



February 2006

Report No. 06-11

Design of Florida's Adult Cystic Fibrosis Program Should Be Reconsidered

at a glance

Abilities, Inc., appears to be performing well in administering the Adult Cystic Fibrosis Program and stakeholders believe the program performs an important function by assisting persons with this chronic disease pay for the cost of medical care. However, the program's design may be outdated and does not consider changing conditions, such as the emergence of adult clinics within cystic fibrosis treatment centers, and the availability of new program financing options.

The Legislature should reassess the program's design and determine whether it should be changed to better address changing conditions. The Legislature may wish to authorize the Department of Health to conduct an updated assessment of the needs of adults with cystic fibrosis, identify potential solutions for addressing the identified needs, and present the Legislature with program re-design options.

Scope

As requested by the Joint Legislative Auditing Committee, we reviewed the state's Adult Cystic Fibrosis Program, which is administered by Abilities, Inc., under a contract with the Department of Health. Our review examined whether the program as designed maximizes the availability of services for adults with cystic fibrosis.

Background

Cystic fibrosis is a genetic disease that primarily affects a person's lungs and digestive system and is chronic, progressive, and terminal.¹ While the Department of Health does not maintain statistics on the prevalence of the disease among Floridians, there are an estimated 600 adults with cystic fibrosis in the state.

Medical advances have dramatically increased the life expectancy of persons with cystic fibrosis. While the median life expectancy of persons with the disease in the 1960s was only five years, cystic fibrosis patients now have a life expectancy of 35 years. Consequently, what was once a childhood disease has also become a disease of adults.

¹ With cystic fibrosis, a defective gene causes the body to create thick mucus that clogs the lungs and leads to lung infections. The mucus also blocks the pancreas, which prevents digestive enzymes from reaching the intestines to break down food.

With increased longevity, adults with cystic fibrosis face various challenges.

- Medical care. Persons with the disease often need to take medications to prevent and treat infections, and may receive respiratory therapy multiple times a day to maintain lung function. They also may experience frequent hospitalizations. In addition to a progressive decline in health status, people with the condition also may experience associated health problems such as diabetes, as well as maladies associated with aging such as cancer and osteoporosis.
- Proper nutrition. Individuals with cystic fibrosis have high caloric needs because they burn up to half of their calories breathing. An estimated 40% of adults with cystic fibrosis need nutritional supplements as well as special foods.
- Employment. Persons with cystic fibrosis often find it difficult to remain employed due to their severe medical condition and large amount of time needed for care. Sporadic employment reduces their likelihood of maintaining health insurance through an employer.
- Paying for health care. Adults with cystic fibrosis who are able to maintain employment may face high out of pocket expenses for health care due to gaps between the accepted standards of medical practice for treating the disease and the coverage provided by private health insurance policies. For example, some insurance policies may not cover the cost of some prescription medications or needed nutritional supplements.

Florida's Adult Cystic Fibrosis Program

Florida's Adult Cystic Fibrosis Program was established in 1998. The program's purpose is to encourage cost sharing by the public and private sectors in financing treatment for adults

with the disease. The program provides services that help adults with cystic fibrosis cover the cost of health insurance, medications, treatments, and support services that are not covered by private health insurance, Medicaid, or personal income. In recent years, program services have been restricted to adults meeting Medicaid eligibility criteria.² The program served 126 individuals in Fiscal Year 2004-05.

