North Carolina Department of Health and Human Services
Division of Public Health

Purchase of Medical Care Services
Continuation Review

Division of Public Health
Executive Summary

The mission of the Division of Public Health is to promote and contribute to the highest possible level of health for the people of North Carolina.

Some of the goals of Public Health include:

- to reduce the spread of communicable disease to ensure the health and safety of all people in North Carolina by improving early detection, initiating prompt investigation, instituting appropriate control measures, and implementing prevention strategies.
- to improve health outcomes and decrease health disparities for the leading causes of death and morbidity including heart disease and stroke, cancer, chronic lower respiratory diseases, and diabetes by increasing capacity and resources.
- to promote optimum health and well being of children, birth through twenty one years, including related services for adults that may affect their children’s physical and behavioral health outcomes. Children’s Health Services provides services that enhance the health, growth and development of children and youth through increased access, health promotion, prevention, early identification, treatment and intervention.
- to improve the health status of women, reduce infant mortality and morbidity, promote the health of persons with sickle cell disease/trait, and reduce related health disparities.

The Purchase of Medical Care Services (POMCS) was created to determine eligibility and authorize payments for participating programs. Each program sets eligibility requirements, policy, and guidelines in accordance with federal and state statutes. Rules governing the POMCS are under North Carolina Administrative Code, with oversight by the Commission for Public Health. Participating programs in the Division of Public Health include Sickle Cell, Kidney, Early Hearing Detection and Intervention (EHDI) Initial Hearing Aid Fund, Cancer, and Adult Cystic Fibrosis. This report includes a full description of each program, with a focus on the POMCS component.

The following report details each of the individual Purchase of Medical Care Services. Per the legislative reporting requirements, information is provided for each service including; what specific services are provided; who is eligible; recommendations for how the program could be improved; and consequences for discontinuing funding. It should be noted that due to required budget reductions for SFY 08-09, services associated with the Kidney, Adult Cystic Fibrosis, Cancer Assistance, Early Hearing Detection and Intervention (EHDI) were suspended to enable a targeted budget reduction. These reductions were not taken because these services were not beneficial to the clients who received them; however the decision to cut these programs was made given the following: factors 1- very few affected individuals participate based on necessary
eligibility and availability (many do not receive benefits although the funds sound significant, because the need so outweighs the budget), 2- coverage is not statewide (i.e., referral is based on who presents for care and the knowledge of the respective provider about funds availability, 3- although important for the individual impacted when receiving the discrete program benefit, the service is not comprehensive and the resources are so limited per client that the potential for any positive lasting health improvement is very listed. Given above, DPH had to offer these resources as hard cuts to protect the Health promotion and population based services that are core to the overall mission of the Division of Public Health. Purchase of Medical Care Services provide ancillary support to these goal of assuring services for populations with chronic illnesses - many of them in frail and irreversible stages of health status – when not otherwise available.

**Programs**

The **Kidney** program provides secondary and tertiary preventive services to persons at risk for end-stage renal disease, and reduces the further risks and consequences of persons with end-stage renal disease by paying some of their expenses for dialysis, medications, incidental supplies and transportation. Eligibility is limited to an annual income of $6,400 for a family of one, now about 60% of the current federal poverty level.

The **Adult Cystic Fibrosis** program is for NC residents who have cystic fibrosis, are 19 years of age or older and have a net annual income at or below 100% of the federal poverty level in effect on July 1 of each year. The program pays for medically necessary health care services related to the client’s cystic fibrosis.

The **Cancer Assistance** program provides free or low cost cancer screening and care for persons with annual income up to 115 percent of the federal poverty level ($12,150) to detect and treat cancer. The service is offered so that low-income and indigent persons can be diagnosed and treated at the earliest possible point to achieve optimal outcomes for patients. The program provides direct reimbursement to hospitals, physicians, therapists and other medical treatment providers for diagnosis and treatment of cancer.

The objectives of the **Early Hearing Detection and Intervention (EHDI)** program are to ensure that infants and very young children needing initial hearing aids and not covered by Medicaid or third party insurance receive them as quickly as possible following diagnosis and that at the time of diagnosis, all infants and young children identified with a hearing loss are referred to Early Intervention (EI) services for coordination of future needs.

The **Sickle Cell** program is available to pay for needed health services for North Carolina residents with sickle cell disease. The program serves clients with annual incomes up to 100 percent of the federal poverty level, are not enrolled in Medicaid, have no health insurance, and have a diagnosis of sickle cell disease. Covered services include medical care, drugs, equipment and dental care.
This Continuation Review report does not include two DPH programs, as both have limited involvement with POMCS.

The Early Intervention Program (listed on POMC reports as the Infant-Toddler Program (ITP)) is a federally mandated program. Because ITP is a federal entitlement program, there is not a separate eligibility determination step. POMC serves as the primary payment mechanism used by the Early Intervention Program to pay for services provided by community-based providers for 14 of the program’s Children’s Developmental Services Agencies (CDSAs). Payments through POMC are made using early intervention state appropriations or federal grant funding. No funding for these payments are POMC allocations; all are directly authorized from the early intervention program.

The AIDS Drug Assistance Program (ADAP) uses POMCS only to determine eligibility for the program. The drugs are dispensed under a separate contracted service. Once ADAP eligibility is established, the POMCS sends authorization to the contracted pharmacy service. There is no payment function for ADAP.

Impact of losing POMCS programs
The Cancer Assistance, Kidney, Sickle Cell, Early Hearing Device Initiative, and Adult Cystic Fibrosis programs are safety net programs in which uninsured and underinsured indigent persons can receive assistance with critically needed medications, services and equipment. In SFY 2008, 3,381 persons received services under these POMCS programs. If the service under these programs were no longer available, these vulnerable persons would likely delay seeking treatment. This would cause them to be sicker when they do seek care, which will make the higher level of care needed much more costly. Their quality of life and health outcomes will be diminished. The medical conditions coupled with the lack of resources for persons now served in POMCS programs would place an excessive burden on the patient, family and state.

Recommendations for Improving POMCS
The DPH recommendations for improving POMCS program services include:

- Expedite the authorization and claims processes in POMCS. DHHS needs to support completion of data system changes to automate processing claims in POMCS. Timely processing would enhance provider satisfaction, reduce billing and payment delays, including Medicaid and third party insurers. Current POMCS protocols allow extensive delays in processing claims, particularly when third party payers are involved.

- Reduce the length of time providers have (currently one year) to submit claims. Shortening the window for submitting claims will enable the programs to more closely project expenditures and will improve the programs’ financial management information.
• Provide each program the flexibility to adapt program coverage to target the critical needs and ensure the greatest impact. This will help to ensure balance between available funding, service demand, and covered services,

• Expedite the rulemaking process to improve alignment between program rules and POMCS rules. Enable programs to adapt rules and services timely to maximize impact. The current rules revision process can take up to 18 months to complete.

• Improve the EHDI program data collection and reporting tools to support program evaluation.

• Expand private health insurance and State Health plan coverage to include hearing aids.

• Realign kidney program funds to support the diabetes education program.

• Provide resources to implement care coordination in Adult Cystic Fibrosis.

The POMCS programs in the Division of Public Health serve some of North Carolina’s most vulnerable citizens, providing payments for medical diagnostic and treatment services which improve health outcomes. Discontinuing funding would eliminate this critical resource.
Purchase of Medical Care Service (POMCS) Overview

The Purchase of Medical Care Service (POMCS) unit determines eligibility, authorizes services and processes payments for certain programs in the Division of Public Health. Each program establishes policies, eligibility criteria in accordance with state and federal program requirements. Most programs set financial eligibility criteria based on the federal poverty level, which is currently $10,830 for a family of one. POMCS staff develop and maintain the appropriate forms, and manage communications with providers and advocates who support potentially eligible clients. Application forms are available on the POMCS web site (www.dhhs.state.nc.us/control/pomcs/pomcs.htm).

Patients must have a Financial Eligibility Application (DHHS 3014) completed annually by a financial interviewer. Staff in physicians’ offices, hospitals and health departments serve as interviewers as do representatives of designated community service agencies. POMCS notifies the applicant and the interviewer when the eligibility determination is complete. Providers may then request authorization to provide services. The POMCS staff reviews each authorization request, and notifies providers of approved authorizations. Once the authorized service is delivered, the provider may file a claim for payment through POMCS.

The DPH POMCS team consists of 13 staff members dedicated to processing eligibility applications and requests for authorization of services. The DHHS Controller’s Office staff, also roughly 13 members strong, processes claims to generate payments.

The payments processed through POMCS are state funds.

<table>
<thead>
<tr>
<th>Program</th>
<th>Source</th>
<th>Pymt SFY2005-06</th>
<th>Pymt SFY2006-07</th>
<th>Pymt SFY 2007-08</th>
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*The EHDI program began in SFY 2008.
Kidney Purchase of Medical Care Services Continuation Review

About the Kidney POMCS Program

The program began in 1971 as a safety net program in which indigent persons may receive assistance with critically needed medications and supplies. This helps these persons to be better able to comply with treatment and medication regimens, improving their health outcomes and quality of life. In addition, the Kidney POMCS program enables greater access to kidney dialysis and care for a significant number of North Carolinians, constituting a life saving investment.

