finding 2)</th>
<th>Number of the 20 States Covering PDN Under State Medicaid Plans with a Similar Mechanism</th>
</tr>
</thead>
<tbody>
<tr>
<td>16-hour a day limit on service(^{ii})</td>
<td>155</td>
<td>0</td>
<td>$394,885</td>
<td>$702,018</td>
<td>$1,096,904</td>
</tr>
<tr>
<td>Recipients must have a trained caregiver available (^{iii})</td>
<td>135</td>
<td>20</td>
<td>1,833,762</td>
<td>3,260,022</td>
<td>5,093,784</td>
</tr>
<tr>
<td><strong>Medical Device</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Acuity tool used for approval and renewal of service</td>
<td>151</td>
<td>4</td>
<td>131,472</td>
<td>233,728</td>
<td>365,199</td>
</tr>
<tr>
<td>Recipients must be technology dependent</td>
<td>151</td>
<td>4</td>
<td>131,472</td>
<td>233,728</td>
<td>365,199</td>
</tr>
<tr>
<td>Recipients must be tracheostomy or ventilator dependent</td>
<td>144</td>
<td>11</td>
<td>286,822</td>
<td>509,906</td>
<td>796,728</td>
</tr>
<tr>
<td>Recipients must be ventilator dependent</td>
<td>89</td>
<td>55</td>
<td>3,477,348</td>
<td>6,181,952</td>
<td>9,659,300</td>
</tr>
<tr>
<td>Recipients must require more care than is available from a visiting nurse or routinely provided by an institution</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>There is no equally effective and more conservative or less costly treatment available</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Recipients must require multiple, interrelated nursing assessments</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Recipients must require hourly nursing assessments and interventions every two to three hours</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Notes:
\(^1\) The potential cost savings are based on the reimbursement rate for private duty nursing services during Calendar Year 2007. Because the reimbursement rate for private duty nursing has increased from $9.43 per 15 minutes in Calendar Year 2007 to $9.74 per 15 minutes effective September 1, 2008, future cost savings could be greater than those shown above.

\(^{ii}\) For the 16-hour limit, the potential cost savings assume recipients currently receiving over 16 hours of care would choose to drop down to 16 hours of care rather than terminate the service.

\(^{iii}\) For the caregiver requirement, the potential cost savings are not offset by the nursing facility costs that might have been incurred had private duty nursing not been provided to the 20 recipients without a willing caregiver.

\(^{iv}\) All 20 states, including North Carolina, implicitly stipulate that recipients must require more care than is available from a visiting nurse or routinely provided by an institution because this requirement is part of the CMS definition of private duty nursing.

\(^{v}\) North Carolina would be the only state requiring that recipients must need hourly nursing assessments and interventions every two to three hours. However, three other states have similar requirements that recipients must need more than two hours of skilled nursing care at a time.

Source: Program Evaluation Division based on Division of Medical Assistance claims data and Private Duty Nursing Team data.
It is difficult to determine how much a 16-hour limit on private duty nursing could save the state. Interviews with private duty nursing recipients and their families suggest families with a recipient currently receiving more than 16 hours of care would work around the limit rather than institutionalize their family member. As a result, projected cost savings of $394,885 to North Carolina only account for a reduction in service hours approved.

However, the 16-hour limit combined with the caregiver requirement might dissuade potential future recipients from choosing private duty nursing if they do not have the family situation necessary to support home care. Based on documentation submitted by providers, the Division of Medical Assistance’s Private Duty Nursing Team estimated that 20 adult recipients did not have a willing caregiver in Calendar Year 2007. A willing and capable caregiver requirement potentially would have resulted in a savings of $1,833,762 to North Carolina. This cost savings is not offset by the nursing facility costs that might have been incurred had private duty nursing not been provided to these recipients.

The revised private duty nursing policy would essentially require that recipients be technology dependent. The policy proposes that nursing needs would only be considered substantial if a recipient’s technology needs meet a minimum threshold on the Hourly Nursing Review Criteria form. Nearly all (97%) of adult private duty nursing recipients in North Carolina were technology dependent in Calendar Year 2007. Therefore, a requirement of technology dependency would produce little cost savings (i.e., $131,472) to the state based on the current private duty nursing population, but it would serve as an explicit criterion for future recipients.