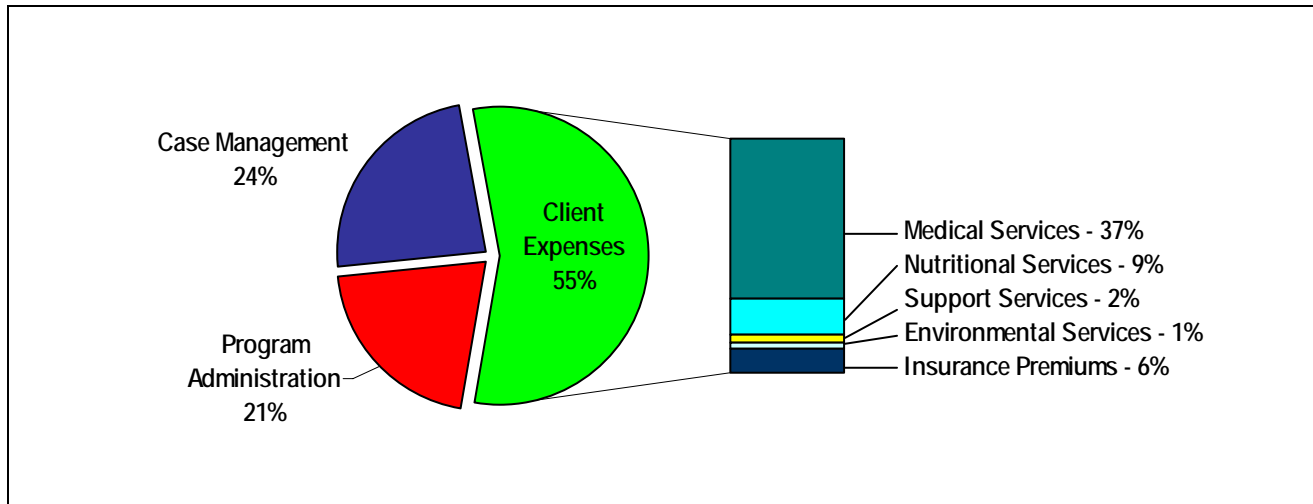
The program is administered by Abilities, Inc., of Florida under a contract with the Department of Health.³ Abilities, Inc., is responsible for determining program eligibility, providing case management, coordinating service provision, and processing payments for services and goods.⁴ The Department of Health's Bureau of Brain and Spinal Cord Injury is responsible for administering the contract with Abilities, Inc.

Under its contract with the department, Abilities, Inc., received \$990,000 in state funds in Fiscal Year 2004-05. As shown in Exhibit 1, medical services accounted for 55% of Abilities, Inc.'s program-related expenditures. The remaining funds were used to provide case management (24%) and for Abilities Inc.'s administrative costs (21%). Program services are paid for with general revenue funds appropriated to the department.

² The program currently uses medical and financial eligibility criteria that have been established for the Adult Cystic Fibrosis Medicaid Waiver.

³ The program was not established in the *Florida Statutes*, but receives funding through the Department of Health's appropriations. It was transferred from the Department of Children and Families to the Department of Health (DOH) in 2002. At that time, DOH was given responsibility for administering the contract with Abilities, Inc. DOH was not appropriated funding to support its program monitoring activities. The department's cost of monitoring the program is absorbed in its Bureau of Brain and Spinal Cord Injury's budget.

⁴ In addition to assisting in covering the cost of medical services, the program may cover the cost of durable medical goods such as pulmonary clearance vests and generators to operate medical equipment in the event of electrical failure.

Exhibit 1**The Majority of Abilities Inc.'s Program Expenditures Were Used for Client Expenses in Fiscal Year 2004-05¹**

¹ Support services include homemaker, housecleaning, transportation, respite care and transportation. Environmental services include air purification and air conditioning.

Source: Abilities, Inc.

Cystic fibrosis care centers

Most adults with cystic fibrosis receive medical care in cystic fibrosis care centers, which are accredited by the National Cystic Fibrosis Foundation. There are presently 18 cystic fibrosis care centers in Florida, of which four specialize in treating adults (see Appendix A).⁵

The centers use a multi-disciplinary model with care teams made up of medical staff who plan and oversee treatment and social workers who assist in identifying resources, including resources available through Florida's Adult Cystic Fibrosis Program. These centers generally see patients three to four times a year in an outpatient clinic setting to monitor their health status and treatment plans. Clinic physicians also coordinate specialty care, as needed, for illnesses such as diabetes, heart disease, and other conditions that may affect cystic fibrosis patients. Either the clinic physicians or local doctors see patients when

they need additional care between scheduled visits.

Findings

Abilities, Inc., appears to be performing well in administering the state's Adult Cystic Fibrosis Program and stakeholders believe the program performs an important function by helping pay the medical treatment costs of persons with the disease. However, the program design may be outdated and does not consider changing conditions or take advantage of current health care service delivery and financing options.