Kidney POMCS Program Services: Pharmacy Assistance and Dialysis

The Kidney POMCS program reimburses participating pharmacies for prescription drugs, over the counter drugs and incidental supplies that are essential to the health of end stage kidney disease patients. Pharmacy assistance is limited to a maximum of $300 per person per fiscal year and the program only pays when there is no other payer source.

This program allows participants to purchase such items as Tums, a simple calcium supplement that strengthens the effectiveness of dialysis treatments. Purchasing these items in the necessary quantity would be cost-prohibitive for program participants. The program is the payer of last resort, meaning it only covers items for which there is no other payer source.

Patients are referred to the program by providers, usually social workers in dialysis centers. The eligibility application is processed by the POMCS unit. Eligible clients and their providers are notified. The providers file reimbursement claims, which are processed through the POMCS unit and paid form Kidney program funds.

Kidney POMCS pays for dialysis for patients who meet the eligibility criteria and for whom there is no other source of reimbursement. This is not a common occurrence, as only two persons received this benefit in FY 2007-08. Dialysis payments are paid at $100 per treatment with a maximum of 149 treatments per year (per person). The $300 limit does not apply to payment of dialysis claims.

Most patients qualify for Medicare (no matter their age) if their kidneys no longer work and they need regular dialysis or have had a kidney transplant. Medicaid coverage, however, is not automatic with dialysis or kidney transplant, and has financial eligibility requirements.
Demographics

As shown in the chart below, the majority of persons participating in the Kidney POMCS program are African American, women, and over 60.

<table>
<thead>
<tr>
<th>Demographics of Eligible Kidney POMCS Program Participants</th>
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<tr>
<td></td>
</tr>
<tr>
<td><strong>Total number of eligible program participants</strong></td>
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<tr>
<td>FY 2007-2008</td>
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<td><strong>Continued Participants</strong></td>
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<tr>
<td>Black</td>
</tr>
<tr>
<td>American Indian</td>
</tr>
<tr>
<td>Asian</td>
</tr>
<tr>
<td>Native Hawaiian/ Other Pacific Islander</td>
</tr>
<tr>
<td>Multiracial</td>
</tr>
<tr>
<td><strong>Latino/Hispanic</strong></td>
</tr>
</tbody>
</table>

*These are the only categories from which applicants may self-select race.

**In addition to these categories, applicants may also choose to select ethnicity of Latino/Hispanic origin.
This is not a required field, so reports may not adequately reflect this population.

The map below shows the number of persons, by county, participating in the program for SFY 2008-2009.
Eligibility

Kidney POMCS program eligibility is limited to legal residents of North Carolina with end stage kidney disease who have an annual income up to $6,400 for a family of one. This equals about 59% of the 2009 federal poverty level. In FY 08-09, 1203 persons met the financial eligibility requirements of the program.

The Kidney POMCS financial eligibility scale has not increased since the start of the program in 1971. An annual income of $6,400 equals a monthly income of approximately $533/month. The Kidney POMCS income eligibility requirements are lower than all other POMCS programs and are lower than Medicaid’s eligibility threshold ($867/month maximum as of 4/08).

Benefits of the Program from the Participant’s Perspective

No other programs provide this type of assistance to these financially needy persons. The program has had a significant impact on the quality of life and health of those who are served by it.
C.K.¹, a 67-year-old woman from Roanoke Rapids (Halifax Co) has been on dialysis for 3 years. She has also been battling breast cancer for the past 2 years. She is disabled and says, “The program has meant the world to me.” She further says, “I thank God for dialysis and for the kidney program.” On her limited income, without the Kidney POMCS program, she would not be able to afford to purchase items such as Tylenol, anti-diarrhea medications, bandages, a blood pressure cuff or a cane. Because of the resources from the Program, she is able to use her limited funds to buy groceries. Without the program, she would have to make some hard decisions on whether to get her necessary medicines or purchase food. C.K. said, “There is no other program, no other support available to me. The program makes a difference in having or not having. It means a world of difference and people need it.”

Luv Johnson² is a 29-year-old woman from Beaufort (Carteret Co). She has been on dialysis for 10 years, since the age of 19. She has been a participant in the Kidney POMCS program for about 8 years. Before she knew about the program, she had trouble meeting her needs. The program has been so helpful to her because it covers items that Medicaid does not cover. Ms. Johnson appreciates the help she gets buying medicated lotions, as the dialysis dries her skin so badly it cracks and bleeds. She is able to get Tylenol, bandages, gauze pads, Tums for phosphorus control etc. that she would otherwise not be able to afford. On Mondays, Wednesdays and Fridays every week for the rest of her life, she spends at least 8 hours a day going to dialysis, enduring the treatment and recovering from it. The abdominal cramps, leg cramps and muscle cramps keep her from activity on treatment days. She would like to work, but is having a hard time finding a job with a flexible schedule that would allow her to continue dialysis. Ms. Johnson said, “I don’t know how I’d survive without the program. I would have to make choices between buying food and buying medicine.” She also said, “Dialysis is emotionally devastating and people on it have a lot of depression. Having the program support has helped, because there is one less thing for me to worry about.”

Lemar Brown³, a 29-year-old man from Rocky Mount (Nash Co), has been on dialysis for 11 years, and has been on the kidney transplant list for 4 years. He has lived in Rocky Mount his whole life, and is currently taking classes at Edgecombe Community College to obtain his high school equivalency degree. Mr. Brown says, “I use the program to buy Tylenol and aspirin for my aspirin therapy and I get over the counter medicines and bandages.” Since he is not working now, he said, “Without the program I would have to make choices between eating and paying for medicine.”

Michelle Magee⁴ is a 43-year-old woman from Lincolnton (Lincoln Co.) who was on dialysis for 4 years before receiving a kidney transplant. Through the kidney program, she has purchased items such as Band-Aids, bandages, peroxide, alcohol, cotton swabs etc. Ms. Magee believes in keeping herself as healthy as possible, so she exercises and eats healthy. Because of the Kidney POMCS program, she can get vitamins and over the

¹ Initials used with permission
² Name used with permission
³ Name used with permission
⁴ Name used with permission
counter medications that she credits with allowing her to decrease the number of prescription medicines that she has to take. She states, “This program is such a godsend. If the program went away, I’d have to choose between buying food or medications and supplies, or I would not be able to turn on my heat.” Further, Ms. Magee says, “The program is a cushion that allows me some peace of mind.” Finally, she wonders, “Is it better to not give people what they need or to pay the hospital bill? This program saves a lot of money and it saves the patient’s health.”

**Consequences of Discontinuing the Kidney POMCS Program**

If the service under these programs were no longer available, these vulnerable persons would likely delay seeking treatment. This would cause them to be sicker when they do seek care, which will make the higher level of care needed much more costly. Their quality of life and health outcomes will be diminished.

The medical conditions coupled with the lack of resources for persons now served in Kidney POMCS programs would place an excessive burden on the patient, family and state. Without the program, as demonstrated in the comments above, these patients would likely forego medications and treatments, leading to poor health outcomes. Once treatment is finally sought, the patients will likely be in poorer condition, with more extensive and expensive treatments necessary.
Adult Cystic Fibrosis POMCS Program

About the Adult Cystic Fibrosis Program

The Adult Cystic Fibrosis (ACF) program serves North Carolina residents 19 years of age or older with cystic fibrosis to maintain or improve their current health status and prevent complications related to their cystic fibrosis. The ACF program funds pay for medically necessary health care services that cannot be paid by another payor.

Adult Cystic Fibrosis Program Services

This program uses funding to pay for requested medically necessary services. POMCS staff determine financial eligibility, complete reviews and authorizations, and processes claims. A Medical Consultant in the Children and Youth Branch reviews the requests for medical necessity.

The program provides reimbursement for services that have been reviewed and approved by the Medical Consultant with funding earmarked for the program.

The funds provided by this program have prolonged the lives of clients and decreased hospitalizations and emergency room visits. The program pays for at least one hospitalization per year for most clients for an exacerbation of their CF that causes a significant decline in their lung function. Many clients receive intravenous antibiotics one or more times a year at home for up to two weeks following a hospitalization or instead of a hospitalization. The program pays for preventive services that allow clients to receive ongoing health care and to continue to receive their needed medications and nutritional supplements. Many clients are at risk for malnutrition and require oral nutrition supplements to maintain their weight and nutritional status.

Many clients have been employed and/or go to college even while sick, as a result of services that are paid for by the ACF program. The program has purchased some medically necessary equipment for a limited number of clients. For example, the respiratory therapy vest has been purchased for some ACF clients in the past. This vest has significantly improved daily airway clearance and reduced the number of debilitating sick days for these clients.

Clients with CF can easily develop significant vitamin deficiencies that result in complications such as osteoporosis, night blindness, and coagulopathies if vitamins are not available for ongoing use. These vitamins are covered by the ACF program and have prevented or helped to ameliorate the complications.

The ACF program also covers hypertonic saline. Hypertonic saline is a key part of a client’s daily airway clearance therapy that maintains or improves their lung function.
The Adult Cystic Fibrosis Program has used a program formulary of drugs and formula since late 2006. The composition of the formulary was based on drug and formula claims over a five year history. The formulary was implemented to ensure that limited program dollars are used for medications and formula directly related to the treatment of cystic fibrosis. In addition to cost control, this has expedited timely treatment and the best use of program funds since standard drugs are included on the list based on the medical needs of cystic fibrosis clients, the effectiveness of the drugs, and the availability of lower cost generics. The medical consultant serves as the program manager and may authorize non-formulary medications based on individual patient situations with specific medical needs related to cystic fibrosis or its complications.

