THE SENIOR RESPITE CARE PROGRAM

PLANNING

I was hired 12/4/83 to implement a new program in the Portland, Oregon area, a respite care program.

The idea for starting services in the area had begun two years earlier. A community survey of 112 caregivers, many of them Alzheimer's Disease families, had indicated that their primary need was the ability to get away from their caregiving responsibilities for "a few hours now and then."

With this information, a community-based task force of 22 individuals representing home health agencies, social service agencies, hospitals, churches, colleges, the nursing profession and caregivers met for nearly a year planning the program and trying to secure funding. The group formulated goals and some very basic guidelines for the program. The primary purpose was to prevent premature or inappropriate institutionalization of the frail or impaired elderly by providing short-term respite care. The committee decided: 1. the program would be accessible to all income levels; 2. there would be no limitations on the number of times respite care could be provided to a family; 3. although the program might expand, initially services would be directed at providing respite breaks of a "few hours or more" and, 4. the program would use paid and trained providers.

Although I was not part of this decision-making process, these
guidelines were excellent and showed considerable thought and research to make this program a success.

Under the name of Good Samaritan Hospital & Medical Center, the task force applied for and received monies from the Area Agency on Aging to develop a training program for providers. A second funding award was received by the local Alzheimer's Disease and Related Disorders Association from an Oregon foundation to set up the program. The $56,482 was awarded in fall, 1983 and was expected to cover an 18-month period. It has actually lasted 26 months. At the time it was decided the program would be co-sponsored by the ADRDA and Good Samaritan. The ADRDA had offices at Good Samaritan. The co-sponsorship gave access to different areas of expertise. The hospital, an established and respected community institution, provided support in the areas of accounting, risk management, marketing and administration. It also donated space, telephone and mail services and equipment. The ADRDA, a very new organization, provided time and direct access to families, their needs and concerns.

The new program was called the Senior Respite Care Program. Although it primarily focuses on Alzheimer’s Disease, the program serves families caring for anyone over 60 years of age and/or coping with dementia. We are in the process of changing the name to Caregiver Respite Program which we feel better describes our services.

Hiring a director was completed by early December. My prior experience included administering a family planning agency in New
York State. As director, I had been responsible for grant proposals, budgeting, planning and staffing. I had had no experience in working with the elderly or directly with clients. This caused some concern among the hiring committee and I was interviewed a second time before a final decision was made.

Looking back I think the committee made a wise decision hiring an individual with strong administrative experience. There were basically no program policies and someone had to develop fee schedules, payment and billing arrangements, etc. as well as deal with liability issues. Additionally the challenge of future funding had to be tackled almost immediately. Eighteen months is a very short time to develop, implement and find continued support for the program. In addition to administrative duties, I was also responsible for training providers. In family planning, clinics have a position called "All Purpose Person" and this title aptly described my new job.

I spent the first month planning how to operate the program and familiarizing myself with both the aging process and Alzheimer's Disease. The director of ADRDA was an invaluable resource in helping me formulate operation guidelines. Because respite care is such a new service, we had no way of knowing what worked and what didn't work.

First of all we had to decide who should receive respite and for how many hours. Since the costs of operating the program were subsidized by a foundation grant, we wanted to insure that as many families received the service as possible. We also wanted to focus the program on homebound caregivers who needed
"a few hours now and then" versus the working caregiver or someone who had to be out of the house for extended periods. We decided to limit the number of hours to 16 per week per family. After two years of operation, I would suggest that 10-12 hours a week is the maximum most families want for respite care. Indeed most caregivers schedule less than six hours per week.

Defining service limitations was a bit more difficult. The task force had defined respite care as "care provided by a substitute care provider which allows the resident to be away for one or more hours." This provided little information on what the respite provider would do during the visit. The intent of the program was not to duplicate services in the area and respite providers are not home health aides. We decided that respite providers would help with eating and toileting but not bathing.

We simplified the definition of respite care to "supervised companionship." I am quite firm with families about exactly what the provider can and can not do. In the beginning, there was a great deal of confusion and respite providers were mowing lawns, giving baths and even defrosting refrigerators. At one home, the provider cooked the family meals for an entire week and froze them. When I had to replace her, the family was most dissatisfied with the new provider because she didn't cook. Providers also cannot administer medications or drive the impaired individual anywhere. We have made further limitations and now say in an introductory letter about the program that we don't lift (we help transfer) or deal with "heavy" incontinence.