Abilities, Inc., appears to be performing well in administering Florida's Adult Cystic Fibrosis Program

Stakeholders are generally satisfied with Abilities, Inc.'s management of the program.

⁵ While most of the cystic fibrosis care centers in Florida treat adults, the National Cystic Fibrosis Foundation provides "adult program" designation to the four centers that treat over 40 adults.

We contacted a variety of stakeholders, including adults with cystic fibrosis and their family members, Department of Health managers and employees, representatives of Abilities, Inc., medical and support staff of seven Florida cystic fibrosis care centers, and representatives of the National Cystic Fibrosis Foundation. These stakeholders were generally satisfied with the work of Abilities, Inc., and asserted that the program performs an important function by funding services not paid for by private health insurance or Medicaid. As shown in Exhibit 1, the program provides funding to help pay for clients' medical, nutritional, environmental, and support services. In Fiscal Year 2004-05, funding support for individual clients ranged from \$72 to pay for one client's medications to \$17,887 to pay for another client's respiratory therapy services, caloric supplements, medications, and medical equipment.

Further, the Department of Health's monitoring report for Fiscal Year 2004-05 indicated that Abilities, Inc., was meeting contractual requirements, such as correctly applying program eligibility criteria and assessing client satisfaction. The monitoring report also indicated that Abilities Inc.'s provider payment and client records were accurate, complete, and submitted on time.

The program's design should be reconsidered

While the program is functioning reasonably well, it is based on a design that may need to be revised to reflect recent changes in the health care environment. The program design was established based on recommendations of a 1996-97 Adult Cystic Fibrosis Task Force convened by the Suncoast Health Planning Council in conjunction with Florida's Department of Children and Families and Agency for Health Care Administration. The task force assessed the needs of adults with cystic fibrosis and recommended that the state establish a program to encourage cost sharing

by the public and private sectors in financing the cost of treatment.

However, two major changes have occurred in the health care system since the task force's needs assessment was conducted and are not considered in the program's design. First, since 2000, cystic fibrosis care centers have begun establishing separate clinics that focus on treating adults with the disease. These centers provide a variety of services, including assessing client conditions, developing treatment plans, monitoring client progress, and facilitating access to needed specialized medical care. These services can duplicate those provided by the Adult Cystic Fibrosis Program, particularly client assessment and case management services. For example, both the centers' and Abilities, Inc.'s staff assess an individual's medical and other support needs. Coordination between these entities will become increasingly important as the cystic fibrosis population continues to age and require additional treatment for maladies associated with aging such cancer and osteoporosis.

Second, in 2002, Florida obtained a Medicaid waiver from the U.S. Department of Health and Human Services that presents new opportunities for funding Adult Cystic Fibrosis Program services. The waiver, when fully implemented, will allow the state to leverage its resources by matching general revenue funds with federal dollars. It will also allow the state to use federal matching funds to pay for services not regularly covered by Medicaid. For example, Medicaid historically has not paid for some cystic fibrosis treatments and support services prescribed by physicians such as nutritional services.⁶ In anticipation of receiving federal funds under the waiver, the Department of Health reduced the amount of funds provided Abilities, Inc., from \$990,000 in

⁶ The waiver also removes reimbursement limitations on respiratory therapy and other services needed to maintain the lung function of adults with cystic fibrosis, and covers some case management costs.

Fiscal Year 2004-05 to \$709,831 in Fiscal Year 2005-06 (a reduction of 28%).

While some of the program's clients have been enrolled under the waiver, providers have yet to be paid for providing waiver services. The delay in making payments to providers is caused by problems with the Medicaid payment system and slow progress in establishing reimbursement rates for program services, such as case management and durable medical equipment.⁷ Agency for Health Care Administration managers anticipate that the problem with the payment system will be resolved by early 2006, and that reimbursement rates will be established by July 2006. Department managers told us that they are considering amending the contract with Abilities, Inc., to allow it to use state general revenue funds which are already set aside to be used as Medicaid match to pay service providers until the waiver is fully implemented.