Many young adults with cystic fibrosis either do not have health insurance or have inadequate coverage through their insurance to meet all of their medical needs related to the disease. Medicaid and Medicare do not cover several of the needed over the counter medications and oral formulas and these daily medications and formulas can often be very costly. Many adults with Cystic Fibrosis require costly inpatient admissions due to this condition even with good health management. Individuals with this disease require frequent follow up with specialists and primary care providers to prevent problems and to monitor treatment.

The adult cystic fibrosis population is varied in health status, employability, and need. Some are employed full time, some part time, and some are unable to work. In many instances, those who are employed do not have health insurance. The medical center staff nurses and social workers often assist clients in applying for disability when they become unable to work. Once they become SSI eligible, Medicaid covers most – but not all of their medical costs. The Adult Cystic Fibrosis program is an essential resource to those who have unmet needs related to the treatment of cystic fibrosis.

CF clients are not guaranteed Medicaid or Medicare. Income is a factor in determining if an adult or child qualifies for either SSI (Medicaid for the disabled) or SSDI (Medicaid for the working disabled). CF adults qualify for SSDI if they have accrued enough work credits and meet the disability requirement. However, these qualified adults must wait two years for Medicare Part A benefits. For SSI you must meet the disability requirements and income requirements / resource limits. If you get SSI then you will receive Medicaid. However SSI (and the Medicaid benefit) is often lost when income or resources increase even when the disability remains.

Not all clients with CF qualify for disability payments. It is very difficult for CF clients to meet the medical requirements for disability through SSI or SSDI. Anecdotally, clients and social workers have shared that it can take 2 or 3 rounds of applications for clients to be approved for SSI. CF clients are not guaranteed Medicaid or Medicare. Income is a factor in determining if an adult or child qualifies for SSI or an adult qualifies for SSDI. Adults qualify for SSDI if they have accrued enough work credits and meet the disability requirement. However, according to UNC staff and clients, these qualified adults must wait two years for Medicare Part A benefits. Clients must meet the disability requirements, income requirements and resource limits in order to qualify for SSI. If a
client is approved for SSI, then the client can also be covered through Medicaid. However, SSI and Medicaid can be lost if income or resources increase even when the disability remains.

Community Care of North Carolina (CCNC) case management is not available for Medicare clients at this time. CCNC case managers evaluate Medicaid SSI clients to determine the need for case management.

SSDI is more beneficial to the client than the Adult CF program since the client can eventually (in two years) be covered by Medicare when SSDI eligible. A benefit of SSI is that the client is covered by Medicaid. Another benefit of SSI is that case management through CCNC may be available.

The CF Care Centers and other hospitals treat CF patients without resources according to their individual policies. There is limited financial assistance for services at UNC CH for their patients. The Ambulatory Care Center pharmacy has an income-based drug assistance program that is able to assist a small portion of CF clients with some medication needs.

The CF Foundation has established links to some drug companies for specific drugs. There is also a CF Foundation Patient Assistance Fund that is limited but is an option for some of the drugs. The CF Foundations does not have resources to offer clients to assist with hospital visits, equipment, outpatient visits or other costs.

The Cystic Fibrosis community has a strong advocacy group. There is a NC Chapter of the Cystic Fibrosis Foundation with very committed social workers and other providers at the tertiary medical centers. These advocates work with the program manager to try to effectively to meet needs of adults with cystic fibrosis.

The High Risk Insurance Pool is an option for clients who can pay the required premiums. Anecdotally, many clients served at the UNC CF Care Center would not be able to afford premium costs based on their incomes. Many clients cannot afford vitamins that cost about $30 per month.

Demographics

In North Carolina, an estimated 45% of persons with cystic fibrosis are at least eighteen years old. The clients who have accessed the Adult Cystic Fibrosis program over the last three fiscal years have ranged in age from 21 years to 44 years of age. There have been clients that have accessed the ACF program from about 27 different counties across NC. Information is not available on race and ethnicity. The numbers of female and male clients over the last 3 fiscal years have been approximately equal in number.

Reports that were run in January 2009 indicate the following:
• FY 2006 ACF enrollment was 16; FY 2007 ACF enrollment was 24; and FY 2008 enrollment was 30.
• In FY 2007 there were 11 “newly enrolled” clients who did not receive services in FY 2006.
• 10 clients received services in both 2007 and 2008;
• In FY 2008, 12 “newly enrolled” clients had not asked for services in either FY 2006 or FY 2007.
• Eight clients received services during all three fiscal years.

It is not clear why the number of enrollees have increased. Some considerations are described below.
1) Recently, the poor economy has resulted in loss of jobs and loss of health insurance coverage. CF clients are often not able to work full time so many have jobs without health insurance. This program offers some assistance for those clients with no insurance.

2) CF is a pre-existing condition that makes it difficult to obtain insurance.

3) The UNC CF Care Center served 51 more adults in 2007 (249 clients) than in 2006 (198 clients).

4) There are more clients that use the ACF program to cover only some of their medications and nutrition needs. A client may be on 7-10 medications and only ask the ACF program to cover the cost of their vitamins, hypertonic saline, and oral nutritional supplements. These items are not covered by Medicaid, Medicare or many private insurance companies. In addition, clients enrolled in Medicaid and Medicare are not able to get coverage of vitamins and other medications such as hypertonic saline by private drug companies. Clients with private insurance are more able to get these same medications covered by private drug companies.

5) Survival is improving, with average national predicted survival at 36.9 years in 2006. The Cystic Fibrosis National Patient Registry reported in 1990 that approximately 30 percent of people in the registry were 18 or older. In 2006, that has risen to nearly 45 percent.

**Eligibility**

Eligibility is limited to persons with annual income up to 100% FPL ($10,830 for an individual). In most but not all situations, a social worker or nurse from the medical center that treats a client refers a client for services after other resources are exhausted. The medical center staff and pulmonologists who work with adults with cystic fibrosis are diligent in preserving program resources as a last resort option.

**Benefits**
A 31 year old client qualified for the ACF program in the spring of 2008. He had four hospitalizations and five emergency room visits in 2008. He was admitted in 6/08 for eight days with a history of weight loss, malnutrition, hair loss and a flare of his CF. He was readmitted with chronic malabsorption and severe malnutrition in 8/08 and was hospitalized for 11 days. He was started on total parenteral nutrition (TPN) through a central venous catheter in his chest. He was not able to take in enough nutrition any other way and he was severely malnourished. He was discharged with home TPN for 10 hours/day and oral nutrition. He received TPN at home for about two months. He was readmitted to the hospital in 10/08 with an infection of his central line. The home TPN alone cost about $10,000 per month. His weight improved greatly on the home TPN and the central line was removed. He was sent home on IV antibiotics and is doing well with his oral nutrition. Since 8/08, the program has paid out over $50,000 in claims for this client. This cost does not reflect all of his incurred costs because providers have up to one year to submit a claim. Despite being sick, he continued to work part time at the News and Observer for $175/week and at Advanced Auto Parts for $200/week.

Another client worked part time and attended school full time while he was on the ACF program. Before he qualified for the program he could not get health insurance through his work or school because of his pre-existing condition. He could not stay in school consistently before qualifying for the ACF program. His costs included about $5000 per month for 5-7 medications. This did not include his doctor visits or hospital stays. He went to regular doctor appointments and was hospitalized once a year. He was on the ACF program for about 3 years. He eventually did not qualify because he was healthy enough to work full time. Over the next nine months, after he lost his ACF program coverage, he had to quit his job because of a significant decline in his health. He was able to get SSDI after two application attempts. He said that he was lucky to qualify for SSDI. He said that many people with CF are not able to work because of their health condition and often cannot accrue enough hours to get SSDI. He went two years without health insurance until he was finally able to get Medicare. He still has outpatient visit charges from the time when he did not have health insurance. He admits that he kept fewer of his doctor appointments during that time.

Another client, 25 years of age and a sophomore at NC State, was not able to stay on her parent’s health insurance plan and did not qualify for SSI. She shared that the ACF program allowed her to work part time, go to school and have medical coverage. At the time, she was taking over a dozen medications and needed to be hospitalized several times. She valued the ability to do several of her IV antibiotic therapy treatments at home which allowed her to get out of the hospital faster and be in a “more healing environment”. She said “…one of the most fantastic things the ACF program did was pay for the purchase of a respiratory vest which has become the cornerstone of my daily airway clearance therapy. The vest I have retails for about $13,000 – it was WAY out of my budget. Before I got the vest, I was doing less frequent and vigorous daily treatments. Having the vest has undoubtedly led to fewer sick days and hospitalizations than I have had otherwise: it has improved my quality of life immensely.”
Several years ago, a client had a double lung transplant. He was relying on the ACF program for coverage of all of his immunosuppressive and other CF related medications, outpatient visits, hospitalizations, and other needs. He had applied for SSI twice and did not qualify. He finally was able to qualify for other coverage after almost two years of efforts.