Some states further restrict the benefit to recipients on ventilators and/or recipients with tracheostomy tubes. This requirement would produce slight cost savings (i.e., $286,822) to North Carolina, but it would eliminate the option of private duty nursing for patients with complex medical conditions other than ventilator and tracheostomy dependency (e.g., those dependent on oxygen and continuous or biphasic positive airway pressure). North Carolina would only see substantial cost savings (i.e., $3,477,348) by restricting the private duty nursing benefit for adults to those who are ventilator dependent.

As required by N.C. Gen. Stat. § 108A-54.2, the Division of Medical Assistance plans to present its revised policy to the Physician Advisory Group in early 2009. The Physician Advisory Group’s Long Team Care Subcommittee will review the policy; then, the full Physician Advisory Group will discuss the policy and adopt the subcommittee’s recommendations. The Division of Medical Assistance will consider the Physician Advisory Group’s changes and then post the revised policy to its website for public comment for 45 days.

The Division of Medical Assistance will need to amend its state plan and submit it to the United States Centers for Medicare and Medicaid Services (CMS) for approval. The North Carolina Administrative Code will need to be revised to reflect changes in the private duty nursing policy. Once the policy is changed, recipients will have to qualify for the benefit under the new service definition. The Division of Medical Assistance cannot grandfather anyone in who has been receiving the service.
1-B. The General Assembly should direct the Division of Medical Assistance to formulate a waiver proposal that covers private duty nursing for adults by May 1, 2010. North Carolina can impose limits on the state plan's coverage of private duty nursing for adults faster than it can transition to waiver coverage of the service. However, covering private duty nursing for adults under a Medicaid waiver is a long-term solution for containing the costs of the benefit. The Division of Medical Assistance has more control over the number of waiver recipients and the cost of their care than it does over state plan services, which all Medicaid-eligible recipients are entitled to receive. Home and Community-Based Services waivers allow states to provide services only to certain subgroups.

Fifteen states cover private duty nursing for adults through Medicaid waivers covering at least one of the following groups: disabled, mental retardation/developmental disabilities, aged, human immunodeficiency virus (HIV)/acquired immunodeficiency syndrome (AIDS), and technology dependent. Adding continuous skilled nursing to North Carolina’s Community Alternative Program for Disabled Adults (CAP/DA) and/or to the Community Alternative Program for Persons with Mental Retardation/Developmental Disabilities (CAP/MR-DD) is not feasible. CAP/DA and CAP/MR-DD—unlike the Community Alternatives Program for Children—do not currently cover continuous skilled nursing care, and adding this service would greatly increase the costs of operating these waivers.

North Carolina does not have any Home and Community-Based Services waivers specifically targeted to the aged, persons with HIV/AIDS, or persons dependent on technology. Because only 4% of private duty nursing recipients are 65 and older, it does not make sense to offer the benefit through a waiver for the aged. Similarly, a Home and Community-Based Services waiver targeted to persons with HIV/AIDS would not capture much, if any, of the private duty nursing population.

A technology-dependent waiver, however, would capture most of the private duty nursing population. North Carolina could define technology dependent as broad as needing a medical device to compensate for loss of a vital body function or as narrow as ventilator dependent. Offering private duty nursing through a technology-dependent waiver would allow the Division of Medical Assistance to limit the number of recipients and set budgets for their care. As with revisions to state Medicaid plan coverage of private duty nursing, the Division of Medical Assistance could not grandfather anyone into a technology-dependent waiver who has been receiving private duty nursing under the state Medicaid plan.