Further, recent actions to reform Florida's Medicaid Program may also affect the program. During the December 2005 special session, the Legislature passed legislation (HB 3-B) that authorizes major changes in the Medicaid Program, including moving participants into managed care programs and providing them counseling in selecting health care plans that offer the most appropriate benefits.

Other states' adult cystic fibrosis programs have different service and administrative structures

Other states with adult cystic fibrosis programs have established different service and administrative structures than Florida. As shown in Appendix B, Florida's eligibility criteria, service delivery, and cost sharing requirements are different from those of six other large states. For example, Florida ties

program eligibility to eligibility criteria for the Adult Cystic Fibrosis Medicaid waiver. In contrast, California and Michigan do not require participants to meet financial eligibility criteria, but do require cost-sharing by higher income individuals. California and Ohio primarily implement their programs through their systems of accredited cystic fibrosis care centers, while Florida currently implements its program through a contracted entity that provides case management and billing services.

Conclusions and Recommendations —

Abilities, Inc., appears to be performing well in administering the Adult Cystic Fibrosis Program and stakeholders believe the program performs an important function by assisting persons in paying for the cost of treatment. However, the program's design may be outdated and does not consider changing conditions such as the emergence of adult clinics within cystic fibrosis treatment centers, and the availability of new opportunities for funding program services through a Medicaid waiver. Further, once operational, the Medicaid reform initiative authorized by the Legislature in the December 2005 special session may have an effect on the program.

Given these changes, we recommend that the Legislature reassess the program's design and determine whether it should be changed to better address current conditions. The Legislature may wish to authorize the Department of Health to conduct an assessment of the needs of adults with cystic fibrosis, identify potential options for addressing the identified needs, and present the 2007 Legislature with program re-design alternatives.

⁷ Under the waiver, providers will bill Medicaid directly for the cost of services. Previously, providers would be paid by Abilities, Inc., for providing program services.

In conducting this needs assessment, the department should obtain stakeholder input, including adults with cystic fibrosis and their family members; providers of cystic fibrosis care and treatment, including representatives of cystic fibrosis care centers; representatives of health planning councils; and representatives of state agencies responsible for delivering and financing health care programs. The needs assessment should consider the role of the cystic fibrosis centers as well as alternative program designs used by other states. It also should consider the effects of shifting from general revenue funding to the Medicaid waiver.