Consequences of Discontinuing Funding for the Program

Adult Cystic Fibrosis clients would not have needed medical services for this disease covered financially since these funds are used when none other are available. This could prevent the clients from receiving essential treatments, which could lead to reduced employability and poor health outcomes.

Recommendations for statutory, budgetary, or administrative changes needed to improve efficiency and effectiveness of services delivered to the public.

The following changes are being considered:

- Changing the administrative rules to include a cap on the maximum amount of funds spent on any one client during a fiscal year.
- Limiting the number of inpatient hospital days that can be covered per client in rule.
- Formalizing, in administrative rule, the use of a program drug and formula formulary.

Recommendations for improving services or reducing costs or duplication.

State costs could be reduced if all potentially eligible clients applied / reapplied for SSI benefits so that Medicaid would cover many of the services. Care coordination should be provided to those clients that are high cost and high risk. Currently there are no resources to provide this service. Only one health care provider should be requesting items per client. Requests from multiple providers should be coordinated by one health care provider or the client’s medical home.
Cancer Assistance Purchase of Medical Care Service Program

About the Cancer Assistance Program

The Cancer Assistance program provides screening and treatment for patients at either no or minimal cost to detect and treat cancer. By making these services available at the earliest possible point the program hopes to achieve optimal outcomes for patients. The program provides direct reimbursement to health care providers including hospitals, physicians, therapists and other medical treatment providers. To be eligible for the program, a person has to have an annual income of up to 115% FPL and no health insurance or insufficient health coverage. There are no age restrictions for the program.

Cancer Assistance Program Services

In 2006, cancer overtook heart disease to become the leading cause of death in North Carolina, accounting for 17,267 deaths in that year. Every day in our state, 116 persons will be diagnosed and 46 will die as a result of cancer. Cancer is a group of more than 100 different diseases, but all are characterized by uncontrolled growth and spread of abnormal cells. Every day in North Carolina many individuals face a diagnosis of cancer with no financial resources to cover treatment. All patients diagnosed with cancer experience fear, anxiety and emotional distress, but low-income, uninsured patients also have to contend with considerable financial stresses. Each year, over 40,000 North Carolinians are diagnosed with cancer, and it is estimated that between three and eight percent of these individuals do not have health insurance. This figure will rise as the unemployment rate increases.

A cancer diagnosis can be financially devastating for persons without insurance and without the resources to pay for care. The diagnostic workup of a patient with suspected cancer, for example a breast lump or an elevated prostate specific antigen (PSA), might cost well over a thousand dollars. Treatment, which could include surgery, radiation, or chemotherapy, might cost thousands to tens of thousands of dollars. Families living in poverty, faced with these costs, might be forced to choose between forgoing needed care or going deep into debt.

This program provides financial assistance to citizens unable to afford diagnostic procedures for symptoms or conditions highly suspicious of cancer, and provides reimbursement to medical service providers for cancer treatment. For those patients receiving services, the program provides access to services which would not otherwise be available to them. The service demand exceeds available program funds, which means there are unmet needs. The program estimates that roughly 10% of eligible clients are being served.
Patients are eligible for 8 days of diagnostic services and 30 days of treatment services during each enrollment period. Treatment can consist of chemotherapy, radiation, surgery, or any other treatment modality deemed medically necessary. However, certain types of high-cost drug treatments require patients to supply evidence they are not eligible for drug manufacturers subsidized program.

In state fiscal year 2006, some of the services provided included:

- Physician evaluation and management services for 214 patients
- Anesthesia services for 71 patients
- Surgery for 306 patients
- Radiology services for 61 patients
- Radiation therapy for 29 patients
- Pathology services for 121 patients
- Laboratory studies for 94 patients
- Pharmaceuticals for 31 patients
- Medical supplies for 6 patients

Administrative and operating expenses have always been kept at a minimum, with over 90% of expenditures going toward medical care. This assures that the primary mission of the program, to provide financial assistance for cancer services to people with very limited resources, is fulfilled.

The state does operate a Medicaid program to provide health care for individuals at or near the federal poverty level (FPL). However, eligibility for adults age 19 to 64 is severely limited. Generally, Medicaid eligibility is intended for children 18 years old or younger, pregnant women, disabled adults, and the elderly (65 or older) at or near the poverty level. Some parents with dependent children may be eligible, but with family income restrictions ranging from 37% to 57% of the federal poverty level. Even the disability status in Medicaid generally would not generally help the population served by this program since disability status is based on total disability expected to last 12 months or longer, or a condition expected to result in death. Therefore, this program is one of very few resources available to adults with limited income and no health insurance. Adults in the 40 to 64 year old range are especially unlikely to qualify for Medicaid because of family eligibility guidelines, while this is the age range where cancer incidence begins to increase.

The North Carolina Task Force on Covering the Uninsured, April 2006 cites data from the State Center for Health Statistics showing the uninsured are four times more likely to report instances in the prior 12 months they needed to see a doctor but could not because of costs. This data indicates a primary reason the uninsured are diagnosed with cancer at later, less treatable stages. In addition to the increased mortality due to late diagnosis, later treatment is often more expensive and debilitating. Although the individuals financially eligible for this program have very limited financial resources, over 50% of the uninsured adults at or below 100% of the poverty level are employed either full time (over 33%) or part time (over 17%). In addition to the debt incurred, treatment for later
Stage cancer typically restricts the person’s ability to work to varying degrees, causing further financial difficulties.

Most of the people receiving Cancer Assistance services are employed either full time or part time. However, many lower income jobs do not offer any health insurance coverage, and clients’ incomes are too low to allow for purchase of individual health insurance policies. These individuals are generally not eligible for Medicaid, since Medicaid primarily covers children, parents of young children, and the disabled. Although cancer can strike at any age, incidence begins increasing at age 40, an age at which most no longer have young children in the home. Because of the Cancer Assistance Unit’s requirement of a 25% or greater five year survival, its patients generally are not sick enough yet to meet the disability criterion of Medicaid. Therefore, the services the program supplies are not duplicated by other governmental programs.

**Demographics**

The majority of Cancer Assistance program participants are in the 30-55 year age range. The program is not currently being utilized statewide but is available on a first come basis. Data analysis demonstrates the Cancer Assistance program is not reaching everyone who could benefit from the program.

The Cancer Assistance Unit serves both men and women and covers services for most types of cancer, but services have primarily been utilized by women. Women account for over 94% of diagnostic services and 82% of treatment services. There are no program policies that account for the higher utilization rates for women. A major factor affecting this rate is that many of the referrals for services are arranged through local health departments, which serve many women through their family planning and maternity care programs. Most local health departments also participate in federal and state programs for breast and cervical cancer screening and diagnosis. However, the breast and cervical cancer screening programs have strict age requirements for eligibility, with a preferred age range of 50 to 64 years old, significant limits on screenings for women 40 to 49 years old, and no breast cancer screenings for women under 40. Additional restrictions in that program prevent any coverage of treatment services for women receiving a cancer diagnosis outside of the breast and cervical cancer screening program. These local health department activities result in a much higher percentage of women relying on health departments for services and referral than men do.

The Cancer Assistance Unit disproportionately serves areas of the state that have limited health care resources. As seen in Table 1 below, the highest enrollment per 1,000 persons living in poverty is seen in the western and northeastern regions of the state. The counties with the highest utilization of the program are shown in Table 2. Many counties with high utilization are health professional shortage areas (HPSAs).
### Table 1: Geographic Distribution of Patients Served by Program

<table>
<thead>
<tr>
<th>Region</th>
<th>Patients Served per 1,000 Persons Living in Poverty: Diagnostic Program*</th>
<th>Patients Served per 1,000 Persons Living in Poverty: Treatment Program*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Western</td>
<td>0.702</td>
<td>2.827</td>
</tr>
<tr>
<td>North Central</td>
<td>0.477</td>
<td>1.627</td>
</tr>
<tr>
<td>South Central</td>
<td>0.304</td>
<td>0.750</td>
</tr>
<tr>
<td>Central</td>
<td>0.157</td>
<td>0.559</td>
</tr>
<tr>
<td>Southeastern</td>
<td>0.483</td>
<td>1.511</td>
</tr>
<tr>
<td>Northeastern</td>
<td>0.899</td>
<td>2.608</td>
</tr>
</tbody>
</table>

* Derived from county-level census estimates of number of individuals living in poverty. For definitions of regions, please see map below.

### Cancer Assistance Program Regions

- **Western**
- **South Central**
- **Southeastern**
- **North Central**
- **Central**
- **Northeastern**

- ▲ Non-Commission on Cancer Facility
- ○ American College of Surgeons Commission on Cancer Approved Facility
- ★ Medical School / Major Academic Medical Center

### Table 2: Counties with the Highest Program Utilization

<table>
<thead>
<tr>
<th>Counties with the largest number of program participants</th>
<th>Counties with the highest number of program participants per capita</th>
</tr>
</thead>
<tbody>
<tr>
<td>Guilford</td>
<td>Tyrell**</td>
</tr>
<tr>
<td>New Hanover*</td>
<td>Perquimans*</td>
</tr>
<tr>
<td>Mecklenburg*</td>
<td>Pasquotank</td>
</tr>
<tr>
<td>Wayne*</td>
<td>Martin*</td>
</tr>
<tr>
<td>Davidson*</td>
<td>Camden</td>
</tr>
</tbody>
</table>
The Cancer Assistance Program has experienced increasing demand for services due to (1) the number of individuals living with cancer in the State has increased due to increased incidence and decreased mortality; (2) the number of individuals without insurance is increasing; (3) the number of patients who are eligible for Cancer Assistance is rising.

