

## **CAREGIVING ISSUES**

# ***GEMA G. HERNÁNDEZ***

**TELLING THE TRUTH**

**MADE THE FORMER SECRETARY OF THE  
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A "CONTROVERSIAL" ADVOCATE**

Here is a selection of her incisive articles in her struggle to defend the rights elders.

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## CONSUMER DIRECTED CARE IN DANGER OF EXTINCTION

Gema G. Hernández

Consumer Directed Care began in nation in 1998 and in Florida in the year 2000. Since the beginning of the program it has been the most effective program in improving the quality life of the elders and their caregivers. It is a program that makes sense not only because it allows the elder and/or the caregiver to direct his or her care by selecting the services and providers they like, but also because it saves money. The program has been in such demand that it makes me wonder why it has not been extended to the middle class families and why there are still areas in the country where it is totally unknown to the public.

In times when the financial resources are very limited we need to explore ways to serve as many elders as possible and do it in a way that will not compromise their well being. What better way to accomplish both goals than by allowing elders to choose the services and the programs they need to be kept at home. While Consumer Directed Care is an ideal program to help families manage their care, the program was designed not necessarily to help Medicaid recipients, but to contain costs. In government language the program was and is a budget neutral program. The hope was that the program will eventually become a cost avoidance program for the Medicaid budget. This means that the success of the program was going to be based solely on the amount of dollars it saves the Medicaid budget.

With more individuals becoming frail and living longer with frail conditions that require around the clock care, more resources are needed to keep them at home, therefore, the original cost savings anticipated by the program designers is not being realized, and this is making government officials think twice about continuing the program. It is very possible than even though thousands of elders and individuals with disabilities have improved their quality of life because of this program, Consumer Directed Care may be cancelled because the financial bottom line, not the human bottom line has not been reached and the expected savings are no longer there. This is a sad commentary in the way our elected officials and bureaucrats do business because they continue to balance the federal and state budgets on the backs of frail and vulnerable people.

Before the ax falls on another good program we should become involved in the fight to save the Consumer Directed Care and all the other Medicaid waivers programs in existence today. We need to convey to our elected officials that Consumer Directed Care should be part of a legislative mandate in each of our states. We need a legislative mandate that allocates state funds under the framework of the consumers' wishes and direction. Once that is accomplished we should also need to make sure that the federal Medicaid program makes Consumer Directed care a permanent Medicaid waiver program and not just a research project. Research projects have their own set of rules that are not necessarily the best rules for the caregivers or the frail person. The success or failure of programs for frail persons should not be based on how much money the government saved but in how much the program has increased the quality of life of participants. If money is saved, then it should be an added value to the equation, but not the only value.

Consider the following:

Some families are not earning enough money to survive, some families cannot afford health care, some families have given up their jobs to take care of their loved ones at home and some families are not paying into the Social Security system. Under the present system, these families are in danger. They are mortgaging their future and the future of their children. Consumer Directed Care offers the option to pay family members a salary similar to the salary they pay now to private agencies for the work they do. If family members are able and willing to perform certain services they receive payment and a contribution to their Social Security. Paying family members at the lowest range of the payment scale saves money because family members provide more hours of services than an agency does for the same amount of money. In addition, sometimes the differences between the lowest cost and the next lower cost agencies charged to perform those services exceed \$2.00 dollars per hour. And \$2 dollars per hours times millions of hours of services represents a real savings. But this type of savings comes within the human aspect of the equation.

Some families are not able or willing to provide services themselves but they would like to choose the agency or individual worker who in turn will provide services to their loved ones. When families choose agencies and workers we discover they also pay attention to the unit cost, and in the majority of cases, select those individuals or agencies with the lowest cost, but the same quality of services. This is what having choices is all about, the ability to select the best providers for our situation or the most appropriate services for our condition. I have known of so many elders that are not happy with the services they receive but because they are not able to change agencies they have no choice but to accept those services. If an agency is not providing the services the way a frail person wants or desires, elders or caregivers should have the right to change providers, no questions asked. After all, the service delivery system exists not to protect agencies or to guarantee their existence but to protect and serve elders. Having the power of changing agencies should be the right of the consumer in any government funded program, not left to the discretion of an agency director, whose bottom line is to increase his or her budget, not the well being of the frail person.