The fee schedule is based on the federal poverty guidelines.
It is a sliding fee scale with the lowest fee $2 per hour and the highest $5. We charge according to household income. We reasoned the family was purchasing services not the impaired person. Any household with incomes 200% above the poverty level pays full fee. The task force had decided that everyone would pay some fee and initially the lowest fee was $1. We raised it to $2 in summer, 1985.

Originally we had five fee levels with the highest being $7 and $8 per hour. Using this schedule we felt we could make the program self-sufficient with a high enough volume.

We quickly lowered the high fee. We did not want to be in competition with the home health agencies. There was a second important reason. The intent of the program is to actually encourage families to take regular breaks from caregiving by offering low cost and convenient services. I, myself, was more comfortable with $5 as a maximum fee. It was easier to discuss fees with families. We are essentially the lowest rate in town. Even private providers usually charge $5 per hour. By serving all income levels, we are also able to avoid the stigma of being a "welfare agency." Today at least half of our clients pay $5 per hour.

I now send out the fee schedule with the application. The fee schedule contains instructions on how to figure out the appropriate fee. I never ask families for documentation and I accept what they say they ought to pay. In the two years of operation, only three families have indicated a fee lower than what I felt it should be. I should also add that we experience
very little difficulty on collecting fees from families. We rarely have anyone who owes us money. A professional caregiver is the only client who has left the program with an outstanding bill.

The liability issue which appeared to be an enormous problem was not. The hospital assumed liability for the program under its general insurance policy. It costs the hospital about 75 cents per encounter. I did some checking about liability policies and it seemed they were readily available on the market. The hospital's risk management department advised us against having the providers bonded as the only way a family can collect is by a conviction in court. The chance of getting a conviction with an Alzheimer's Disease victim in the house is slim. We have never had any problem with thievery. One family which had been "burned" before left rings and money around their home to see if a provider would pocket them. After six months, the caregiver told the provider she had passed their test and was completely trustworthy. I only hire individuals who are established in the community or are enrolled in school.

Providers are paid $3.35 per hour. Providers are independent contractors with the hospital and nothing is taken out of their pay which minimizes the bookkeeping. The hospital does all the bookkeeping for the program. At first we did not pay transportation but found it increasingly difficult to get providers to travel more than a few miles. We now reimburse 21 cents per mile or pay bus fare. Providers can be paid as often as twice a week. Some wait until they fill in their time sheets;
others send in time sheets each week. If someone really has an emergency we ask the accounting department to cut a check. It is important to pay providers frequently as a method of reward. Families are billed monthly, and we have to watch the cash flow. If we have a light month followed by a heavy usage month, our cash reserves dwindle. Respite care use tends to have cycles. November and December are traditionally light months with summer and fall fairly heavy.

IMPLEMENTATION

Program operations began in 1/84 with the recruitment of providers. We had long debates about what type of provider we should recruit. Some individuals felt that nursing students would be excellent providers and easily recruited. ADRDA members strongly disagreed feeling that most families would feel more comfortable with an older and more mature person. I have hired both college students and older individuals and have found all ages to be suitable. However, I have found that middle age and older people are more likely to stay with the program reducing the turnover rate. I even have providers who previously received services from our program.

One of my greatest fears was that nobody would apply to be a respite provider. It seemed unlikely that anyone would want a job that required a great deal of patience, was possibly boring and paid so little. A single advertisement in the Sunday paper brought over 100 responses. Our application form is an excellent screening tool. It includes a checklist of different situations
people indicate they can handle. The list includes: controlled seizures, belligerence, incontinence, confusion, etc. Only 25 applications of the 100 were returned. Some people think that respite care is easy work. It is not. I know I went out on an assignment to see what the work was like. I could hardly wait for the four hours to end.

We charge $25 for training and return the money to the individual after they have logged 24 respite care hours. In the beginning, I negotiated with individuals who couldn’t afford the training fee. I no longer do this for consistently they quit before they provide the 24 hours.