At the same time, the cost of medical care has increased, resulting in a higher cost of care for each patient served by the program. In the US from 1987 to 2000, the cost of cancer care for an individual with cancer increased by 41.9%. The rate of increase in the cost of cancer care has likely accelerated in the last several years due to increased use of targeted cancer therapies and advances in diagnostic technologies. All of these trends contribute to a rise in the cost of running the Cancer Assistance Program and the need for increased funding.

**Eligibility**

Eligibility is restricted to persons with annual income up to 115% of the federal poverty level (or $12,454) with a 25% or better expected survival rate. Inpatient treatment is limited to eight days per year. The maximum reimbursement per claim for inpatient services or outpatient/physicians services is 1% of the program’s annual budget. Based on the 2008-2009 annual budget of $2,531,934 the cap for this year would be $25,319.

Over two-thirds of the people in this program actually earn less than 85% of the poverty guidelines, which would be $9,206 for a single person, $12,385 for a couple, and $18,743 for a family of four. Patients must also meet residency and medical criteria. Applicants must live in North Carolina and be US citizens, have a citizenship application in process, have a permanent resident visa or an application for one in process, or be a migrant farm worker. In addition, applicants must not be eligible for Medicaid or Medicare and must not have health insurance that covers the service in question. To be medically eligible for the diagnostic services, a patient must have a condition strongly suspicious of cancer and the services requested must be medically necessary to confirm or rule out cancer. To be medically eligible for treatment services, the patient must have cancer or a precancerous condition and must have an expected 25% or greater five-year survival. The treatment services requested must be related to the patient’s cancer diagnosis. Payments are limited to a maximum of 1% of the authorized budget (currently about $25,000, based on reimbursement account lines) per hospitalization or claim. A total of 621 people received treatment services and 2,370 received diagnostic services in state fiscal year 2006.
Patients are referred to their nearest Local Health Department or Hospital to meet with a Social Worker or Financial Counselor who can assist them with the application process. Patients are required to provide documentation regarding income and insurance that the Financial Counselor or Social Worker will verify to determine if the patient meets the financial requirements for the Program. Financial Eligibility Applications are submitted to POMCS for review and processing. POMCS Authorizations Unit checks the patient’s gross income and Medicaid status. Eligible patients are assigned a case number and have an enrollment period that covers 12 months. Providers (physicians, hospitals, local health departments, clinics and community health centers licensed by the State of North Carolina to provide cancer diagnostic and treatment services) must then obtain an approved authorization for payment of services. In order to monitor and maintain program performance and effectiveness, the Cancer Assistant Unit’s Medical Consultant reviews most claims and determines if services provided meet the medical requirements of the program.

Benefits

Early diagnosis and treatment are the best way to survive cancer. For example, localized breast has over a 98% survival rate, whereas breast cancer that has spread to distant sites of the body has only a 26% survival rate. Patients with colorectal or bladder cancer that has spread to distant sites fare even worse, with less than 10% chance of survival. Generally, earlier treatment is also less costly and less debilitating to the patient.

The Cancer Assistance Unit is providing a crucial service to uninsured North Carolinians with very low incomes, particularly in some of the neediest areas of the state.

<table>
<thead>
<tr>
<th>Measure</th>
<th>SFY 2006</th>
<th>SFY 2007</th>
<th>SFY 2008</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unduplicated number served</td>
<td>2671</td>
<td>1284</td>
<td>1640</td>
</tr>
</tbody>
</table>

With the increasing unemployment rate state wide, more and more people will be in need of the services provided by the Cancer Assistance program. This will affect every county in the state, but the impact will be more severe in the rural counties that are already underserved in terms of medical service providers and local assistance programs.

In April of 2007, I began to have issues with my health. At the time I was 26 years old, with a wife and a 1 year old. Things began to get progressively worse by the fall and my local physician began running test. She didn’t want to do too much because I did not have insurance, however, I was experiencing greater and greater problems. I went for CAT Scans and blood work and the doctor bills began to pile up. Even with all the tests they could not identify what was going on so they sent me to ECU. My blood sugar would drop to dangerously low levels in the 30’s and even into the 20’s. The doctors were very concerned that I could die before they could find what was causing this to happen. I would have to eat every 3 hours just to maintain proper levels. Even at night I would have to get up and eat, or in the morning I would be so messed up that I could not communicate or move. Several times my wife had to call for help to save me. During this time I still had my responsibilities at my job as a Pastor and Bible College Director. My wife
stayed home with our child and had just found out that she was pregnant. So the stress of bills, my sickness, being pregnant and taking care of me and our 1 year old weighed heavy on her. After they finally discovered that I had a tumor on my pancreas, someone suggested the Cancer Fund. Not only did they help, but also I was able to have the surgery, hospital care, doctor visits and my past medical care taken care of. The debt would have bankrupted us and we would have lost our home. Today I am 28 years old, financially secure, cancer free, with two beautiful little girls, and a wife who is glad to have a healthy husband she can enjoy a long, long life with. I thank God for this program being available for me.

Consequences of Discontinuing Funding for the Program

Although there is no way for us to know for sure what would happen to the individuals served by this program if the program no longer existed, the program staff regularly receives phone calls from persons in need of care who state that they are unable to find physicians who will provide cancer diagnostic or treatment services to uninsured patients unless they can be assured payment in advance. Many of these calls are from areas of the state that are already underserved, mainly in the eastern and western portions of the state.

In all likelihood, some proportion of the patients currently served by the Cancer Assistance Unit would forego or postpone care if Cancer Assistance funds were no longer available. They would likely present in later, less curable stages of disease when they could no longer postpone care. They might present for care in hospital emergency departments. According to a report from the Kaiser Family Foundation,

> Only emergency departments are required by federal law to screen and stabilize all individuals. If the uninsured are unable to pay for care in full, they are often turned away when they seek follow-up care for urgent medical conditions. When the uninsured do receive care, they are typically billed for any care they receive, often paying higher charges than the insured. Those bills can lead to medical debt for the unemployed, who already may be struggling to pay daily expenses on a limited income. (The Kaiser Commission on Medicaid and the Uninsured, Schwartz, K., Health Coverage in a Period of Rising Unemployment, December 2008, pg 6)

The law prohibits withholding emergency care based on income or insurance status, but there are no regulations requiring such treatment prior to it becoming an emergency. Early stage cancer is not considered an emergency; essentially, it is not immediately life threatening. Many chronic diseases may result in death or disability, including conditions such as hypertension, arthritis, diabetes or digestive disorders. However, left untreated, cancer almost always results in death.

If Cancer Assistance funds were no longer available, some patients would attempt to pay for care out of pocket, if they could arrange payment plans with local health care providers. When paying out of pocket, uninsured patients are often billed at a higher rate than insured patients. Families with incomes less than 115% of the federal poverty guideline would need to make tradeoffs between healthcare and other basic needs, such as housing, food or utilities, in order to pay their healthcare expenses out of pocket. If they were unable to keep up with payments, they might have their healthcare bills referred to collections agencies, thus running into future credit problems.
Still other patients would rely on hospital charity care programs and other healthcare safety net providers. While these patients might not suffer the difficult choices of the patients described above, an influx of patients into hospital charity care programs would result in strain on a healthcare safety net system that is already stretched in the current economic climate. According to the Kaiser Family Foundation,

The cost of uncompensated care provided by physicians is not directly or indirectly reimbursed by public dollars: Financial pressures and time constraints, coupled with changing physician practice patterns, have contributed to a decline in charity care provided by physicians. The percent of all doctors who provide charity care fell to 68% in 2004-2005 from 76% in 1996-1997. (The Kaiser Commission on Medical and the Uninsured, The Uninsured – A Primer, Key Facts About Americans Without Health Insurance, October 2008, pg 12)

Many rural communities in North Carolina have an inadequate healthcare safety net, or no safety net to absorb these patients, leaving a significant number of patients without options. If financial assistance through other, more distant facilities could be identified, people falling in the eligible income categories might not be able to arrange transportation or lodging for treatment. In addition, some financial assistance programs at more distant sites are limited to local residents. Even if patients receive some subsidized health care, certain services may not be covered. For example, we recently had a claim for a patient with recurrent cancer. A hospital agreed to donate its services, but the patient was still faced with bills from radiology and oncology services.

If the program no longer existed, many patients would likely delay care, presenting in later, less treatable stages of disease with a lower survival rate. Many would attempt to pay for care out of pocket but might then be faced with an inability to meet other financial needs. An already stretched healthcare safety net would be further stressed as it attempted to absorb the cost of an influx of uninsured patients with cancer.

**Recommendations for statutory, budgetary, or administrative changes needed to improve efficiency and effectiveness of services delivered to the public.**

Too much time elapses between when a provider submits a claim for reimbursement and when the claim is paid. In order to provide a consistent level of service over time, the program needs additional funding, a reduction in the 12 month window for providers to file claims, or a reduced menu of services, targeting the greatest possible impact of diagnostic and treatment services.