Consumer Directed Care provides not only control and higher satisfaction, but actually avoids the following cost: 1.195 million in case management services, 3.949 million in homemaker services, 3.917 million in personal care and 3.782 million in transportation costs. Add to the avoidance of the above costs another 3.251 in home delivered meals and the cumulative cost avoidance figures reach 16 million in one year. This is an impressive amount not to be easily discarded. These figures are based in the cost of services in Florida in 2000 with a total of 3,000 individuals in the program. The savings may vary in other areas of the country and with more or less individuals in the program.

This 16 million generated by avoiding a higher cost to be paid to agencies could be used to provide services to 2,500 to 3,000 more elders. It is a win-win situation for the elders, for the families and for the community at large. In a time when the federal government is considering eliminating the Medicaid program as it exists today and making Medicaid a Block grant to the states the warning has been given. It is up to us to fight for the preservation of those programs and services that make a real difference in people's lives.

## **CASE MANAGEMENT CHALLENGES**

*A new Case management proposal will cost more and will provide fewer services to elders.*

Gema G. Hernández, Secretary Elder Affairs (1999-2001)

The idea of capitating the cost of case management services is not new. It has been around since the days of Secretary Bentley Lipscomb. Despite extensive and expensive analysis that lasted one year by a famous accounting firm, the capitation idea has never generated a higher quality of life or more services for elders.

There are several reasons why the capitation of case management costs as a way to save dollars from the state and federal budgets is an Urban Legend. First, Community Care for the Elderly programs have managed to include in the hourly cost of case management services a number of expenses that are not truly related to the activity of case management services. A report by a legislative watch dog OPPAGA (2001) and a memo from me to the Governor (11/14/2000) lists all the unrelated expenses and asks for those expenses to be excluded from the hourly cost. To my knowledge, no one has bothered to investigate the numbers not even the new consultant hired last year to come up with new contract language and new numbers.

Negotiating a capitated rate per hour of case management services before first “cleaning” the non related expenses built into the hourly unit cost will do a disservice to Florida’s elders because more financial resources will go to pay for an activity that is full of unrelated expenses. Trimming the fat needs to come first, but the trimming should be done by an outside party like OPPAGA; otherwise, the capitated rate will be a well orchestrated compromise to give more money to friendly agencies while telling legislators this is a cost saving measurement.

Second, unless state government also capitates the maximum number of hours per elder consumer that case management agency can bill their respective Area Agency on Aging. The case management entities have already figured out a way to over bill for hours. If they are not able to fatten the cost they will definitely fatten the hours. This creates a financial windfall for the agency and not for the frail elders.

Three years ago we heard testimony of a case management entity that evaluated the effectiveness of their case managers not by the number of elders that were still in the community a year later or by demonstrating increases in their quality of life but by the total number of hours they billed both the Medicaid and the state Community Care for the Elders Program. One of these agencies was so successful in making sure their case managers met their monthly “case management quotas” that their case managers were billing the equivalent of 47 hours per week just doing case management services and nothing more. One wonders 47 hours of just doing case management services with a work schedule of 8 to 5, 5 days a week leaves no room to do anything else. One also wonders what 47 hours per client per week times an inflated capitated cost can do to the state budget. My humble prediction is that it could absorb the entire Department of Elder Affairs budget in just seven months, leaving no money to pay for other services like personal care, home delivered meals, home health or adult day care.

Third, capitation goes against market forces. If we truly want to control costs, open the process to competition. For example, allow the senior centers to also become case management entities. Have more than one case management agency providing services to Volusia, Flagler and St John's Counties or any other county for that matter. Open the process to faith-based entities and allow intergenerational organizations or Alzheimer's associations to take a shot at the funding.

In a budget year that appears to be challenging we need to make sure we don't create the equivalent of an Enron accounting practice in our state system. Aggressive accounting could precipitate a budget fiasco sooner rather than later. The idea of capitation without verification for justifiable costs is setting the stage for more demands for the shrinking dollars. Add the fact that there are just a limited number of case management entities „allowed%o to provide this service exclusively. The intriguing part of this proposal is that when elders and caregivers are asked which services they need and value the most, case management is not listed among the top ten favorites. As a matter of fact, many elders and their caregivers would rather use the money the Area Agency on Aging gives these providers to buy diapers, obtain home delivered meals or transportation instead of case management.