I interview each applicant and check references before accepting them for training. I have learned a great deal about hiring providers. I usually don’t hire smokers, individuals who are looking for full-time work or who really need the money. If an individual indicates they can only work a minimal number of hours or travel within a very small geographical area, I don’t bother to train them. Respite care work is not steady. One month you may have five families and the next month, four of them are no longer with the program.

Some people just aren’t suited for respite care. I hired one woman who later dropped out because she became so bored and nervous while providing care. She found she worked better with small children.

I also don’t hire people who tell me in great length about their personal problems during the interview. I do not solicit such information and I can’t believe families in stress will
want to hear such information. I still make mistakes in hiring. Sometimes I am too eager to get a new provider and hire despite some misgivings. At the beginning I was training every month which is exhausting and time consuming. Now I train only a few times each year. Most of the providers have been with the program for at least a year. They are caring, calm and extremely competent individuals and many have a special relationship with their families.

I really consider them volunteers and I work hard to be as flexible as possible with their schedules. If they want to take a vacation, I arrange for substitute help. Some providers took the entire summer off. Since I have students who are looking for work during the holidays and vacations, this is an ideal situation. I also talk with most of my providers at least twice a month. I consider them peers working with me to provide a quality service. Because of that, I think they feel that what they are doing is worthwhile. We do provide a minimal raise each year.

Before accepting anyone for training, references are checked by mail so we have a permanent record. The reference form asks several probing questions including: "Would you trust this person to provide respite care in your home?" Some responses have indicated problems not apparent during the interview or on the application. Although it may not be fair, if there is any indication of a problem I don't hire the individual. One day as I was interviewing an applicant I thought I smelled alcohol. I wasn't sure and the janitor had been cleaning with chemicals
quite near us. The reference check indicated there had been a problem with alcoholism in the past. I didn't hire the individual and I still don't know whether I really smelled alcohol but the combination of the smell and reference check made me decide against the person. Some agencies who are working with the unemployed or disabled have tried to use our program as a way to meet their program's goals. Most of time this hasn't worked out. We are not in the business to rehabilitate providers.

Training usually takes two full days. The training program was developed by the caregiver education coordinator at Good Samaritan. I, who had no background in aging or Alzheimer's Disease and had never taught in my life, can provide a very good training program. The program not only sensitizes individuals to the aging process but also shows them management skills. It is really remarkable to see people who know nothing about Alzheimer's Disease begin to discuss ways of handling problem situations. Not only do they have an understanding of the disease process but also some of the techniques for working with impaired individuals. We have recently added training sections on Stroke and Parkinsonism, populations who may also suffer from dementia but need different care. During the training session, the group meets with a stroke recoveree and Alzheimer's Disease and Parkinsonism caregivers. They have an opportunity to learn first hand about the impact of these chronic disorders.

The first training program had nine individuals. That many people made interaction lively. However after training, I had
nine people wanting to work, eager to apply their new knowledge to a home situation. Unfortunately I had no families. I learned a painful lesson not to hire more people than you can place. Once individuals are trained, it is difficult for them to wait for work. Most will leave the program within a few weeks. If I can not place an individual within a month, I return their $25 training fee. I now only train two to three people at a time.

Training gives me an opportunity to view the potential providers for an extended period. There have been a few I have trained but never placed. There was something that made me uncomfortable during the training. The bottom line for me is how I would feel about this person taking care of my mother or father.

Lack of families was very worrisome. After all the community survey had indicated a great need for respite care in the Portland area. I only had one family in the first month and two in the second. There was no way I could check my experiences with other programs as respite care was so new. I now know it is a common experience and it takes a long time to build up a clientele. To new programs I caution patience. Even as an established program we only add six to eight families per month. At the same time we may lose six to eight to placement or for other reasons. In one year, a program could serve 150 families but only average 40 to 50 families per month.

There are barriers to respite care. Many families are unaware of the service or even what the word "respite" means. They are afraid of strangers being in their home. They are
ashamed they can no longer take care of their loved ones and have to seek outside help. They feel guilty about spending even a small amount of money for services. Women, in particular, devalue their time. They want on-call services and do not want to commit themselves to a set time period. Often women tell me "they only want to go shopping once in while." Male caregivers are more likely to schedule regular respite sessions for recreational purposes — swimming, golf, bridge, etc. Men and adult children also seem to schedule respite care earlier in the disease process than female spouses. Quite often I am called into a home with a wife caregiver after some crisis has occurred. Several times permanent placement has occurred just before or shortly after we started respite care.