In order to address the challenges of increasing demand while continuing to provide quality services to those in the greatest need, steps were taken in SFY07 to change medical procedures that are eligible for reimbursement; no longer cover targeted therapies that can be obtained through pharmaceutical patient assistance programs; and narrow the scope of the program to limit coverage to cancers which screening and early detection improves outcomes. A change in administrative rules of the program was initiated and is under consideration by the NC Department of Health and Human Services and the Office of Administrative Hearings.
Recommendations for improving services or reducing costs or duplication.

Because of the difference between requests for coverage and available funds, the program has prepared a rule change to narrow the scope of the program, limiting coverage to cancers for which screening and early detection improves outcomes. This rule change proposes that diagnostic and treatment services be covered only for breast, cervical, colorectal, prostate, lung, skin and oral cancers because science indicates that patients with these cancers can benefit from early detection and early treatment that can lead to cure. Adoption of the rule change would allow the program to be more closely aligned with the prevention mission of public health. Funds would be directed to patients who would most benefit from early detection and would allow more patients to be covered by the program.

The change in administrative rules of the program has been initiated and is under consideration by the NC Department of Health and Human Services and the Office of Administrative Hearings.

Ultimately, program management would like to see support and funding for cancer screening activities, similar to the Breast and Cervical Cancer Control Program, particularly for colorectal cancer screening. This would further our goal of earlier detection of colorectal cancer, which has a very high rate of successful treatment if diagnosed early, but a very poor outcome if diagnosed in later stages.
Early Hearing Detection and Intervention (EHDI) Initial Hearing Aid Program

About the Early Hearing Detection and Intervention Program

The objective of the Early Hearing Detection and Intervention (EHDI) program is to ensure that infants and very young children with hearing difficulties receive initial hearing aids as quickly as possible. The program provides funds to purchase the first hearing aid and related parts for children at diagnosis who are not covered by Medicaid or other third party insurance.

In addition, the EHDI program wants to ensure that all infants and young children with a hearing loss are referred at the time of diagnosis to Early Intervention (EI) services for coordination of future needs.

Early Hearing Detection and Intervention Program Services

98% of babies born in hospitals receive an initial hearing screening. Each year, four to five hundred children are identified with hearing loss.

Babies begin to develop speech and language in the earliest months of life. Research has shown that babies are “programmed” to learn certain skills at certain times. It is widely accepted that the first few years of life is the time during which children learn language skills most efficiently. The number of experiences that young children have with language during the first few years of life will affect their ability to communicate throughout their lifetime. During the early period, sound stimulates the growth connections between the infant’s ear and the area of the brain that makes sense out of the sound. Babies with hearing are stimulated with sound 24 hours a day. All of this stimulation results in a rich network of nerve pathways between the inner ear and the auditory center of the brain. When the ears do not work properly, the auditory center of the brain does not get the stimulation needed to grow and develop. The earlier a child receives hearing aids, the sooner his/her brain has access to sound, which is instrumental in the child's development of listening skills and in the development of speech.

It is important for babies with hearing loss to start using hearing aids as soon as possible so that they can hear speech. Because of the rapid development of infants, every day counts. Research supports the need to diagnose and treat infants/very young children that have a hearing impairment as quickly as possible to obtain the maximum benefit and therapeutic outcome for the child. These infants need to be fitted and receive their initial hearing aid(s) and accessories at the time of diagnosis, or within a matter of days.

Examining a group of 69 infants, the researcher at University of Colorado found that neonates identified at ages 0-2 months and receiving amplification and intervention "scored significantly higher in general development and expressive language than subjects identified at a later age." {Seminars in Hearing, 16 (2), 124-139}. Left
undetected or untreated, hearing loss in infants can negatively impact not just speech and language acquisition, but also academic achievement, and social and emotional development. With early treatment, children enter kindergarten on par with their peers. Children who experience delays in treatment will exhibit developmental delays.

The Early Intervention program serves children 0-3 who have or may be at risk for developmental delays. EI is a federal entitlement program, with stringent time standards for evaluating children and developing service plans. The EI program has 45 days from the time of referral to do a service plan (IFSP). Following the development of an IFSP, which should include the need for a hearing aid for the child, the parents would still need to set up an appointment with an audiologist for hearing aid fitting. This process would add additional days between diagnosis and access to sound for the baby. With the EI process, parents may have to pay (based on a sliding fee scale) for the hearing aid(s) prior to its receipt. For a child with hearing loss, these additional factors in the process add up to precious weeks or months of sound lost.

The EHDI program intentionally intervenes prior to a referral to the EI Program. The purchase of the hearing aid and referral to the EI program, in most cases, is done at the same time. This process eliminates any possible gap in the time from a child’s diagnosis of hearing loss to the intervention (access of sound) that the child needs most. Though Early Intervention services are certainly needed, the most critical step is to provide sound to the child as soon as possible. Although children who have a hearing loss may be deprived of meaningful access to spoken language, their brains are fully equipped to acquire language and they must be exposed to it in meaningful ways which is not possible without a hearing aid(s).

Demographics

Four per thousand children born will have a congenital hearing loss. In North Carolina, this is currently about 520 babies each year born with a hearing loss. About half of these will require hearing aids. Of those, 55% will be covered by Tricare or Medicaid, and approximately 130 children will request reimbursement from the EHDI fund.

Eligibility

Families are often unable to fund the initial hearing aid(s) and accessories for their infant/young child. Most private insurance, including the State Health Plan, does not cover hearing aids. About half of the identified children are covered under the Medicaid program, which covers the cost of hearing aids. Approximately one hundred thirty children each year will not have insurance or Medicaid coverage, and are eligible under the EHDI program.

Benefits
Rachel was born on September 17, 2003. She was the product of a full-term, uncomplicated pregnancy, and the second child born to David and Natalie. Rachel, unlike her older sibling, was unable to pass her hearing screening prior to discharge from the hospital. Two weeks after her birth, Rachel returned for her rescreen and again, failed. On October 14, 2003, at less than one month of age, Rachel was officially diagnosed with a severe to profound sensorineural hearing loss in both ears. Approximately one month later, Rachel’s family took her for a second opinion. Test results confirmed Rachel did, in fact, have a severe to profound hearing loss in both ears. Earmold impressions were taken the same day and Rachel was scheduled to be fit with hearing aids, paid for with previous DPH Assistive Technology funding, at age 3 months. Rachel was referred for and received Early Intervention (EIDHH) services. From a very young age, she wore her hearing aids consistently and followed-up on appointments. As a result, Rachel is a 5-year old girl with speech and language abilities equal to those of her peers. Thanks to Universal Newborn Hearing Screening, Early Intervention, Assistive Technology funding, and commitment to follow-up from parents, there are many stories like Rachel’s.

There are two Early Intervention programs for children with hearing loss. Both programs are directly impacted by the Early Detection and Intervention program.

The Early Intervention Program in DPH benefits by having the process completed at the time of referral which saves clinical time in their program and processing time for staff. It also reduces the time between referral and an IFSP. With the audiological diagnosis of deaf or hard of hearing, the child is automatically determined eligible for the EI program.

The benefits to the Office for Educational Services’, Early Intervention for the Deaf and Hard of Hearing program are that initial remediation has occurred when children are admitted to their program.

**Consequences of Discontinuing Funding for the Program**

There is no other program to assist with the cost of initial hearing aid(s) and accessories for infants and young children not covered by Medicaid prior to their enrollment into Early Intervention (EI) services. Evaluation and service planning in ITP can take several weeks to accomplish, which delays the child receiving an initial hearing aid. Many of these children will not receive their initial hearing aids until after one year of age. Valuable time will be lost that will negatively effect their hearing, communication, speech and school readiness. This has a direct impact on the child’s development, school performance and potential as an adult.

Without the EHDI program, public schools will need to provide additional support to help these children catch up and additional resources to educate children with hearing impairments. The children will lose the opportunity to maximize their potential and join the workforce.
Early Hearing Detection and Intervention (EHDI)

**Hospital – At birth**
SCREEN ALL INFANTS PRIOR TO HOSPITAL DISCHARGE

***Pass

**REFER (Fail)**
Parents given information and appointment for outpatient rescreen

**Hospital – by 1 month**
OUTPATIENT RESCREEN

***Pass

**REFER (Fail)**
Parents given list of NC Infant Diagnostic Audiologic Evaluation sites available from North Carolina Division of Public Health
[www.ncnewbornhearing.org](http://www.ncnewbornhearing.org)

Parents obtain physician referral for audiological evaluation, if needed

**Pediatric Audiologist – by 3 months**
AUDIOLOGICAL EVALUATION

***Pass

**CONFIRMED PERMANENT HEARING LOSS**
Referral for medical evaluations (Primary Care, Genetics, ENT, etc.) required for hearing aid

**Hearing Aid Evaluation**
Referral to Part C Early Intervention (CDSA)
Referral to BEGINNINGS
Referral to Office of Educational Services (EIDHH)
Referral to Regional Child Health Audiology Consultant

**Pediatric Audiologist – before 6 months**
HEARING AID FITTING

**REPORTING RESULTS:** Results for each stage should be submitted using
1) Hearing Link
2) NBS form (DHHS 3105)
3) Hearing Screening Report
4) Diagnostic/Amplification Report

For assistance call (919) 707-5635

**TRACKING:** Families not completing recommended rescreen, diagnostic, or amplification should be contacted by telephone and letter. The primary care provider should also be notified.