Let us ask our elected officials to study the issue before we jump into a sinking ship head first. Cheers!

## **ELDER ABUSE ON THE RISE**

Gema G. Hernández.

The safety and the security of our elders, disabled adults and children should be one of the most important priorities of government. After all, if there is a role for government to play, it is in making sure all its citizens are safe and protected. Keeping our elders, disabled adults, children and their caregivers safe is a multi task approach that starts with the individual family, but on a broader level it requires the involvement of a variety of agencies and programs. Creating a safe environment for our families begins with education and with knowledge of what constitutes abuse, neglect, abandonment and financial exploitation and how we can prevent those things from happening to our loved ones.

To truly address abuse the first thing we need to acknowledge is that abuse, neglect and exploitation could be committed by a person or an institution inside or outside the individual's family setting. While the total number of abuse cases are not known, the assumption has been that most cases of abuse take place at home is not necessarily true, but leaves the perception that the majority of abuse cases are done by a family members. This assumption is misleading and immediately stigmatizes family caregivers, who are trying to do their best for that frail individual. It is true, some cases of abuse, neglect, abandonment and exploitation are committed by family members; but it is also true that any and all forms of abuse is not confined to family caregivers or confined to the victims' home.

The problem that I see is that if the nation passes the National Elder Abuse Law still thinking that most of the cases are committed at home by family members, this will present an unfair bias to the understanding, investigation and reporting of abuse. To make the National Elder Abuse Law a powerful and protective legal instrument it must include explicit sections on institutional abuse, on abuse committed by agency workers, and on abuse, neglect, or exploitation committed by a for profit businesses. It must have a section that addresses caregivers that are being abused while performing that role.

I understand it is more difficult to document or to prove the non family related cases of abuse for a number of reasons, but the protection of our elders, disabled adults and children is paramount to our society. To make the law effective the first step is to include in the act a definition of abuse, neglect and exploitation that is broad in nature; inclusive of all possible scenarios and situations.

Secondly, it is important that only one database be used to record all forms of abuse from all sources, family, institutional, business, etc. Now in some instances, if the abuse is committed by an agency, it is recorded under one category; investigated and penalized under different rules. Some states do not include financial exploitation done by a contractor or a company among elder abuse cases and only record financial exploitation cases committed by a family person. Other states exclude the investigation and findings of nursing home ombudsmen's reports from the traditional abuse cases. The ombudsmen's reports are handled outside the criminal justice system unless a family member brings criminal charges. In the majority of these cases, the abusing

entity gets financial penalties, penalties that are not openly publicized or known, penalties that may be paid to a government agency, not to the family member or to the elder.

One reason the abuse, exploitation, neglect and abandonment committed by non family members are less documented is due to the hesitation of authorities or agencies to believe the testimony of the frail person or the caregiver versus the testimony of a legal guardian, administrator of a facility or business person. The more we understand what constitutes abuse, neglect or exploitation, the more cases will make it to the final phase. Knowledge is power, and we need the knowledge to properly identify, report, and assist in the investigation of these cases. This is why it is so important for caregivers to be on the alert and to properly report abuses committed by non family members against their loved ones. If we don't report abuse it is very possible that the passage of the National Elder Abuse Law will have a slight tendency to concentrate more on the case of family abuse than intuitional abuse, placing caregivers in jeopardy if their good intentions are misinterpreted by a government agency.

Assisted Living Facilities have almost no cases of abuse, exploitation or abandonment. It is not clear whether there are no cases because they truly do not exist or whether the events are handled internally and never reported to the police, events like petty theft or the disappearance of property from the resident's home. Perhaps the limited financial value of what was taken; anywhere from \$100 to \$500 discourages any further investigation from the authorities. After all, the law doesn't measure the emotional value the items, just the financial one.