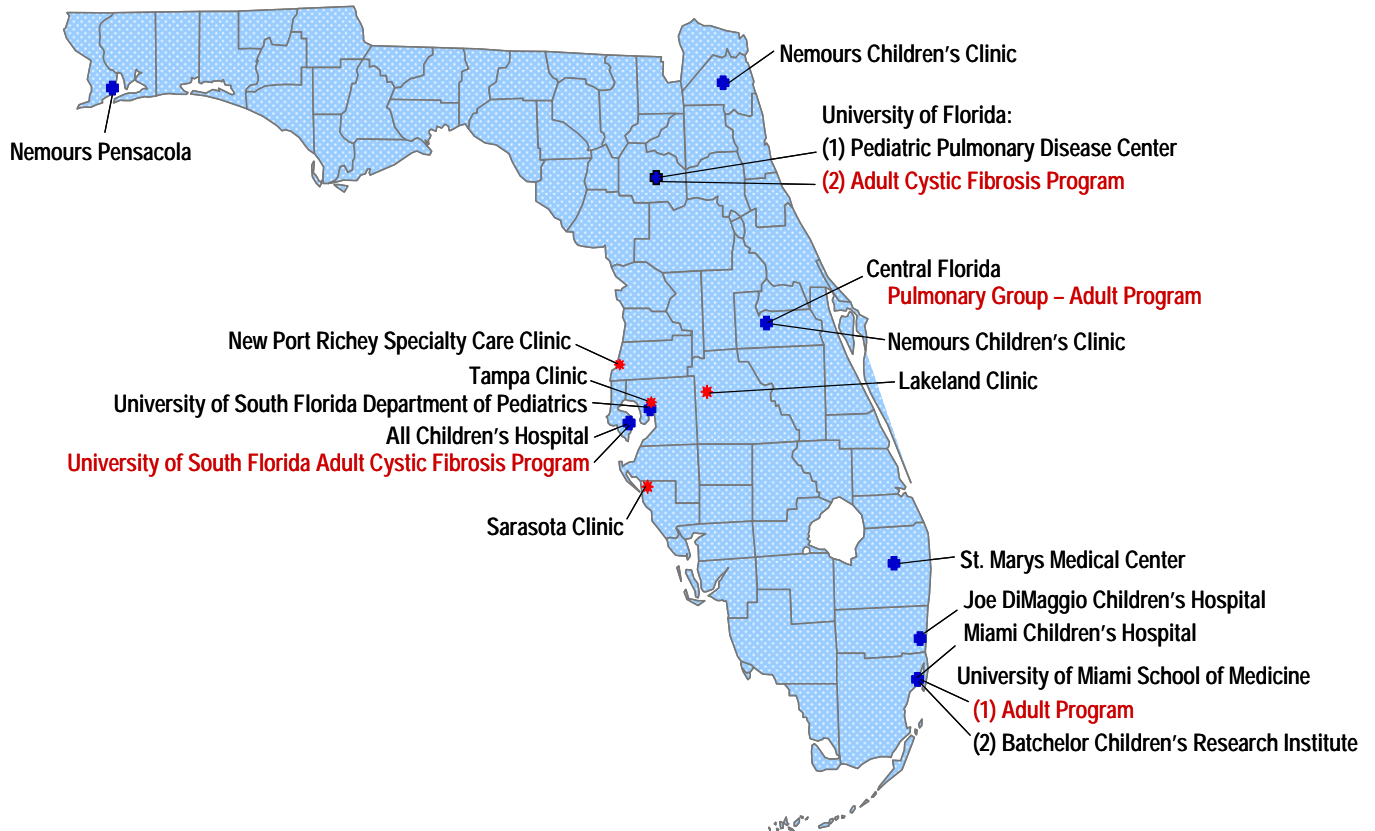
Agency Response————

In accordance with the provisions of s. 11.51(6), *Florida Statutes*, a draft of our report was submitted to the Secretary of the Department of Health for his review and response.

The Secretary's written response is reproduced in its entirety in Appendix C.

Appendix A

Florida's 18 Designated Cystic Fibrosis Care Centers Are Located Throughout the State



Source: National Cystic Fibrosis Foundation.

Appendix B

States Use Different Approaches to Assist Adults with Cystic Fibrosis

States vary in their approaches to providing support to adults with cystic fibrosis. Table B-1 provides a comparison of Florida's program with six other large population states' programs. Eligibility criteria, service coverage, and cost sharing requirements differ among the states. However, in all cases, state programs are the payer of last resort.

Table B-1
Adult Cystic Fibrosis Program Designs Vary Among States

	Eligibility	Service Providers	Cost Sharing
California	<ul style="list-style-type: none"> No financial criteria (i.e., all adults with a diagnosis of cystic fibrosis may participate in the program). 	<ul style="list-style-type: none"> Participants are required to be seen in accredited cystic fibrosis care centers. Providers must accept payment at the Medicaid rate. Program provides administrative case management for the sub-set of program clients enrolled in the state's Medicaid program (MedCal). 	<ul style="list-style-type: none"> Based on income, participants may be required to pay an enrollment fee.
Florida	<ul style="list-style-type: none"> Must meet eligibility criteria for the Adult Cystic Fibrosis Medicaid waiver (income must be at or below 300% of the federal poverty level). 	<ul style="list-style-type: none"> Program currently reimburses for services provided by both Medicaid and non-Medicaid providers. Program provides medical case management to develop care plans that identify needed services, and administrative case management to address eligibility and billing issues. 	<ul style="list-style-type: none"> No cost sharing expectation.
Michigan	<ul style="list-style-type: none"> No financial eligibility criteria. 	<ul style="list-style-type: none"> Participants can be seen by any medical provider, with the approval of program doctors. 	<ul style="list-style-type: none"> Participants with incomes above 250% of the federal poverty level share in the cost of services.
New York	<ul style="list-style-type: none"> Must <i>not</i> be eligible for Medicaid. 	<ul style="list-style-type: none"> Providers must be part of the state's Medicaid provider network. Program relies on local physicians and cystic fibrosis care centers to identify needed services. 	<ul style="list-style-type: none"> Participants contribute 7% of their income to help pay for the cost of their care.
Ohio	<ul style="list-style-type: none"> Financial eligibility is examined on a case-by-case basis. 	<ul style="list-style-type: none"> Treatment is provided at the state's accredited cystic fibrosis care centers. 	<ul style="list-style-type: none"> Participants are required to share some costs based on their ability to pay.
Pennsylvania	<ul style="list-style-type: none"> Income must be at or below 300% of the federal poverty level. 	<ul style="list-style-type: none"> Medications are provided through Pennsylvania's "First Health" managed care program. Other providers must be approved by the program. 	<ul style="list-style-type: none"> The program covers all costs not covered by primary insurance for persons with incomes below 185% of the federal poverty level. Persons with incomes between 185% and 300% of the federal poverty level must share costs on a sliding-scale basis.
Texas	<ul style="list-style-type: none"> There are asset limitations and income must be at or below 200% of the federal poverty level. 	<ul style="list-style-type: none"> Program has a panel of approved providers. 	<ul style="list-style-type: none"> No cost sharing expectation.