**INFORMATION FOR PARENTS:** Parents should receive information about normal hearing, speech, and language development as well as risk indicators for progressive or delayed onset hearing loss.
Sickle Cell Disease Purchase of Medical Care Program

About the Sickle Cell Disease Program

Established in February 1, 1976, the purpose of the Sickle Cell Disease (SCD) POMC Program is to pay for needed health services for North Carolina residents with Sickle Cell Disease, who are at or below 100% of the federal poverty level, do not have health insurance, and have a diagnosis of SCD. Early and often ongoing treatment is essential for survival, to reduce the number of painful episodes, and to prevent frequent, serious complications from Sickle Cell Disease. Without POMC, these individuals are likely to go without or delay obtaining critical health care and suffer severe pain.

Sickle Cell Disease Program Services

Sickle Cell Disease is an inherited blood disorder in which red blood cells are abnormally shaped. The most common complication that adults with SCD must deal with is acute, severe pain. These men and women deal with some degree of pain most days of their lives and pain requiring hospitalization occurs from once every one and a half years to five or more times per year. During these hospitalizations, the patients receive intravenous pain medication and are monitored for further complications which can arise during painful episodes. Clinic and emergency room visits to manage acute pain occur more often than hospitalizations. The second most common acute problem is a pneumonia-like illness called the acute chest syndrome. This requires hospitalization for pain control, antibiotics and oxygen, and sometimes ICU care is necessary. Most of the deaths that occur in people with SCD are due to respiratory problems.

Surgical problems arise frequently for individuals with SCD. The most common surgery is for removal of the gallbladder. Gallstones develop at an early age in people with SCD, and cause problems in the majority of those who have the stones. Often a patient will present with an acute attack of pain from the gallbladder, requiring hospitalization. Surgery must wait until the attack has subsided because surgery on an acutely ill person with SCD can be quite risky. Because of this situation, two hospitalizations are often required to manage this problem. The next most common surgical procedure is hip replacement. By age 35, 50% of people with SCD have at least one hip that has been severely damaged by a complication of the known as avascular necrosis. The percent who are affected continues to rise with age. Surgery is performed when the affected person is disabled either by pain or lack of mobility or, most commonly, both.

The hospitalizations which are required for the management of the complications described above are vital to relieve some of the pain and suffering that people with SCD experience. Some of the hospitalizations are life-saving. None could be considered elective if one cares about relieving pain.

Currently, the specific services covered by POMC are hospital outpatient care including a limited number of emergency room visits, physicians’ office visits, drugs on a formulary established by the program, medical supplies and equipment, dental care to control bleeding, relieve pain and treat infection, eye care when the Division of Services for the Blind will not provide coverage, and a limited number of days of hospital inpatient care.
The medical services to be provided are determined by the Medical Committee of the NC Governor’s Council on Sickle Cell Syndrome and approved through the NC Administrative Code rule making process. To make these determinations, the Medical Committee considers the most recent scientific evidence and cost benefit data available. The program uses the rule change process when changes in the program are necessary.

Approximately 10% of individuals enrolled in the North Carolina Sickle Cell Syndrome Program receive POMC services each year. There is currently no waiting list for POMC services. However, during recent years specific services were curtailed due to budgetary constraints. For example, inpatient hospital care was eliminated for several years and then partially restored for a limited number of inpatient days per client per year. In addition, Sickle Cell POMC has a drug formulary that enables the program to provide pharmaceutical coverage specifically targeted to sickle cell. The Sickle Cell POMC Program no longer covers psychosocial services and obstetrical care, as Medicaid covers these services.

Demographics

During the past five years, between 200-245 clients were served each year of which 95% were over the age of 18 and 55% of the total number served were men. It should be noted that children with SCD are generally covered in the Health Check/Health Choice State program. While the majority of persons with sickle cell are of African descent, SCD has been documented in all racial groups. This is a lifelong illness that affects over 4,500 North Carolinians. Each year through the state’s newborn screening initiative, over 120 babies are identified with SCD and other related blood disorders.

Eligibility

The purpose of the Sickle Cell Disease (SCD) POMC Program is to pay for needed health services for North Carolina residents with Sickle Cell Disease, who are at or below 100% of the federal poverty level, do not have health insurance, and have a diagnosis of SCD. In 2009, 100% of the federal poverty level is $10,830 for a family of one.

Approximately 2,200 individuals with SCD per year participate in the statewide North Carolina Sickle Cell Syndrome Program. Participants enrolled in the state program are provided financial counseling to ensure that they have access to needed medical services. Every effort is made to qualify the participant for Medicaid or Medicare if the client does not have another third party payer source. However, if the participant meets strict financial criteria (must be at 100% of the federal poverty level or lower), this individual is enrolled in the POMC program which is the payer of last resort.

Benefits

The POMC Program annually serves between 200 and 245 clients with SCD. These clients have no other source to pay for their medical care. The program has been diligent in maintaining a cost effective program by eliminating duplication when possible and staying within the prescribed
budget. A medication formulary is used to further ensure cost containment measures while providing necessary pharmaceuticals for SCD clients.

To fully understand the impact of the POMC Program on the lives of persons living with SCD, it is necessary to go beyond the numbers of person affected and the services provided. Each of the clients on the program receives this financial assistance because there is no other source of funding to cover the cost of clinical care. Following are brief statements documenting client use of the POMC Program.

VG is a 49 year old woman with Sickle Cell Disease. She experiences frequent pain and has trouble staying employed due to her frequent health-related absences. She has applied for Social Security Disability but has been denied. She had been living with pain for years, only receiving minor treatment through the local Crisis Ministry. Once she qualified for POMC, she was able to see a hematologist and receive treatment for many sickle cell-related health issues. She has retinopathy and has been able to have eye surgery. She was able to go to a dentist for the first time in years and prevent major infection. She is very thankful for the excellent care she has received from the local hematologist and is now able to prevent a lot of the SCD related pain and other complications.

D.N., a 28 year old with hemoglobin Sickle Cell Disease resides in Union county. He has no insurance benefits with the fast food restaurant that employs him. He became ill last month and his grandmother had to borrow money in order to be seen at the physician's office before he could receive medical services. His grandmother is a domestic worker for a private family and tries with limited success to support him, his ill aunt and her autistic son. His application is currently being processed to participate in the POMC program.

CR is a 25 year old woman with Sickle Cell Disease. While attending college, she experienced frequent pain crises. After graduation she moved in with her parents while looking for employment. She spent several months without a job or health insurance. During this time she developed several major dental issues. She could not afford the procedures recommended by the dentist. However, without treatment she was likely to develop an infection which could have caused a sickle cell pain crisis or other major complications. She qualified for POMC and was able to have the dental work performed. While she did find employment at a group home, she was not able to have insurance coverage through work. She could not afford her own insurance based on her salary and the number of available work hours. She developed a severe urinary tract infection which sent her into a pain crisis. She went to the local hospital. Due to POMC, she was able to get the care, follow-up treatment, and medications she needed to recover.

The letter below from Dr. Darnell Ivy illustrates the impact the POMC program has had upon his life.

To Whom It May Concern:

I was born with Sickle Cell Anemia, and during my childhood, I frequently required medical care to address complications associated with this disease. As I became an adult, I realized that having Sickle Cell Anemia would place a limitation on what I would be able to do with my life. I had always aspired to join the US military, but because of this disease, I learned that the goal of enlistment to serve my country was not possible. While in high school, I developed a severe limp due to a common complication with Sickle Cell known as avascular necrosis.
I decided to go to college with the hope of learning more about my condition and helping others. I was the first person in my family, in all generations of my family including extended family, to attend college. My family was very poor, so I relied heavily on financial assistance from scholarships as well as State and Federal aid programs to attend college. Because complications with sickle cell continued in college, I received assistance from the Sickle Cell Purchase of Medical Care program to help with medical expenses. In 1995, while a junior at North Carolina State University, I was affected by another common complication of sickle cell, acute chest syndrome. Acute chest syndrome is a severe complication of sickle cell and a leading cause of death in individuals with this disease. I required several days in the Intensive Care Unit at the University of North Carolina Hospital. The medical bills from this one incident were expensive, and without the help of the Sickle Cell Purchase of Medical Care program, I would not have been able to cover the expense and continue to attend college. After this hospitalization, I was started on a new therapy for sickle cell called hydroxyurea. This new therapy requires me to take medication daily and to visit a health care professional monthly for blood work. Again, these expenses would have inhibited me from attending college, but fortunately the expenses were covered by the Sickle Cell Purchase of Medical Care program. I was able to graduate from North Carolina State University in 1997 with Bachelor of Science degrees in Zoology and Microbiology.

Driven by my goal to help others suffering from sickle cell disease and other chronic diseases, I enrolled in East Carolina University School of Medicine to become a medical doctor. Again, I was aided by scholarships and financial assistance programs. I also received help with medical expenses from the Sickle Cell Purchase of Medical Care program. Expenses for my daily medications with hydroxyurea and the medical visits to monitor this therapy were covered by the program. This assistance allowed me to focus on medical school. Complications from sickle cell continued, and after my third year in medical school, I withdrew from medical school. I left school to undergo total hip replacement of both hips due to avascular necrosis. This problem is a complication due to sickle cell. After the surgeries and time to recuperate, I returned to medical school and graduated as a medical doctor from East Carolina School of Medicine in 2003.

