



State of Illinois  
Department of Human Services

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# Spousal Caregiver Demonstration Project

Presented Pursuant to *Public Act 96-0351*  
March 1, 2010

## **Overview**

Public Act 96-0351 was introduced as House Bill 39 during the 96th General Assembly. This measure, a joint initiative of Representative Donald Moffitt and Senator David Koehler, was introduced after both members became aware of individuals in their communities who were providing extraordinary care to their spouses with disabilities. Once passed, the final measure provides for a spousal caregiver demonstration project under the Illinois Department of Human Services, Division of Rehabilitation Services, Home Services Program.

As a requirement of the demonstration project, the spouse with a disability must be eligible for services through the Home Services Program and he or she must meet the criteria specific to the demonstration project. The demonstration project is to be operated in selected counties and is limited to serving no more than 100 unduplicated persons. The pilot is to operate for the duration of twelve months and will begin on March 1, 2010. The final report to the General Assembly regarding the pilot will then be issued on March 1, 2011. To enable the General Assembly sufficient time to study the final report and determine the future of the pilot, if any, pilot participants will continue to be served through June 30, 2011. This will also allow all participants to be notified 35 days in advance of termination of the spousal caregiver pilot, if necessary, in order to allow adequate time to arrange alternative services for which they may qualify.

Specific criteria for participation in the demonstration project include customer safety assurances concerning abuse, neglect, or exploitation by the spousal caregiver and the delivery of services by the spousal caregiver. Additionally, the demonstration project includes criteria for determining eligibility, developing service plans, monitoring the customer's health and safety, reimbursement for services, and measuring participant experiences.

The pilot will be funded with General Revenue Funds until or unless it is incorporated in the Home Services Program Medicaid Waivers. The Department hopes, however, to be able to administratively file Medicaid claim for monthly nursing visits which have been incorporated in the pilot as part of its quality assurance plan in an effort to partially offset General Revenue Fund expenditures on the pilot.

## **Development of the Demonstration Pilot**

As customers, disability advocates, and other stakeholders reached out to the Department of Human Services, Division of Rehabilitation Services [DRS] concerning the legislation governing this pilot, DRS began to research the strategies and protocols necessary to implement this significant change within the Home Services Program (HSP). DRS has now responded to Public Act 96-0351 by developing a pilot that meets the demands of the legislation and has incorporated other essential safeguards to increase the likelihood of a successful pilot.

An important consideration in the development of the pilot was the related requirements under Medicaid. DRS collaborated with the Department of HealthCare and Family Services in researching spousal caregiver options under Home and Community Based Services 1915 [c] waivers. At best, minimal information was available to address all issues and concerns related to this multi-faceted pilot. It was determined that only "extraordinary services" may be claimed under a Medicaid waiver, but the criteria must be clearly defined in the waiver application and approved by the Centers for Medicare and Medicaid Services. Since the spousal caregiver option is not currently identified in the three Home Services waivers, the Department would be required to request a waiver amendment in order to obtain Federal Financial Participation (FFP). It was concluded, however, that until the pilot and its analysis had been completed, it is not in the best interests of the Department to pursue this avenue. Therefore, at this time, the spousal caregiving pilot will be funded through the use of General Revenue Funds for all participants regardless of Medicaid status.

During the process of designing the pilot, DRS determined that one county should be selected from each of its five regions to be determined by such considerations as HSP caseload size, size of the community, availability of home health agencies to provide planned quality assurance monitoring, the ability of the local DRS offices to manage the new responsibilities of a pilot, and providing a mix of demographics among the five counties chosen. The resulting selection was La Salle, Knox, Tazewell, Madison and Jackson counties as the pilot sites. The pilot will include all three Home Services Program waivers: the Traumatic Brain Injury Waiver, the HIV/AIDS Waiver and the Persons With Disabilities Waiver.

Outreach material has also been developed to mail to all existing customers in the five pilot counties who may meet the pilot criteria. The data revealed that there are enough customers in these counties if the majorities choose to participate. In addition, the pilot will be available to new customers who are expected to be referred to HSP as a result of the outreach material which has also been shared with local hospitals, disability advocacy organizations, Centers for Independent Living and other human services providers.

The most major undertaking involved in establishing the pilot was the development of policies, procedures and forms to meet the many requirements of the legislation and Medicaid; to ensure the spousal caregiver is qualified to provide the care; to provide quality assurance regarding service delivery; to provide background checks in an effort to better ensure customer safety from abuse, neglect and financial exploitation; and to document the outcomes of each pilot participant. This required extensive changes and additions to existing policies, procedures and forms and involved the participation of many staff as well as input from stakeholders.

### **Implementation Time Lines of Demonstration Project**

Following the comprehensive development activity, the pilot project is being initiated effective March 1, 2010. HSP staff have been trained in assessment of the specific

eligibility for the pilot, the unique considerations involved in service plan development as it relates to spouses being able to provide only “extraordinary services,” and newly created documentation necessary to track participation in the project. Nursing agencies have been contacted regarding their willingness to provide monitoring for quality assurance purposes and have been provided with the required forms and instructions. The DRS MIS unit has modified the current customer case documentation system to enable HSP staff to identify customers as participants in the pilot, to include data collection of all criteria added for the pilot, and to provide a check that the additional criteria have been met. Customers who may be eligible to participate in the pilot project have been identified and outreach has been made to them in anticipation of pilot start up. Customers interested in participating have been encouraged to contact the field offices and it is anticipated that some spousal caregivers may be receiving reimbursement for extraordinary services for the pay period of March 1-15, 2010.

