



The Florida Senate

Interim Project Report 2002-205

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Committee on Children and Families

Senator Durell Peaden, Jr., Chairman

CHOICE AND CONTROL PILOT PROJECT FOR PERSONS WITH DEVELOPMENTAL DISABILITIES

SUMMARY

Section 10 of chapter 99-144, Laws of Florida, directed the Department of Children and Family Services to establish a consumer-directed, choice-based pilot program for providing services to persons with developmental disabilities. The law required the establishment of at least one but no more than three differently structured pilot programs to test a payment model in which the consumer controls the money that is available for his or her care. The pilot programs are repealed on July 1, 2002, and prior to that date, the Department of Children and Family Services must report to the Legislature regarding their progress and the pilot programs must be reviewed by the Legislature.

The choice and control pilot projects should be repealed on July 1, 2002. Funding for the pilots was eliminated during Special Session C which will result in a cost savings of \$851,964 in recurring General Revenue for FY 2001-02. By June 30, 2002, the department plans to transition all 143 persons currently receiving services under the pilots to either the Robert Wood Johnson consumer-directed care research and demonstration project or the DS/HCBS waiver.

No formal evaluation has been completed of the client directed care concepts currently being piloted under the choice and control pilot projects or the Robert Wood Johnson consumer-directed care research and demonstration project. It is recommended that evaluation results of those pilot programs be submitted to the Legislature that describe any client directed care models that have proven to be cost efficient and programmatically feasible.

(department) serves people with developmental disabilities including mental retardation, autism, cerebral palsy, spina bifida, and Prader-Willi syndrome. One goal of the Developmental Disabilities program is to increase choice and control for consumers and family members to improve the quality of life for persons with developmental disabilities. Many consumers and family members believe that greater empowerment and spending flexibility would improve quality of care and client satisfaction as well as enhance cost efficiencies. If given the opportunity to make more of the decisions regarding services, consumers and family members believe that they would be able to purchase only those services necessary, in appropriate quantities, and from providers whom they trust.

Services to persons with developmental disabilities have evolved tremendously over the last decades. Ninety percent of the individuals served today by the Developmental Disabilities program reside, not in institutions, but with their families or even in their own homes. Seventy-three percent of the persons served in the community are on the Developmental Services Home and Community-Based Services (DS/HCBS) waiver, which results in the federal government matching state expenditures for services for those persons at a 45 percent state, 55 percent federal expenditure ratio.

The purpose of the DS/HCBS waiver is to promote and maintain the health of individuals with developmental disabilities through the provision of medically necessary supports and services that will help the individual live in the community and avoid the necessity for institutional placement. Waiver services may only be provided when the service or item is medically necessary. The district Developmental Disabilities program administrator or designee makes the determination of "medical necessity" for each requested service or item. Each individual selects a

BACKGROUND

The Developmental Disabilities program within the Department of Children and Family Services

waiver support coordinator who assists in: identifying and selecting services to receive; developing a plan for those services (support plan); selecting the providers of services; and arranging for the services. Services must be identified in an individual's support plan and cost plan (plan of care) and be approved by the district Developmental Disabilities program office. Most community-based services for the developmental disabilities program are delivered by the private sector, both non-profit and for-profit organizations, and include services such as support coordination, personal attendant services, respite, supported employment, adult day training, companion, and dental services.

In the redesign of the Developmental Disabilities program, the 1999 Legislature directed the department to establish a consumer-directed, choice-based pilot program for providing services to persons with developmental disabilities (section 10 of chapter 99-144, Laws of Florida). The only instruction provided to the department by the Legislature was to "establish at least one but no more than three differently structured pilot programs to test a payment model in which the consumer controls the money that is available for his or her care." General revenue funds to operate the pilots were allocated from the lump sum appropriated in the FY 1999-2000 General Appropriations Act for the Developmental Disabilities program.