I began a residency, but shortly realized that the best way for me to help others with chronic disease was not by practicing medicine. Instead I wanted to create, evaluate and advocate for programs such as the Sickle Cell Purchase of Medical Care program that had helped me to acquire the medical attention I needed to obtain self-sufficiency. This led me to enroll in the Masters of Public Health Program at the University of North Carolina at Chapel Hill. While a student in the MPH program at Chapel Hill, I was not employed, and relied once again on financial assistance from scholarships, State and Federal aid programs. I also relied on the Sickle Cell Purchase of Medical Care program for expenses related to treatment of sickle cell disease. I graduated from the MPH program at the University of North Carolina at Chapel Hill in May 2008.

I was able to secure a job with the federal government in August 2008. I currently work in the National Heart, Lung, and Blood Institute of the National Institutes of Health as a Medical Officer. I work with others to create programs that will help those with chronic disease obtain knowledge and resources for improved care and self-sufficiency. There is no doubt that with the help from the Sickle Cell Purchase of Medical Care program, I was able to acquire the knowledge and resources I needed to not only achieve self-sufficiency, but to also place myself in a position to help others. I hate to think of what my situation would be if the program did not exist to help me become the person I am today.
For this reason, I strongly endorse the continuation of the program. In this time of economic uncertainty, programs such as the Sickle Cell Purchase of Medical Care program are needed now more than ever to help individuals such as myself stay healthy and in a position which allows them to improve their lives. If you have any questions about what I have stated in this letter, please feel free to contact me by phone at (301) 496-1051 or by email at ivyed@nhlbi.nih.gov.

Thank you,

Edward Donnell Ivy, MD, MPH
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Consequences of Discontinuing Funding for the Program

Discontinuing the sickle cell program would result in a loss or delay of treatment and care for low income uninsured persons with SCD. Evidence for this statement was provided when the number of days of inpatient hospital care reimbursed by POMC was restricted in 2000. North Carolina Sickle Cell Syndrome Program participants often chose to live in pain and delayed seeking needed hospital services because they did not have a means for payment. Many delayed medical care until an emergency arose thus increasing the overall cost of the care.

Preventative and early treatment provided POMC prevents the need for an extended hospitalization. Like many chronic diseases, the lack of routine monitoring and treatment leads to more serious medical problems. Ultimately, there is a loss in client productivity and a reduction in the quality of life.

Sickle cell clients are eligible for care coordination services through the North Carolina Sickle Cell Syndrome Program. Through care coordination, clients are informed about the availability of financial assistance through Medicaid, Medicare, and other third party payers. Every effort is exhausted by the program to qualify clients for Medicaid or other third party payers. However, if they do not meet the requirements for any other insurer, the POMC program is used as the payor of last resort. All clients in the POMC program must be at 100% or below the level of poverty in order to participate in the program. Often because of the high cost of the medical care for sickle cell clients, many clients may be off and on the Medicaid roster during their life span. POMC is the only payment mechanism that can sustain them as they spend down resources during this process.

According to statistics provided by the Agency for Healthcare Research and Quality, in 2006 the average cost per admission of hospital care for an individual with SCD was nearly $17,000 in the Southern Region of the United States. This information would lead one to surmise that the POMC program in North Carolina is vital to the sickle cell client who does not have a medical cost safety net.
Recommendations for statutory, budgetary, or administrative changes needed to improve efficiency and effectiveness of services delivered to the public.

Expedite the automation of the authorization and claims process to improve the administration of the POMC Program. The automation of the authorization process will decrease time and manpower used to get persons on the program.

To make minimal modifications to amount of services covered requires a rule change. This process takes over 18 months. Thus it is very difficult to adjust services to fit their cost into a fixed 12 month budget. Decrease the time needed to adjust covered program services in order for program funds to be utilized more efficiently.

Reduce the length of time that providers have to submit claims for payment. Currently, providers have one year to submit claims from the time of service. If the time that the providers have to request payment for services is reduced, it will result in the program having better control over the budget. If services are provided in one fiscal year but are not paid for by POMC up to 12 months later, the money will be taken out of the next year's budget. This process makes it difficult to manage a yearly budget. Consider implementing an automated system health savings account cards.

Recommendation for improving services or reducing costs

Study the option of utilizing POMC funds to purchase health insurance for POMC eligible participants through the NC high risk health insurance pool.
POMCS rules:
10A NCAC 45A .0202 DETERMINATION OF FINANCIAL ELIGIBILITY

(a) A patient must meet the financial eligibility requirements of this Subchapter to be eligible for benefits provided by the payment programs. Financial eligibility shall be determined through application of income scales. The definition of annual net income in Rule .0203 of this Subchapter and the definitions of family in Rule .0204 of this Subchapter shall be used in applying the income scales, except as provided in Paragraphs (c), (e) and (f) of this Rule.

(b) A person is financially eligible for services under the Sickle Cell Program if the net family income is at or below the federal poverty level in effect on July 1 of each fiscal year.

(c) A person is financially eligible for the HIV Medications Program if the gross family income is at or below 300 percent of the federal poverty level in effect on July 1 of each fiscal year, with the following exceptions:

1. If a waiting list develops, priority for enrollment into the Program shall be given to those whose net family income is at or below 125 percent of the federal poverty level, and second priority to those individuals with income above 125 percent and at or below 250 percent of federal poverty guidelines; and

2. At any time that the Program's financial eligibility level is changed, all clients enrolled in the Program during the most recent year or at the time the eligibility level is changed shall be eligible to continue to be enrolled in and served by the Program. This shall be true even if the clients' financial status at that time places them above the newly-established level. The eligibility of these clients shall remain in force until:
   (A) they no longer qualify for the Program other than for financial reasons; or
   (B) they no longer require the services of the Program; or
   (C) their income increases such that they have an income that exceeds the level under which they originally qualified for and enrolled into the Program; or
   (D) they fail to comply with the rules of the Program.

Changes related to the Program's financial eligibility level or status shall be communicated to interested parties within North Carolina's HIV community (e.g., persons living with HIV disease, their families and caregivers, advocates and service providers, relevant local and state agencies) by the Program via electronic or print mechanisms.

(d) A person is financially eligible for the Kidney Program if the net family income is at or below the following scale:

- Family Size 1: $6,400;
- Family Size 2: $8,000;
- Family Size 3: $9,600;
- Family Size 4: $11,000;
- Family Size 5: $12,000;
- Family Size 6 and over: add $800 per family member.
(e) A person is financially eligible for the Cancer Program if gross family income is at or below 115 percent of the federal poverty level in effect on July 1 of each year.

(f) A child is financially eligible for Children's Special Health Services if the child is approved for Medicaid when applying or reapplying for program coverage, except for children eligible under Paragraph (g) and (h) of this Rule.

(g) A child approved for Children's Special Health Services post adoption coverage pursuant to 10A NCAC 43F .0800, is eligible for services under Children's Special Health Services if the child's net income is at or below the federal poverty level in effect on July 1 of each year.

(h) A person is financially eligible for services under the Adult Cystic Fibrosis Program if the net family income is at or below the federal poverty level in effect on July 1 of each year.

(i) The financial eligibility requirements of this Subchapter do not apply to:

1. Migrant Health Program;
2. School Health Fund financial eligibility determinations performed by a local health department which has chosen to use the financial eligibility standards of the Department of Public Instruction's free lunch program;
3. Prenatal outpatient services sponsored through local health department delivery funds, 10A NCAC 43C .0200; or through Perinatal Program high risk maternity clinic reimbursement funds, 10A NCAC 43C .0300; and
4. Diagnostic assessments for infants up to 12 months of age with sickle cell syndrome.

(j) Except as provided in Paragraphs (k) and (l) of this Rule, once an individual is determined financially eligible for payment program benefits, the individual remains financially eligible for a period of one year after the date of application for financial eligibility unless there is a change in the individual's family size pursuant to Rule .0204 of this Subchapter or his family's financial resources or expenses during that period. If there is a change, financial eligibility for payment program benefits must be redetermined. Financial eligibility must be redetermined at least once a year.

(k) For purposes of the Kidney Program and HIV Medications Program, once an individual is determined to be financially eligible, if the application for financial eligibility was received by the Department in the fourth quarter of the fiscal year, the individual remains financially eligible for benefits until the end of the next fiscal year unless there is a change in the individual's family size pursuant to Rule .0204 of this Subchapter or his family's financial resources or expenses during that period.

(l) Children eligible for Children's Special Health Services Program benefits under Paragraph (f) of this Rule are financially eligible for a service if they were Medicaid eligible on the date the requested service was initiated.

(m) If the most current financial eligibility form on file with the Department shows that the patient was financially eligible on the date an Authorization Request for payment for drugs was received, the Authorization Request shall be approved so long as the Authorization Request is received less than 30 days prior to the expiration of financial eligibility and the authorized service does not extend more than 30 days after the expiration of financial eligibility.

Authority G.S. 130A-4.2; 130A-5(3); 130A-124; 130A-127; 130A-129; 130A-205.