Source: OPPAGA compilation of information provided by the National Cystic Fibrosis Foundation.

Appendix C



Jeb Bush
Governor

M. Rony François, M.D., M.S.P.H., Ph.D..
Secretary

February 3, 2006

Mr. Gary R. VanLandingham
Director
Office of Program Policy Analysis
and Government Accountability
Room 312, Claude Pepper Building
111 West Madison Street
Tallahassee, FL 32399-1475

Dear Mr. VanLandingham:

This letter is in response to your January 23 correspondence regarding the preliminary and tentative findings of your report entitled; "Adult Cystic Fibrosis Program Design Should Be Reconsidered." The agency's response to your findings and corrective action plans and recommendations are enclosed.

We appreciate the work of your staff, and we will diligently pursue appropriate resolution to the findings. If I may be of further assistance, please let me know.

Sincerely,

/s/

M. Rony François, M.D., M.S.P.H., Ph.D.
Secretary, Department of Health

MRF/kir
Enclosure

Adult Cystic Fibrosis Program Design Should Be Reconsidered

<i>Finding</i>	<i>Recommendation</i>	<i>Management's Response</i>	<i>Corrective Action Plan</i>
<p>10 1 The Adult Cystic Fibrosis Program's design maybe outdated and does not consider changing conditions such as the emergence of adult clinics within cystic fibrosis centers, and the availability of new opportunities for funding program services through a Medicaid waiver. Further, once operational, the Medicaid reform initiative authorized by the Legislature in the December 2005 special session make have an effect on the program.</p>	<p>Given these changes, we recommend that the Legislature reassess the program's design and determine whether it should be changed to better address current conditions. The Legislature may wish to authorize the Department of Health to conduct an assessment of the needs of adults with cystic fibrosis, identify potential options for addressing the identified needs, and present the 2007 Legislature with program re-design alternatives.</p>	<p>Concur that program's design should be reviewed. However, concerned that the review not be conducted using limited existing program funds, and that the review and reporting timeline as proposed is not realistic.</p>	<p>If funded/projected timelines 2008 deadline: DOH develops and issues RFP Responses reviewed and vendor selected Contract developed and executed Statewide assessment methodology developed Statewide assessment conducted Data analyzed and draft report completed Report reviewed/approved by DOH Recommendations presented to FL Legislature</p>

The Florida Legislature

Office of Program Policy Analysis and Government Accountability



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- [Florida Government Accountability Report \(FGAR\)](#) is an Internet encyclopedia of Florida state government. FGAR offers concise information about state programs, policy issues, and performance.
- [Best Financial Management Practices Reviews of Florida school districts](#). In accordance with the *Sharpening the Pencil Act*, OPPAGA and the Auditor General jointly conduct reviews to determine if a school district is using best financial management practices to help school districts meet the challenge of educating their students in a cost-efficient manner.

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