METHODOLOGY

In order to obtain information about the planning, implementation, and evaluation of the choice and control pilot projects, several meetings were held between staff from the Senate Committee on Children and Families, Senate Appropriations Subcommittee on Health and Human Services, and the department's Developmental Disabilities Program Office. Senate staff also reviewed numerous documents which included the status report of the choice and control pilots submitted to the Legislature by the department on December 1, 2000, and on December 1, 2001. Discussions were held with staff from other agencies such as the Agency for Health Care Administration.

FINDINGS

Choice and Control Pilot Program

District 1, District 4, and a portion of District 2 (Bay, Gulf, Gadsden, Leon, and Wakulla counties) were selected by the department as implementation sites

for the choice and control pilot projects. The differences among the individual pilot projects pertain primarily to the manner in which services are coordinated, the assistance offered for planning purchases, and whether or not the participant is receiving services under the DS/HCBS waiver. The following fundamental elements and practices are common to all three pilot projects:

- Participants and families are empowered to make more decisions regarding their care and also bear greater responsibility for making these decisions than under the DS/HCBS waiver.
- Participants and family members manage the dollars allocated for their care making purchases or selecting the services that will enable them to remain as independent as possible in the community.
- Participants may choose to purchase services which best meet their needs from a variety of providers including formal providers, independent workers, neighbors, family members and friends. Unlike the traditional system, those providing services are not required to be certified by the Medicaid program. Participants can arrange for traditional agencies to provide services or can hire and supervise their own workers—actually becoming employers. They are responsible for selecting providers, negotiating rates, and ensuring sufficient quality.
- Participant's initial purchases must fit within the project's flexible purchasing guidelines which are designed to encourage wise spending, support health and safety, and guard against fraud.
- A department area coordinator is identified in each of the three participating districts who is responsible for the implementation and monitoring of the pilot projects as well as providing training to participants on every aspect of the pilot.
- Participants are responsible for ensuring that their expenses for services stay within the allotted budget, approving payment to providers, and ensuring that payments are made. An approved bookkeeper under contract assists participants with these responsibilities and with meeting state and federal requirements regarding the employment of workers.
- Participants sign an agreement with the

department that specifies the terms and conditions of purchasing and controlling their developmental disabilities budget. A purchasing plan is completed and signed by the participant or their representative and by the department's area coordinator that specifies service goals and needs, persons who will be hired to perform services, frequency of services, monthly cost units, monthly cash needs, natural community supports, and emergency backup plans.

- Funds for purchasing their services are accessed through the bookkeeper. Each month the district area coordinator submits a list of the approved services to a bookkeeper for each participant. The bookkeeper pays for services in accordance with purchasing plans, timesheets, and invoices. The bookkeeper reviews all monthly invoices to determine if there are any inconsistencies with the approved purchasing plan.

The Department utilized \$3.1 million from the lump sum appropriated in the FY 1999-2000 General Appropriations to serve 152 persons (average cost of \$20,099 per participant). Initially, the department planned to serve 300 persons in the pilot projects for an average cost of \$15,000 per person with a total budget of \$4.5 million in General Revenue. Because the cost plan averaged \$19,000 per person, the department reduced the number of clients participating in the pilots.

Robert Wood Johnson Consumer-Directed Care Project

Since 1999 Florida has been a participant in a 5-year consumer directed care research and demonstration project to evaluate an alternative method for meeting the long-term care needs of frail elders and adults and children with disabilities. This project is funded primarily with Medicaid waiver funds that are matched with state general revenue. The Robert Wood Johnson Foundation is funding the evaluation of the demonstration project. The project serves approximately 2,179 persons with developmental disabilities.

Participants in this research project receive 92 percent of the funding they had previously received from the state and manage the dollars allocated for their care to make purchases which will enable them to remain as independent as possible in the community. Consumers

select representatives (caregivers, family, etc.) to assist in the management of their care and in purchasing the most appropriate services from a variety of providers including formal providers, independent workers, neighbors, family members and friends. A wider array of services, supports, and providers are available than on the Medicaid DS/HCBS waiver. However, as in the waiver, purchases must be for purposes of long-term care. Purchases are reviewed by the district office to determine whether they meet purchasing guidelines.