Being aligned with the hospital and the ADRDA gave the Senior Respite Care Program a great deal of credibility in the community. One of the best marketing tools is a flier about the program inserted in every ADRDA information packet. Paid advertising did not work at all but an appearance on a local television station brought a lot of requests for information. I try to meet with support groups and speak at community gatherings. A face-to-face encounter seems to be a very effective way in reaching families.

We have had tremendous support from human services agencies, hospitals and home health agencies. We made every effort to structure our program to link with other services, not take their place. Interestingly most referrals from home health agencies and hospitals do not work out. Many of these referrals have health
care problems which we can't handle. We actually serve the hidden caregiver. Most have had no experience with the human services network. The impaired person is displaying problem behaviors which require constant supervision or for some reason can not be left alone. Often my first impression on making a home visit is that there has been a death in the house. Usually the home is silent and often the drapes are pulled. Everyone including myself talks in a hushed tone.

An excellent source of referrals is the physician community. Female caregivers often call me after their doctors have "ordered" them to get help. Doctors, however, still don't refer as often as they should.

I developed a very set process for linking caregivers with providers. After an inquiry or referral, I would schedule a home visit, usually within two days. I would meet with the caregiver for about an hour and then at the office contact a provider. The provider would call the family and schedule a time to meet the family. If everything went well, respite care would begin on a weekly or bi-weekly basis. After the first respite visit, I would contact the family to make sure everything was going smoothly and encourage them to call if there was a problem. Initially I sent out a written evaluation but found that caregivers were annoyed at having one more piece of paper to fill out. Sometimes the caregiver may have to wait a week or so if I don't have any providers free but most can start care immediately. One thing about this program is that it is never stagnant. One week I need families, the next I need providers.
We have changed the system slightly. I found during the first year, I was making needless home visits. In fact for every two visits, I only made one placement. Even though I had talked to the caregiver on the telephone, when I got to the home the caregiver didn't really want respite care, didn't want to pay, needed weekends, etc. I was on the road everyday and the home visits were quite lengthy. Finally a colleague advised me to begin sending materials, application and fee schedule to the caregiver and require they be sent back before the home visit. The system has worked very well. Sometimes after reading the application, I know we can't handle the situation and refer the family to an appropriate agency. I now make a placement for almost every home visit and have much more free time. Having reduced two very time consuming processes - training and hiring new providers and making needless home visits, the amount of work is less and the program could expand significantly with the same amount of staff.

When I make a home visit, I try to encourage families to use alternative respite programs. In-home care is the most expensive form of respite and there are several adult day care centers available in the area. Many offer transportation as well as bathing for a nominal fee. For some families, day care is not an option. Others I have been able to direct to these programs. We have also developed lists of nursing homes who provide over-night respite care. Getting families to plan for emergencies or for the future is difficult but I give them as much material as is available. We try to include information in every billing to
families. If I find a good article on Alzheimer's Disease and dentistry, we enclose it with the bill. Lack of information seems one of the biggest barriers to getting help. Families rely on the program for information and often call when they encounter a new problem or need help in obtaining services or placement.

Originally we put no minimum amount of time for families and immediately ran into the problem of caregivers wanting an hour or two. Trying to find a respite provider who was willing to go into the home for an hour was near impossible. I also have doubts whether one hour or two is sufficient time to give a break. At a minimum I think four hours is necessary but we have set our minimum amount of time at three hours at least every other week.

Our hours are Monday through Friday, 8 a.m. to 5 p.m. There is always someone in the office when there is a problem. An advantage to having our office at the hospital with the ADRDA and 13 other support groups is that someone can always cover for me if I am on a home visit. We did start the program by offering evening hours but most caregivers don’t out in the evening. Again, I had people trained and no where to place them. We limit our services to weekday hours. Extended family, friends and neighbors as well as volunteer organizations often provide respite during the weekend. I am surprised, however, at the number of churches which have no programs to allow caregivers to go to church. So often, this is the one thing the caregiver misses the most.