In cases when the abuse is committed by a non family member, the victim may feel embarrassed that he or she has been the victim of a financial scam or the victim of an identity theft. On other instances the victim may not know his or her rights and doesn't know the appropriate office or government entity to call. Some victims and caregivers may fear further retaliation by the perpetrator, especially if the perpetrator is an agency or a worker the victim has grown attached to. This could also involve fear that they may lose the services they are presently receiving. Some elders and their caregivers may have no other place to go, and moving to a new nursing home or Assisted Living Facility may be too emotionally traumatic, so they keep quiet. Or the agency could be the only agency in town providing those services, so they see no point in reporting the abuse, neglect, abandonment or exploitation.

I have found that caregivers and their loved ones do not report abuse because they don't know she or he has been the victim of abuse. The truth is that the great majority of caregivers are also victims of abuse. They are victims of abuse when agencies are asking them to do more than they are capable of emotionally, physically or financially being able to do. It is therefore important that if this country finally passes the National Elder Abuse Act there should be a section to protect the caregivers, those women and men that give it all to provide for the safe keeping of their loved ones. They deserve protection from unscrupulous parties.

They know the obvious cases of financial exploitation either through predatory lending, telemarketing, home repairs and remodeling schemes, but they may not know the less obvious cases like when are being told that they need a new roof or a new air conditioner when in reality all they may need is to repair, not replace the entire system. Other elders are buying services and products they really don't need but they are being told they needed. Other cases involve products

sold to the elders that don't do what they are supposed to do. Some schemes involve long term care insurance, reverse mortgages and identity theft. They can all take away the financial safety net elders have built for their retirement. This is why the criminalization of elder abuse must be the third step to be addressed in the National Elder Abuse Act if we want our elders to live in a safe environment.

Individuals and organizations that prey on the elders are counting on the fact that the elderly victim, the disabled and their caregivers would not press charges for fear their intellectual competence would be questioned. In other cases, the caregivers blame themselves for not intervening on time, and therefore the guilt prevents them from reporting the incident. In cases where the elderly person, the disabled person and/or the caregiver decides to press charges, the abuser's first line of defense is to suggest the person is confused and allege that the confusion is associated with old age or disability.

Sometimes not knowing what is normal aging and what is not normal aging provides the framework, which policemen, attorneys, ombudsmen, and protective service workers use to not pursue the case. The myths that exist about aging contribute to a number of reports not being filed. This is why it is so important to educate the public as to the myths and realities of normal aging.

I am proud that during my tenure as Secretary for the Department of Elder Affairs, the Elder Justice Center was created, and under the leadership of Judge Sexton, became a national model. I am happy that subsequent to the success of the project, legislation was passed which led to the expansion of the Elder Justice Center to other parts of Florida. This, coupled with the first Domestic Violence Shelter with an elder component for elder abuse in St. Augustine and the multilingual elder abuse informational campaign with the Tallahassee Senior Center, were solid beginnings to build the safety net our elders and their caregivers need to feel protected. But this effort must not die; it should continue regardless who originated the effort.

Keeping our elders, disabled adults and children safe means teaching them and their caregivers about their rights. We also need to offer them a place where they feel at ease reporting abuse. We need to make sure agencies do not retaliate against caregivers that are trying to protect their family members. Keeping our elders, disabled adults and children safe means having more than just one agency providing services or one option when it comes to nursing home or adult day care facilities or the provision of other services. Having alternative places to live and alternative providers of services is in itself a form of prevention. Safety begins at home, but since the home is now open to other individuals, it is critical that we make sure laws are in place to properly address abuse, exploitation, abandonment and neglect.

## **SUCCESS IS MEASURED ONE CAREGIVER AT A TIME**

By Gema G. Hernández

For eighteen years it was my privilege and my honor to serve as a caregiver for my parents. This experience changed my life forever and gave me a new way, a unique way of looking at things. I am sad and glad I don't have this responsibility any more. Sad because it means my parents are no longer with me and I miss them a lot, some days more than others. Glad because the type of services required to maintain their quality of life despite their frailty and the support I needed to maintain balance in my life, is no longer available. Keeping my parents at home or at least in the least restricted environment, like an Assisted living facility, was a choice when they were alive. Things have changed and that choice may not be available for caregivers at this time.