1-C. The General Assembly should direct the Division of Medical Assistance to determine by May 1, 2010 if independent assessment of recipient need for private duty nursing is cost effective. The Division of Medical Assistance should report how much independent assessment of recipient need will cost and how much it could save. The Private Duty Nursing Team is dependent on a recipient's attending physician and home care agency to determine how many hours of private duty nursing are medically necessary. There is no independent assessment of a recipient's initial and continued need for private duty nursing. The Division of Medical Assistance

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12 North Carolina discontinued its Home and Community-Based Services waiver targeted to persons with HIV/AIDS in 2006.
Assistance could contract for independent assessment of recipient need, but it would increase the cost of offering the benefit. However, the cost of one recipient receiving four more hours of private duty nursing services than is medically necessary is $56,882 a year.

**Recommendation 2.** The North Carolina General Assembly should direct the Division of Medical Assistance to modify the Community Alternatives Program for Children waiver by its 2010 renewal to encourage use of the waiver program by children in need of continuous skilled nursing.

The Community Alternatives Program for Children (CAP/C) is tailored to medically fragile children and their families, offering a package of services designed to improve their quality of life. CAP/C recipients receive more than nursing care. They are eligible for nurse aide services, respite care, waiver supplies such as reusable diapers and oral nutritional supplements, and home modifications. Additionally, CAP/C requires that recipients receive case management. The case manager provides comprehensive coordination of care including assessment, planning, and linking to external resources and funding.

Because CAP/C is a 1915(c) Home and Community-Based Services waiver, the Division of Medical Assistance has more control over the number of recipients and the cost of their care than it does over state plan services. It is important to remember, however, that CAP/C waiting lists, budget limits, and limits on hours cannot be used to deny private duty nursing to children who are financially eligible for traditional Medicaid due to the Early Periodic Screening, Diagnosis, and Treatment Program (EPSDT). CAP/C is up for renewal by the United States Centers for Medicare and Medicaid Services (CMS) in 2010. In order for CAP/C to better accommodate children who are currently receiving private duty nursing under the state plan, the CAP/C waiver will need to be modified in the following ways:

- **CAP/C monthly budget levels need to be adjusted.** There is a large gap between the CAP/C monthly budget for children at the hospital level of care (i.e., $28,729) and children at the skilled level of care (i.e., $3,537). Some children receiving private duty nursing under the state plan would only qualify for a skilled level of care under CAP/C. A budget of $3,537 only covers 91 hours of continuous skilled nursing (and no other services) a month, which amounts to approximately 23 hours a week or 3 hours a day. The Division of Medical Assistance plans to submit a waiver amendment to CMS in Fiscal Year 2008-09 that would eliminate individual monthly budgets in favor of aggregate annual budgets. Aggregate budgeting will give CAP/C enough flexibility to meet the needs of children requiring varying amounts of private duty nursing.

- **CAP/C enrollment needs to be expedited.** To be cared for at home, children often need continuous skilled nursing as soon as they are discharged from the hospital. Presently, CAP/C services cannot begin until an FL-2 form establishes a child is sick or disabled enough to require the kind of care that a nursing home provides.
and a case manager evaluates a recipient in his or her home and formulates a plan of care. The current wait time for CAP/C eligibility can be up to 45 days. Enrollment needs to be expedited for children enrolling in CAP/C from institutions, such as hospitals and other inpatient facilities. Drawing upon CMS's new Home and Community-Based Services Quality Framework, the Division of Medical Assistance plans to address issues such as eligibility, priority policies, and quality management for the CAP/C waiver renewal in 2010.

- **Projection of CAP/C enrollment needs to be increased by approximately 200 children.** In Calendar Year 2007, 172 Medicaid recipients age 18 and under received private duty nursing services under the state Medicaid plan. Almost all of these children would have been eligible to receive continuous skilled nursing under CAP/C. The Division of Medical Assistance plans to submit a waiver amendment to CMS in Fiscal Year 2008-09 that would increase the age limit for CAP/C to under 21 to be consistent with EPSDT. If so, another 19 Medicaid recipients age 19 and 20 that received private duty nursing under the state Medicaid plan would have been eligible to receive continuous skilled nursing under CAP/C. Therefore, increasing CAP/C enrollment by approximately 200 will accommodate the children currently receiving private duty nursing under the state Medicaid plan.