Because we include so much information about the program in
the packet we send out in response to an inquiry, the home visits usually last about 30 minutes. My purpose in a home visit is to meet the caregiver and to get some feel for the type of care that is needed. The home visit also helps me to work with the respite providers if there is a problem. At least I have met the family and impaired person and have a point of reference. If the individual is having a catastrophic reaction, I know their size and whether the provider can handle a bad reaction. I am also able to brief the respite provider about the family before the visit in addition to giving them a copy of the application.

REFINING THE PROGRAM

By 7/84, we had provided services for six months and had served 40 families. I had six providers on contract although I had trained more than 25. Most I couldn't place and lost to other work. We were beginning to get a balance of families paying different fees and by September the fees were paying for all the costs to the providers including their mileage. Record keeping was relatively simple. The only ongoing work for the full-time secretary was the monthly billing and making check requests for provider payments. It became clear that I did not need a full-time secretary and we dropped her hours to 18 per week.

In July we entered into a contract with the Area Agency on Aging in an adjacent county to provide respite services. The Area Agency on Aging paid us $5.35 per hour minus what we collected from families. The fee schedule used by the county and
throughout the state for home health services was slightly more liberal than the one we developed. Also, adult children's income was not included in computing the fee if they were caring for a parent. Only the parent's income was counted and so many families paid nothing for respite care.

At the end of the first year, we did not bid to continue services. We may bid in 7/86 if we can work out a cooperative arrangement with RSVP to find providers. My biggest problem in serving the county was the geographic distance. Not only was I traveling every day but also I simply could not find local providers. I had to send providers from metropolitan Portland to provide respite care 20 or 30 miles away and transportation was extremely costly.

There were a number of differences between programs run on private funding and public funding. All of a sudden I had a great deal more paperwork and meetings to attend. I was spending a higher proportion of my time in the county where I was serving less families. One form I had to fill out assessed the risk of institutionalization for the impaired person. (Respite was being funded under the Medicaid waiver.) The form focused mainly on the physical ability of the individual. Alzheimer's Disease victims tended to rate at low or moderate risk and the physically handicapped at high risk. Yet the Alzheimer's Disease victim could not be left alone even to run to the store for a few minutes. At one point, I was told to drop services to moderate or low risk individuals. I did not have to because the contract ran out before I had to take action. But it seems that there is
a need not only to educate the public about dementia but
government officials too.

There was also a different orientation to the program. Since
I was on a limited budget with the county, I had to decide who
would get services. No longer did the family have the control, I
did. The program was complementing family management, it was
supplanting it. I think it would have been better for families
to pay some fee and have additional income rather than having me
ration services.

Within the next 12 months, we encountered every problem we
thought could happen but probably wouldn't. Many of them were
caused by me stepping out of the program guidelines. For a time,
I tried to help everyone. I learned the hard way that the only
thing we did well was to provide short-term respite to
caregivers. Amazingly the initial guidelines established for the
program have only been modified slightly.

In a short time I learned that the program could not provide
respite when the caregiver did not live in the same house. We
had been asked to check in on relatives while a family was on
vacation. Nor could we be part of a piecemeal of services for
the working caregiver. Our program works well because three
people are assuring quality control. The caregiver who does not
feel her mother is being taken to the bathroom often enough will
call me after the first visit or talk to the provider. The
provider who has a problem can immediately solve it when the
caregiver returns. If someone becomes ill or can't travel in an
ice storm, the respite visit can be cancelled. Because we had
problems with these situations, we only provide services when the caregiver is at home when the provider arrives and returns.

Although there is a great need for relief for foster care providers and professional caregivers, we decided we would concentrate only on families. The one time we did provide respite for a professional caregiver, she quit her job and left us with an outstanding bill.

Twice I tried to help families get live-in help by matching one of my providers whom I couldn't place. Both times, the match didn't work and the families were very annoyed at me. I now refer families to placement agencies. Locating live-in or or extended home help is very troublesome and a low cost placement service would be a nice addition to the program. We have requested foundation funds to expand our program into this area.

I have tried to keep the program as informal and flexible as possible. This is a support service for an informal caregiving system. Families and respite providers can change schedules, cancel visits (if not too often), and even arrange for private care between themselves during non-office hours. I do not give the provider's home phone number to the family but I encourage the provider and caregiver to make their own arrangements but keep me informed of any changes in schedule. I know where the providers are during the week. Some of them have served the same families for months, one for nearly two years.