### **Criteria for the Pilot Project**

The Spousal Caregiver Pilot has been created by integrating the specific criteria outlined in PA 96-0351 with additionally developed protocols necessary to protect the health and well being of the customers served by the program.

All customers who seek participation in the Spousal Caregiver demonstration project must meet the Home Services Program criteria of eligibility as outlined in the Illinois Administrative Code 682 (Appendix i). Pilot participants and their spouses must also meet unique criteria designed for the pilot and be willing to accept other conditions concerning service delivery and/or employment prior to accessing services.

A Home Services Program Spousal Caregiver Pilot Fact Sheet has been developed for community outreach efforts and informational purposes. Attached as Appendix ii, it provides fundamental details concerning the pilot that will enable customers and their spouses to make an informed choice when exploring pilot participation. The document is also ideally suited to enable physicians, social workers, vendors and advocates to familiarize themselves with pilot requirements and to inform the individuals with whom they work of this opportunity.

For the purpose of this report, the criteria for participation that is not outlined within the legislation can be separated into three categories: Spousal Employment requirements, Prevention of Abuse and Neglect, and Quality Assurance.

#### Spousal Employment Requirements

Spouses employed as caregivers will be required to have a Caregiver Capacity Certification completed by their physician. This requirement will ensure that the individual has the cognitive, emotional and physical abilities to perform the specified unmet care needs for the disabled spouse. The documentation will also afford the opportunity for physicians to inform the Department of any physical or emotional health-

related concerns that would contraindicate employment as a spousal caregiver. This will potentially reduce Workers' Compensation claims for job-related injuries to customer or spouse as well as risk to customers related to caregiver burnout as a result of the pilot.

Any Certified Nurses Aides, Licensed Practical Nurses or Registered Nurses who are being considered for the spousal caregiver pilot will be denied participation in the event sanctions are identified against their certification or license. Illinois Department of Public Health and the Department of Financial and Professional Regulation websites will be accessed for every vendor with a certificate or license prior to approval for the pilot. Spouses of customers with disabilities that have committed fraud against the Dept of Human Services, Home Services Program, or have convictions of spousal abuse or domestic violence will be denied the opportunity to participate in the pilot.

#### Prevention of Abuse and Neglect

PA 96-0351 includes language reflecting universal concerns regarding the potential abuse and neglect of persons with disabilities. The pilot process requires all spouses who desire payment to spousal care to agree to a background check prior to enrollment. Individuals refusing to comply will be denied participation in the pilot. The Home Services Program will assume all costs of background checks and will maintain the findings in a confidential manner centrally that will not be accessible to field staff or other entities interacting with the customer.

#### Quality Assurance

Every customer participating in the Spousal Caregiver Pilot is required to cooperate with a monthly nursing visit for the duration of the pilot. Licensed Practical Nurses or Registered Nurses from nursing agencies will conduct interviews, complete an evaluation of the health status of the customer, and monitor the quality of spousal care. Monthly reports will be submitted by the nursing agencies when billing for services.

All customers interested in securing paid services through a spousal caregiver must be able to communicate and direct their own care at the time they are enrolled in the pilot. As customer choice is an integral part of the independent living model and a valuable tool in service plan development, HSP will verify that it is the customer's choice to use his or her spouse to provide care in the stead of other care provision options.

Mandatory back-up providers are an essential component to any in-home care quality-based program. Customers are counseled to secure an action plan and resources which may be counted on should an unexpected loss of caregiver suddenly occur. This plan may or may not include paid caregivers but could immediately be relied upon for needed services in an emergency situation. Spouses become ill and may have accidents or other obligations. In order to reduce the likelihood of the premature institutionalization of the customer, staff will work with the customer to develop and document this plan.

## **Next Steps**

DRS has met the initial challenge of designing and implementing the spousal caregiver pilot. Efforts will now turn to finalizing and implementing an extensive data collection system to enable substantive analysis of the pilot from all perspectives and in preparation for completing the final report to the General Assembly. Examples of factors to be included in data analyses are as follows: age of caregivers and related health issues; percentage of existing HSP customers who choose to participate in the pilot; percentage of existing HSP customers who decline participation in the pilot and the rationale for their decision; the effect of spousal income considerations on the decision to participate in the pilot for customers who receive Medicaid and or other public benefits; characteristics of customers who do not meet the pilot-specific eligibility criteria; characteristics of individuals who seek participation in the pilot who are not already HSP customers. DRS will also track data regarding costs including a comparison of pilot participants to comparable non-pilot waiver recipients and the potential budget impact, if any, of projected numbers of existing HSP customers who would choose spousal caregiving if given the opportunity. The final action necessary to meet other requirements within the legislation is monitoring of participant experience. HFS will determine the tool and methodology for surveying a representative sample of participants during the third quarter of the pilot. Findings will be included in the joint final report to the General Assembly. A final effort will be an attempt to assess the potential for increasing applications to the program if the pilot is expanded and continued. It is believed that these analyses will assist the General Assembly in determining the cost benefit of continuing and/or expanding this program once the pilot is completed.



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