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**Agency Response**

A draft of our report was submitted to the North Carolina Department of Health and Human Services, Division of Medical Assistance for review and response. Its response is provided below.

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**PED Contact and Staff Acknowledgments**

For more information on this report, please contact the lead evaluator, E. Kiernan McGorty, at kiernanm@ncleg.net.

Staff members who made key contributions to this report include Catherine Moga Bryant, Carol Shaw, Pamela L. Taylor, and Elizabeth Walker. John W. Turcotte is the director of the Program Evaluation Division.

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13 The Quality Framework serves as a common frame of reference for states engaged in quality management and improvement efforts for their Home and Community-Based Services waivers.

14 Some children currently receiving private duty nursing services under the state plan and receiving services under CAP/MR-DD may not be eligible for CAP/C because of behavioral conditions. If they are Medicaid-eligible outside the CAP/MR-DD waiver, however, they will still be entitled to private duty nursing under EPSDT.
November 19, 2008

John W. Turcotte, Director
Program Evaluation Division
North Carolina General Assembly
300 N. Salisbury Street, Suite 100
Raleigh, NC 27603-5925

Dear Mr. Turcotte:

We appreciate the opportunity to review the Program Evaluation Division’s Report for Medicaid’s Private Duty Nursing (PDN) program. We found both the review process and the draft report to be very thorough. Our formal response is as follows.

Recommendation 1. North Carolina should adopt one or more of the cost-containment mechanisms used by other states for its private duty nursing benefit for adults.

The North Carolina General Assembly should direct the Division of Medical Assistance to present its revised private duty nursing policy to the North Carolina Physician Advisory Group and adopt the revised policy by October 1, 2009.

The General Assembly should direct the Division of Medical Assistance to formulate a waiver proposal that covers private duty nursing for adults by May 1, 2010.

The General Assembly should direct the Division of Medical Assistance to determine by May 1, 2010 if independent assessment of recipient need for private duty nursing is cost effective.

DHHS Response:
We concur that the NC General Assembly should direct the Division of Medical Assistance to present its revised private duty nursing policy to the NC Physician’s Advisory Group and adopt the revised policy by October 1, 2009. DMA agrees with the recommendation to formulate a waiver that would target technology dependent recipients and to evaluate the cost effectiveness of independent assessments of recipient need for private duty nursing.
Recommendation 2. The North Carolina General Assembly should direct the Division of Medical Assistance to modify the Community Alternatives Program for Children waiver by its 2010 renewal to encourage use of the waiver program by children in need of continuous skilled nursing.

- CAP/C monthly budget levels need to be adjusted
- CAP/C enrollment needs to be expedited
- Projection of CAP/C enrollment needs to be increased by approximately 200 children

DHHS Response:
DMA concurs with the recommendation that the NC General Assembly should direct the Division of Medical Assistance to modify the Community Alternatives Program for Children waiver by its 2010 renewal to encourage use of the waiver program by children in need of continuous skilled nursing. Under the current CAP/C waiver, continuous skilled nursing is already provided to both hospital level and skilled level recipients. DMA is currently considering the submission of a waiver amendment for CMS approval to allow for expansion of budget limits from an individual basis to an aggregate basis. The aggregate method will allow DMA flexibility to meet recipient needs while maintaining cost neutrality within the waiver. Our goal is to expand service definitions within the CAP/C waiver to further enhance the number of children who may be served under the waiver. However, EPSDT requirements will not allow DMA to limit PDN recipients for children.

Again, we wish to commend your staff, under the leadership of Kiernan McGorty, for taking the opportunity to conduct home visits with our PDN recipients and their families. Certainly, this additional step adds value to the report and contributes to the understanding of the magnitude and scope of our PDN services provided in the community.

If you have any questions with these responses, please contact Teresa Piezzo, RN at 919-855-4385 or teresa.piezzo@ncmail.net.

Sincerely,

Dempsey Benton, Secretary

cc: Dan Stewart, DHHS
Tara Larson, DMA
Patti Forest, DMA
Lawrence Nason, DMA
Teresa Piezzo, DMA