We lose several families every month. Right after Christmas seems to be a time for placement. Usually we know when placement
is imminent. The caregiver and provider have discussed the situation and we frequently furnish materials to help make the decision easier. The hospital has an excellent education program for caregivers and we have audiotapes and written materials both on nursing home and foster home placement. This is a very difficult time for the caregiver and I like to think our help and concern eases the pain.

When a respite provider is ill, generally the caregiver does not want a replacement. Usually another time can be substituted. The program is successful because we send the same person every week. High provider turnover does create problems as caregivers do not like have to acquaint new providers with their family and their home.

I used to spend a great deal of time on the matching process. I have learned, however, that if I do correct hiring, most families are pleased with whom I send. I have excellent providers, several have medical backgrounds. Others have worked in nursing homes and many have had personal experiences with caring for the disabled or elderly.

The providers work very hard to make the respite visit pleasant for the impaired person. They take them on walks, bring books from the library, play games, etc. One home a minister with Alzheimer's Disease and the provider talked about his sermons. The man was in the late stages of Alzheimer's Disease and the family even had hired additional help. We thought perhaps we weren't needed but the family said the few hours spent with our provider was the only time during the week the elderly
man had some dignity restored to his life.

If a match doesn't work I replace the provider. Usually matching is more of a problem for the provider. Since I generally don't hire smokers, finding someone to provide respite in a house of smokers is difficult. One time, we provided services in a home that was both filthy and flea-ridden. The caregiver was exhausted and seemed both to me and the provider unable to get the energy to clean. The provider bought a flea collar for the dog and persuaded the caregiver to get the rugs cleaned and the house fumigated. We also were able to get her housekeeping services though the senior center.

I try to balance easy and pleasant respite assignments with hard ones. I "burned-out" several providers before I realized this.

We are often able to link caregivers with other services. I include time during the training program to talk about community resources. The Veterans Administration in Vancouver, Washington has a free two week residential respite program for veterans. Several of our families have used this service and reported having a wonderful two week break. Most caregivers have no idea how to negotiate the human services network so we make the referral for them. Providers have also located services on their own including finding firewood for a family in need or signing up the family for bookmobile library services.

Families unable to obtain much help from the community are those caring for dementia victims under the age of 60 years. Home care services such as Meals-on-Wheels and personal care
are available only to the elderly. Our program is one of the few that makes an exception and serves Alzheimer's Disease families regardless of age. We now make the same exception for stroke and Parkinsonism. Although our training covers management behavior, I never really expected we would encounter some of the problems we talked about. Well, we have had them all and others we didn't expect. I have found that despite a home visit and an extensive application form, families are not always honest about problem behaviors. Partially this comes from embarrassment, a fear that services will be denied or a belief that the behavior happens only around the caregiver.

We have dealt with belligerence, sexual exposure and drinking. Most of the time, we have worked with the caregiver and have been able to continue services in the home. One Alzheimer's Disease victim was extremely hostile to a provider and spent all the time loudly complaining about her. The provider was very upset and I went back for a second home visit. It turned out that the woman did not like fat people. I replaced the provider with a thin person and there were no further problems.

On another assignment, the Alzheimer's Disease victim began digging up the flowers in the garden. The provider could not distract nor make him stop. Short of physically restraining him, there was nothing she could do. Naturally the caregiver was very upset when she arrived home and told the provider she should have slapped the man to make him stop. We stopped providing services in that household.

We have had a few problems with caregivers. One caregiver
grabbed a young respite provider and kissed her. The caregiver desperately needed respite so I solved this situation by replacing the provider with a larger and older woman who towered over the caregiver.

I have only turned down one family for services after a home visit because of a behavior problem. The individual suffered from Alzheimer's Disease and Parkinsonism and was a retired minister. He was extremely hostile to me during the home visit. One minute he would be speaking calmly and the next demanding to know if I was saved. At one point he shook his fist at me. I did not want to place a provider alone with him. I learned later he frequently hit his wife.