The Caregivers' Initiative program is still a secret for the majority of caregivers. First, they have never heard of the Initiative, secondly the initiative has gone primarily to maintain the same type of services that existed before with very few innovations introduced to try new ways to alleviate the burden. Thirdly, the number of caregivers waiting to receive services and financial assistance has increased at a time when some of them have lost their jobs.

Perhaps the problem exists because the way government defines success is different from the way caregivers define success. The two groups interpret success differently. If success is defined by the fact more people, corporations and the general public know and understand the role of the caregiver in an aging society, then we have achieved success because society in general is more aware of the challenges facing caregivers. Being aware of the joy and burden of caregivers is one thing, but meeting the challenge they face as they feed, bathe, shop and drive their loved one is another. It is important to achieve consensus as to what constitutes success because the Caregivers' Initiative Program is the benchmark the government will use to measure its effectiveness in the social and human arena. It is also the Bush administration's only program that was implemented under his watch.

Because this is the benchmark the government is using I think it is important to suggest they collect data connected to real day to day needs. As a caregiver I wanted to know the numbers of new caregivers receiving services since the initiative began. I also think it is important to know the increases in the type and the amount of services given to caregivers as a result of this initiative. Where has the money gone in real dollars and cents? Unfortunately, the numbers are not there to objectively confirm the success of the program.

This is especially true when some caregivers are saying that the funding for the Caregivers' Initiative program has replaced, not increased the available funding for a wide variety of in home and community based services. If you add all former program budgets and compare those numbers with what the Initiative has done we discover that the same money or less money has been earmarked for services to help the caregivers maintain their loved ones at home.

As a caregiver I think we need to define success in terms of every single caregiver. When every single caregiver of a disabled child, a frail elder, or a brain injured person receives the financial and physical support they need to keep their loved-ones in the most comfortable environment possible, we have achieved success. People would say to you this is impossible. It will cost a lot and it will require manpower beyond our present capabilities. Under the present system this may be right. Let us take one example from Florida. Waste and fraud in the Medicaid program and in the community care for the elderly program costs the state of Florida in 2001 in excess of 700 million dollars. Imagine what we could have done with 700 million more from one state alone. Take the 700 from one state and multiply that by 50 states. The amount is unimaginable. And this is without raising one penny in taxes.

Creating a system that is caregiver friendly is possible if government, federal, state and local, begins to

- 1) stop fraud at the provider levels,
- 2) allows consumers to direct the care of their loved ones, and
- 3) and empower the inspector general to be a truly independent agent watching the contracts and the dollars. I think it is time to start a budget campaign similar to the one which focuses on the school program. Let us not leave one caregiver behind. We need to talk at the national level not only about not leaving a child behind but also not leaving one single caregiver behind.

I think it is time to start the Leaving no Caregiver Behind campaign. Because as long as we have one caregiver suffering, in need of help and in need of care we cannot proclaim that the program that was specifically designed to help caregivers is a success. Success is not a state of mind but a real issue with real data and real stories. Success should be measured one caregiver at a time and should not be based on how long the caregiver is able or willing to care for the family member at home, but it should be measured based on the type of services, the cultural competence of the providers and the general well being of both the caregiver and the care recipient.

The more I talk to caregivers the more I am convinced that if we listen to their requests, if we pay attention to their proposals, we will come up with a budget neutral program. Also, the manpower shortage issue will be moot because caregivers will constitute a new pool of workers never before tapped. These should be the core principles of the Caregivers' Initiative Program because it will give more, not less to those in need of care. Providing support to a caregiver can reduce the budget deficit because for the same amount we pay a provider to do the shopping, the bathing and the feeding we can pay a caregiver who in turn will provide 24 hours a day of unconditional love and care.

Yes, success should be measured one caregiver at a time, and until that time, the final assessment is still out there for the only tangible program the Administration on Aging has implemented in the last three years.

## **MY INTERVIEW WITH JEB BUSH**

By Gema G. Hernández

When Governor Jeb Bush interviewed me for the position of Secretary of the Florida Department of Elder Affairs in December, 1998 I told him I was a caregiver. I further stated that my mother was suffering from Alzheimer's disease and that I have dealt with the entire aging service providers from the role of caregiver. My statement to him "I am a caregiver" was meant to define my priorities and disclose my biases. I was putting him on notice that my most important contribution to the job of Secretary would be as a caregiver, not as a political appointee, politician or defender of businesses and agencies. I gave him in those four words "I am a Caregiver" fair warning where my decisions and programs would be focused.