The Robert Wood Johnson consumer-directed care research project uses a consultant service which is an alternative to traditional support coordination. Consultants provide training and support for consumers who assume more responsibility for directing their own care. Consultant responsibilities include providing training to participants and representatives; encouraging and supporting participants and representatives in making independent choices about services, purchases and workers; discussing the satisfaction of the quality of services being purchased; monitoring spending; and answering questions or providing technical assistance in resolving problems. Otherwise, participants themselves determine the set of services that are received, find providers and negotiate rates, ensure the services they receive are of sufficient quality, and either arrange for bill payment using a bookkeeper or receive cash and pay bills themselves using a dedicated account. Enrolling new clients in this project will cease on June 30, 2002, and this special Medicaid waiver expires October 8, 2003.

Differences Between Pilots/Evaluations

The department reports that through the choice and control pilot projects and the Robert Wood Johnson consumer-directed care research project, a total of 10 different models of consumer-directed care are being tested. Eight of these models are being tested in the choice and control pilot project and include methods for service coordination, budgeting, and incentives for wise spending. The major differences between the choice and control pilots and the Robert Wood Johnson project are: 1) source of revenue, and 2) use of broker or consultant (optional for choice and control).

The department anticipates that the data collected on these models will enable them to examine cost effectiveness as well as the ability of the models to sustain positive client outcomes on a long term basis.

The department's status report of December 1, 2001, reports that because data collected thus far on the choice and control pilots are limited, it is not possible

to determine if the pilot projects have been successful in achieving cost control measures or programmatic goals. Twenty-nine percent of the clients have received services for 9 months or less and there have been delays in collecting data on client spending. The status report states that the average monthly expenditures increased by 26 percent from \$1,274 to \$1,615 for a sample of clients participating in the pilots. Results from a client survey and results from focus groups held with participants support that “participants prefer choice and control over providers; have improved flexibility of services; and have more autonomy.” The next evaluation report of the choice and control pilot projects is due to the department from the School of Social Work at Florida State University in March, 2002.

According to the Agency for Health Care Administration, there have been no preliminary results or feedback from Mathematica Policy Research, Inc., the national research group that is conducting the evaluation of the consumer-directed care pilot projects in three states--Florida, Arkansas, and New Jersey. The evaluation of Florida’s project will be included in the evaluation of all states participating in the special Medicaid waiver and the report may not be completed until 2005.

It is imperative that the Florida Legislature be informed as to the final results of all evaluations of consumer-directed care concepts. Florida’s Office of Program Policy Analysis and Government Accountability (OPPAGA) stated in their 1999 performance review, *Home and Community-Based Waiver Systems, Controls Should Be Improved*, that some research indicates that not all clients with developmental disabilities benefit from consumer-directed service systems. OPPAGA points out in this review as well as in their Justification Review of the Developmental Disabilities program published in November, 2000, that community-based services must be delivered by providers in the most cost effective and efficient manner, assuring that service or cost plans are developed and services are delivered that meet the client’s individualized needs.

Funding for the choice and control pilots was eliminated during Special Session C which will result in a costs savings of \$851,964 in recurring General Revenue for FY 2001-02. The Department plans to transition all 143 persons currently receiving services to one of the Medicaid waiver programs, either the consumer directed-care research and demonstration project or the traditional DS/HCBS waiver by June 30, 2002. The policy decision to transition these clients to the DS/HCBS waiver will result in maximizing federal funds.

It is recommended that the department and the Agency for Health Care Administration submit a report to the Legislature summarizing the results of the final evaluations of the choice and control pilot projects and the Robert Wood Johnson consumer-directed care project and specifying those client directed practices, if any, that have proven to be cost efficient and programmatically feasible.

RECOMMENDATIONS

The choice and control pilot projects should be repealed on July 1, 2002, as specified in section 10 of chapter 99-144, Laws of Florida.