Women seem to have a difficult time arranging for respite care. Quite often they want to bring the impaired person into the discussion about services. Of course, he wants nothing to do with me and if the subject of fee arises, he usually orders me out of the house. Often female caregivers cry during a home visit. I can well imagine how difficult it is to talk to a stranger about these highly personal problems.

Extended families are extremely supportive of respite care. Sometimes the children contact the program and arrange for services. After some 300 home visits, I am aware that caregivers are reluctant to impose on their families and often would rather pay for services than ask for help from the family. I think many times the extended family could help more but simply doesn't know how. Lack of help from my perspective is generally not an unwillingness but just not knowing what to do.
Caregivers are often very concerned about leaving their loved ones and think the impaired person will never accept a stranger. We really have had no problem if the caregiver simply leaves. When the caregiver makes a fuss usually the leaving is very difficult.

Although many caregivers think a man would provide good company for their husbands or fathers, this has generally not been so. Quite often the male provider is seen as a threat. One 96 year-old-man locked the male provider out of the home. Male stroke recoverees are often very hostile to a male provider. When I talk to the families about the situation, usually there has been a similar incident with a male relative or in-law.

We have had very few emergencies on the program. Generally the individuals we care for are physically healthy. Indeed it is often the caregiver who is suffering from ill health. Five times in 11,000 hours of service, providers have called an ambulance. None of the situations have involved Alzheimer's Disease victims and two have involved the caregiver. One caregiver had immediate brain surgery after the respite provider got medical help and the family credits the provider with saving their father's life.

We also have had two near disasters. One provider left an Alzheimer's Disease victim alone when her time was completed. She thought another family member was in the house and left as she had been instructed to do a prior time. Nothing happened but certainly the potential was there. After that we required that time sheets be signed after each visit. Last summer, one of our providers contracted tuberculosis. Fortunately his families
tested negative but we now require a yearly TB test.

There may be more problems. I usually try to keep in contact with the caregiver and always call right after the first assignments. We did an evaluation of the program and received "rave" reviews from caregivers. Yet I know caregivers are loathe to complain and I now call each caregiver at least quarterly to chat.

One area where the program fails families is when the impaired person begins to requires different care than we can provide. If the individual becomes bedridden, totally incontinent or seriously ill, the level of care increases. For three families, we have stopped services. Unfortunately there is no higher level of respite to replace us. Just when the caregiver may need time to make personal arrangements, there is no help.

ESTABLISHMENT, EXPANSION AND THE FUTURE

At the end of first full year of operation, the program had provided respite care to 75 families and logged 4,026 hours. The majority of caregivers were spouses, 28 wives, 14 husbands, followed by 23 adult daughters. Most of the families (37) were caring for Alzheimer's Disease victims, 12 for stroke recoverees and 10 for the frail elderly.

By the end of the first year, the foundation monies were primarily being used for salary and fringe. Less than $5,000 during the first year went to supplies and payment to providers. Total cost of operating the program after deducting income was $34,000.
In the second year, the foundation funds were used exclusively for salary and fringe. The money collected from families not only paid the providers and their transportation costs but also purchased supplies. The hospital continued to provide in-kind support. Family payments amounted to $33,600 out of a total budget of $60,390. We nearly doubled the hours of service to over 7,000 and expect they will increase to 11,000 in 1986.

Quite obviously, a critical issue facing the Senior Respite Care Program is funding. To make the program self-sufficient, each family would have to pay $7.50 per hour. (As volume increases the hourly rate is reduced.) Services at this price are already available in the community from private agencies or individuals.

Not many families can afford these high fees. One caregiver wrote on the initial community survey: "In my case, we are too rich for outside help and too poor to afford to pay for it ourselves."

While the subsidized costs of the program have steadily decreased, the program is far from self-sufficient. As the program grows toward its goal of serving 200 families each year, income for administrative expenses is expected to reach $1,000 or more per month. Presently we are studying ways to expand the funding base. Potential sources of income are from government contracts, donations and development of new income producing services. The program is also seeking foundation funds to move the program from its developmental stage to a cost-effective service. Unfortunately most foundations do not like to provide
funding for ongoing operations. Approximately $6,000 of our income per year comes from sale of materials and consultations/honorariums.