Disclosing where you are coming from is, in my opinion, the ethical and moral thing to do because you are telling the world your values, your biases, and the lenses you will be using to assess different situations. I became a caregiver in 1981 when the issues and concerns of caregivers were kept at home, not discussed in public forums. I became a caregiver when the responsibilities and magnitude of the task was still in the definition stage. We were defining at that time "who was a caregiver and what duties and responsibilities that carried."

Today caregiving is different. For one the rewards and tribulations are openly discussed and more people are willing to disclose the financial, emotional and physical challenges the position requires. The rewards and the burdens of caregiving are interchangeable and up to a point help balance our lives one day at a time. But even though caregivers today have more information they do not necessarily have more support. Even though the information is printed in multiple languages, caregivers are still facing tremendous handicaps because they really don't know how the laws, program policies and program procedures protect them.

As a case in point, a couple of years ago the federal government began implementing the Olmstead Act. This is an Act designed to enforce the delivery of services to our most vulnerable, those individuals that regardless of age are now living in a Nursing Home. Olmstead forces States to provide enough funding to support in a community setting those individuals now living in Nursing Homes that are willing, able and give their consent to move out of the Nursing Home back to the community, if not necessarily back to their homes.

As caregivers we must learn about the Olmstead decision because it could help define what real progress our individual state has achieved in first, complying with the law, and second in enhancing the service options and quality of life of our family member. Few states, and Florida is not one of them, have taken advantage of the President's Freedom of Choice Initiative by submitting a proposal to obtain additional federal funding to comply with Olmstead. Taking advantage of the President's initiative means that your state has written a grant to specifically tackle the diversion of individuals in Nursing Homes back to the community. It means that your state has a plan to begin to provide Medicaid patients with what they to maintain is the highest level possible of performance in a community setting.

Some of us caregivers faced with no services, long waiting lists, inflexible programs and regulations that offer no choice but to place our loved ones in a Nursing Home are getting tired

of waiting for government to look at our situation. Others of us caregivers have given up our jobs giving up not only our family's financial stability by becoming a full time caregiver, but we have also forfeited pension plans, higher social security premiums and future earnings representing an estimated lost of \$640,000 per caregiver in our lifetimes.

The implementation of a variety of Medicaid waiver programs may or may not have alleviated this situation, but without the willingness of government to help families, the existing shortage of services and funding will continue and family caregivers will continue to carry the entire burden in our society.

Learning about laws and policies in place is as important if not more important than learning about just services and agencies, which provide services in our community. Having the law or a piece of legislation on our side that supports family caregivers moves from just being political rhetoric to funding realities. The lack of knowledge of laws and government mandates is our true challenge. This, coupled with our assumption that my loved one or I are not entitled to services, creates confusion and denies us services that are legally and rightfully ours.

An example of how this lack of knowledge affects our ability to receive services can be found in Miami, Florida when last year, in a routine monitoring of an agency, we found approximately 250 Medicaid clients not receiving Medicaid waiver services, but instead receiving a much lower intensity of services under the state's general revenue program called Community Care for the Elderly Program (CCE). The funds to support the CCE program are limited. This translates into less services, less frequency, less hours and less options. We were told the Medicaid clients and the caregivers didn't want to be Medicaid waiver clients and therefore they remain in the lower intensity program.

As a caregiver, this information is of extreme value. Not knowing the differences between Medicaid services, state funded programs and united way funded programs can deny your loved one the type and frequency of services they need. Yes, Jeb, I was, am and forever will be a caregiver, and yes, Jeb, I was, am and forever be a Democrat, a product of the Great Society.

## **PROMISES TO KEEP: OLMSTEAD ACT**

By Gema G. Hernández

Since the passage of the Olmstead Act several years ago caregivers have been waiting for their individual states to implement the mandates of the Act. This responsibility has fallen on the shoulders of units on aging and departments of elder affairs nationwide. Unfortunately, with so many new elected officials coming on board and with so few caregivers aware of the implication of the Olmstead Act, no significant progress has been made to implement the Olmstead Act as mandated by the courts.

The implementation of Olmstead was supposed to be a funding and policy priority, but it has not been. The plan for the implementation of the Olmstead Act is very simple; it provides more funding for community-based services so more frail individuals could be moved from nursing home back to the community and homes they love. Olmstead provided a simple message: More funding to community based programs and less funding to institutional care, more funding to Medicaid waiver programs and more “pilots” under Medicaid waivers designed so families can keep their loved ones at home with the support they need. Support in the form of personal care, home health, meals, senior companions, respite, adult day care and assisted living options.

In Florida the effort has only experienced one brief shining moment back in 2000 when a group of nurses and social workers working for the state aging program evaluated 600+ nursing home residents to see if they could be safely moved back to the community. This heroic effort on the part of the dedicated state workers resulted in 21 nursing home residents being moved back to the community. These 21 nursing home residents were moved back with the consent and blessing of the 21 residents themselves and their families. Jeb Bush, my boss at that time, appeared with me in a press conference declaring victory. He showcased the result of the government workers’ effort in his 2001 State of the State address by mentioning the story of one of the residents.

Of those 21 individuals, one has been in the Nursing Home for approximately 10 years, a second one was a nursing home resident for 7 years and a third one for 5 years, proving that even individuals that have been living in an institution for a long time can be supported in the community with the appropriate services and the appropriate funding. If this was possible, imagine what can be done with those frail individuals that are still at home or residing in an Assisted Living Facility.

This magnificent effort on the part of the CARES units and of the Department of Elder Affairs has been forgotten. While the action we took in 2000 has a tremendous human value, it was also a magnificent Cost Avoidance program. There is no question that the program could be replicated all over the nation if elected officials are willing to make a commitment to support appropriate funding and authorizing new agencies and new services to be part of their aging providers’ network. I mentioned adding new service providers to offer services because the existing service providers’ network has cornered the market with its exclusive contracts, limiting the number of clients they can serve and the geographical areas where these options will be available to caregivers and elders.

This effort faded away in Florida in 2002, and I am not aware of any other state that replicated the effort. It is time to educate our caregivers. The more they know about the laws the better they will be when it comes time to protect the people we love.

If you are a caregiver you need to find out what your individual state did under the Freedom of Choice presidential funding award. Ask for a copy of the grant or request, through your elected official, where the funding went. If your state did not apply for the funding or failed to address this important population, it clearly demonstrates it has no serious intention to comply with the Olmstead Act not now, not ever. Your request to your elected officials should also explore the amount received by your state aging agency under the Caregivers' Initiative Program, most importantly, how your state aging agency used the money to support caregivers in their daily tasks. Some states like Florida are using the money for training, posters, travel for the officials, and billboard ads when in reality the money should go for Respite, Adult Day Care and even diapers.

The caregivers' Initiative was conceptualized under the Clinton Administration with bipartisan support. This administration has changed the focus somehow by showcasing caregivers for their efforts, but limiting the funding when it comes to increasing the number of hours of services they can receive or reducing the waiting list for services. Look between the lines and make sure the dollars are going where they are supposed to go and not to cover other programs and deficits. Olmstead is more than a promise, it is a legal mandate to the states to look at the Nursing Home population and better yet, to reassess that nursing Home population for a possible return to the homes and families they left behind.

## **A CALL TO ACTION**

By: Gema G. Hernández, D.P.A.

Caregivers are the backbone of this society and as such, the country must begin to honor and support their needs and desires. Without caregivers willing to give up their personal lives to keep their loved ones at home, the economic crisis we are presently facing as a country will be much worse and the Medicaid deficit may reach a trillion dollar amount within the year. It makes economic sense to allow caregivers to direct the care of their family members, especially if the family member is not longer able or willing to care for himself or herself and the caregiver is willing and able to take this responsibility. After all, without the caregiver there is nothing that will keep a frail person at home.