The program receives a great deal of support from the hospital. The hospital formula for computing in-kind support put its donation to the program at over $20,000 a year. This includes direct services as well as administering the program. I report regularly to the director of the Neurological Sciences Center Education and Family Support Project of Good Samaritan Hospital and Medical Center. Other respite programs that are starting are also linked to an established agency. The Denver and Orange County chapters of ADRDA are developing similarly-structured programs to ours. Once a respite care program is established, it requires less and less administrative time. This provides me the opportunity to expand services and seek additional funding.

Certainly the case for respite care is hampered by the lack of research programs which document its effectiveness at reducing institutionalization. That respite care reduces caregiver burden must certainly be true. Our own experience with families testifies to this fact. We have provided respite care in homes up to a few weeks before death. The caregivers have told us that they would not have been able to keep the impaired individual at home without regular respite services.

At the least respite care strengthens the caregiver's ability to keep the relative or spouse at home. However, it seems to me that each family has established personal criteria on when to place. Some families can not deal with incontinence or violent
behavior. No matter how much respite is provided, families place when these situations occur. Others are determined to keep the impaired person out of a nursing home and will do so at any cost.

I have hardly mentioned any board or formal structure to the respite care program. Other groups interested in developing respite care programs often ask for descriptions of the advisory board and its functions.

The program does have an advisory board which includes a physician, educator, respite provider, government official, ADRDA representative and a nurse practitioner. The advisory board meets infrequently. Because the program is co-sponsored by both a hospital and the ADRDA, I turn for counsel from both organizations. If I need financial help, the hospital staff is there to meet with me. If I have to make a decision concerning policy affecting families, I have ADRDA members to help me. Other organizations may have to rely more on the expertise from an advisory board if they lack the combination of talent provided for me.

The future of the program depends largely upon its funding. If we receive approval of the foundation grant, we will be able to expand services and hopefully achieve near self-sufficiency with continued hospital support. If the proposal is turned down, other funding avenues will have to be sought. My belief is given the time, the program could become cost effective and require minimal subsidy.
Congress of the United States  
Office of Technology Assessment

LOSING A MILLION MINDS:  
CONFRONTING THE TRAGEDY OF ALZHEIMER'S DISEASE AND OTHER DEMENTIAS

Contractor Documents

Part 3:  
Special Care Programs and Facilities

March 1987

THE OTHER 7 TITLES APPEAR ON THEIR OWN INDIVIDUAL MICROFICHE UNDER THE APPROPRIATE CLASS NUMBERS.

Designing a Residential Care Unit for Persons with Dementia, Dorothy H. Coons, 
Institute of Gerontology, University of Michigan, Ann Arbor, Michigan 48109

The Senior Respite Care Program, Louise Dunn, Senior Respite Care Program, Good 
Samaritan Hospital and Medical Center, Portland, Oregon 97210

Experiences of the Atlanta Area ADRDA in the Development and Management of the 
Community Services Program, Carolyn J. French, Atlanta Area Chapter, Alzheimer's 
Disease and Related Disorders Association, Atlanta, Georgia 30340

The Family Respite Center: Day Care for the Demented, Lyn E. Noyes and Richard 
Wittenborn, Family Respite Center, Inc., Falls Church, Virginia 22043

The Family Survival Project, Diana M. Petty, Family Survival Project, San Francisco, 
California 94115

Evaluation of a 24-hour Care System for Persons with Alzheimer's and Related Disorders, 
J. Daniel Sands and Judy Belman, Harbor Area Adult Day Care Center, Costa Mesa, 
California 92627

Institutional Approaches to the care of Individuals with Dementia, Audrey S. Weiner, The 
Hebrew Home for the Aged at Riverdale, Riverdale, New York 10471

Urinary Incontinence in Alzheimer's Disease, Thelma J. Wells, School of Nursing, 
University of Michigan, Ann Arbor, Michigan 48109

These are contractor documents that were used in preparing OTA's final Assessment Report. OTA makes these contractor documents available for the use of readers desiring a more detailed or technical discussion of an issue than can normally be accommodated in our final Report. As an OTA contractor documents, they have not been reviewed or approved by the Technology Assessment Board. The findings and conclusions expressed are those of the authors and do not necessarily reflect the views of OTA, the Advisory Panel or the Technology Assessment Board.