It also makes human sense to provide financial assistance to the caregivers. Some of them will need to give up their jobs because employers may not be sensitive to the caregivers' needs or would be willing to allow for the missing days and missing focus. Caregivers should be financially helped if they are willing to provide the services; this way the entire family can financially afford to take care of a frail child or a sick elder at home. However, even though it makes economic and human sense to change the existing policy and to begin to invest in the caregiver and in the family, no government official has taken the lead of faith to change the system. On the contrary, we continue to invest hundred of millions of dollars in supporting and expanding Nursing Home placement while family members watch in horror how their physical, emotional and financial strength begins to disappear.

Why, we may ask, if it makes sense to help families direct the care for their loved ones and even receive payment for what they are willing to do, is our government maintaining a system of care driven not by the consumers, but by the agencies. It is a system of care that gives control and decision making authority to the agencies and businesses and not the person or the family. This system is very expensive, very impersonal and inflexible at a time that we need the opposite. It is my belief that unless we the caregivers of the nation come together to demand with one voice that our loved ones be given the option of direct control of their care, the system will not change and the resources we need to make our family situation more manageable will continue to go elsewhere. It is important to realize that the only power we have is the power of our voices, and if our combined voices are synchronized demanding that our state provides a consumer directed care option this will never happen. It will never happen because we are not part of the dialogue, and negotiations take place at the time of budget allocations where we have no representation.

I am a firm believer in Consumer Directed Care. It is the only mechanism that exists that allows the consumers, this could be the frail person or the caregiver, to choose the providers and to select the best combination of services to meet their unique needs. This is particularly important in the rural areas where consumers may be waiting to receive services, not because the money is not available to pay for services, but because there are not enough workers to provide services to the person. There are not enough workers or agencies willing to transport the individual, to

deliver daily meals or to bathe the patient. In situations like this, it makes sense to hire a family member, and I say, hire, because in some cases the family doesn't have the financial resources to survive without a job. The investment of keeping a family member or a neighbor well will generate a bigger return than any other investment I know. It is a cost effective way to deal with the aging of the population and in meeting the demand for quality care. What we have found is that the family member or neighbor hired to perform the homemaking or transportation or personal care job will be given more than the one, two or three hours of services the worker from an agency will be able to give for the same compensation.

Consumer Directed Care is one of the solutions to the budget crisis we are presently facing. It eliminates some of the administrative costs that are now consuming more and more of our tax dollars. It also caps the cost of providing services because family members are more willing than providers to accept the existing payment system and do much, much more with the same and not ask for a higher reimbursement rate or for increased benefits. Let's face it, now as caregivers we have no benefits, no salary, and no options. We will be happy with just a little support and more control of the lives and dignity of our family.

Maybe the way to go about this is to make sure Consumer Directed Care is not forgotten is to add a Consumer Directed Care option to each of the existing states' laws and to incorporate the Consumer Directed Care program as an integral part of the Administration on Aging's new Caregivers Initiative program. This is our window of opportunity to incorporate in the implementation of the Caregivers' Initiative program at the local level this option. It really meets the expectations and dreams we have as caregivers when we hear of the initiative. The Caregivers' Initiative at the federal level was designed to support new ideas and new efforts to make the life of the caregivers easier. So far the funding for the local programs has not met the expectations. What I have seen is that the programs that are getting the financial support are not really introducing new ideas but just expanding some of the already tested concepts like additional Respite hours to cover weekends and nights, more regional conferences, or adding multilingual support groups. All these are good expansions, but they are not truly focusing in the intent and purpose of the Caregivers' Initiative. Consumer Directed Care can do what it can to meet the goals and objectives of the Caregivers' Initiative program while introducing a more humane way, a more dignified way for our caregivers and their family members to age in place, age with the security and purpose in the home and community they love.

Whether Consumer Directed Care makes it to the general public and it becomes a household idea is up to all of us. If we don't ask for the program we will never get it and it may go away because of lack of demand. We need to take a more active role to assure that our generation of caregivers is given the option to stay at home without more sacrifices than what is needed. We need to allow the caregivers to do what they do best without worrying about their own futures. The time is now to request the establishment of Consumer Directed Care as a service option. If we remain silent, we will never be able to achieve the control we desire in the care of our elders, our children and our most frail citizens. This is your wake up call a call to action now.