Final Report

Assessment of Disorders Causing Dementia

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The Family Survival Project

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In the early 1970s I worked as a volunteer with a group of disabled Vietnam veterans. Most of the young men in the group were paralyzed, but a few were struggling to achieve rehabilitation or adaptation to other physical and mental conditions. Bill, a Marine Corps officer, had returned to California after being shot in the knee during the siege at Khe Sanh. While undergoing physical therapy for his knee, he began to experience blackouts and seizures.

When Bill's blackouts first occurred, he was admitted for psychiatric evaluation. For eight months he was treated for psychiatric disorders without receiving a neurological examination. Over time he experienced more intense seizures more often; brief blackouts occurred every few minutes. He argued that he was not psychotic, and, ultimately neurological testing revealed that he had a form of epilepsy that affected motor-sensory functions. The identified cause was the constant barrage of mortar rockets exploding near him in Khe Sanh. Bill's epilepsy was manageable but severely disabling. It was combat related. Yet it took another seven years for him to be classified "disabled" by the Veterans Administration and eligible to receive disability income—even though at times he had as many as eight seizures each day and frequently could not follow conversations because of blackout periods.

More than any other experience, Bill's case exemplifies for me the "state-of-the-art" for adults with brain damage and chronic brain diseases in the last decade. Although his treatment occurred in the Veterans Administration, what happened to him was common in other health care and social service programs.

The similarities between Bill's problems and those of other persons with degenerative diseases that cause dementia are numerous: the symptoms are often misunderstood, and misdiagnosis is common; communication between
psychiatry or psychology service units and medical providers is poor or does not occur; public benefit programs take a wary view of those with "invisible" mental impairment; and society tends to blame brain-damaged patients (and other mentally impaired persons) for causing their own problems.

Bill's case signified to me a horrifying inadequacy of an otherwise rich health care system. But my principal interest at the time was as a journalist and friend; I had no professional involvement in health care. In 1978, Steve Thompson, a health care policy consultant from Sacramento, called me at the San Francisco public relations firm where I worked and asked if I would talk with members of a group who were seeking a project director. I knew Steve's firm held a contract over the previous year to study the impact of brain damage on families and social programs. The group, sponsored by the local Mental Health Association chapter, had received a one-year state mental health grant to set up a family support project and to subcontract with Steve's firm for the study in San Francisco. Four months remained on the group's contract for "The Family Survival Project" and the project director had resigned. Steve believed that at this early stage a writer and publicist with legislative and fund raising experience could help the group more than could a health or social services professional.

I met with three members of the FSP steering committee: Anne Bashkiroff, Chairman, Libby Denebeim, the Mental Health Association's president, and Jane Ophuls, the association member who first brought the subject to the association's attention. A public relations consultant was present, too, as the group planned to publicize the results of Steve's study. I heard about the problems the group wanted to address, answered questions about my background, accepted an invitation to attend a steering committee meeting the following week and left with a copy of the needs study, a few newspaper
reprints about the Project and some other literature.

The literature made me understand the group's purpose. I read a feature article about Anne Bashkiroff's efforts to find care for her husband, a victim of "presenile dementia", later believed to be Alzheimer's disease though never diagnosed as that. The article quoted Mental Health Association staff and an attorney about the dearth of services and the misunderstood problems of both brain-damaged patients and their relatives. I read Steve's report and understood what he already knew: a person stricken with brain damage in adulthood fell through the cracks of America's categorically organized services. It did not matter what the individual diagnosis or cause might be. It did not matter if income status or sex or race or age made them eligible for various public programs. What mattered and seemed remarkable was that no program for health care and social services in the United States provided assistance to meet the needs of those with organically-based disorders. Steve Thompson had spent his professional life in health care and mental health care policy. I had spent mine in journalism, politics and community agency public relations. He understood the problem from a "social policy" perspective because he knew a great deal about the reasons. I understood it because I had seen how government operates and had published a county human services directory for three years. I understood because of Bill and because of relatives and friends who had suffered from inoperable brain tumors, strokes, and "senility". In fact, now in my eighth year with Family Survival Project, I have yet to meet anyone who could not tell me about someone they knew, someone they cared about, who had experienced brain damage as an adult.

But as I soon learned, brain damage and its consequences are not easily understood by the public. It seems that the issues are too broad, the problem too common in our lives to be grasped quickly. I believe, too, that the
distance and isolation caused by embarrassing symptoms, enormous care demands and the long duration of many patients' disorders keeps these issues out of the public's viewpoint which is shaped by a mania for fast-breaking news. When I met the Project's steering committee for the first time, the members struck me as being shell shocked. A group of about 10, half were relatives of a brain-damaged person and half were professionals. Several were both. They knew they were facing a large problem. They struggled with the enormity of the job to be done and the smallness of their project.

The group's history was interesting in terms of successful community action. Nonprofit and private groups frequently identify social problems years before governments and large institutions can act; Family Survival Project was a striking example of solutions following far behind need.

Today, Family Survival Project's annual budget exceeds $1 million. It has a staff of 20, several independent consultants under contract, service provision subcontracts with home health agencies, day care centers, and health and mental health professionals. It has sponsored two landmark bills in California that first established a pilot project to find a model of comprehensive services and now is establishing a statewide system of regional resource centers for families based on that model. It is under contract to the State of California to serve as one of those centers in the San Francisco Bay Area and also to coordinate the development of the statewide program, including social policy research, training, and an information and technical assistance clearinghouse. Its mission is to address the problems that result when chronic or irreversible brain disease and injury occur in persons after the age of 18. It seeks to assist family members and other caregivers; to increase knowledge and understanding of the extent of brain disorders and their impact on individuals, families and communities; and to build new
services and programs for this population.

History: The Family Survival Project began in 1976 because Jane Ophuls, a 20-year member of the Mental Health Association's board of directors, received a call from a friend who served on a local hospital's board. The board's secretary, Anne Bashkiroff, was living in a nightmare with her husband. In his form of dementia, he exhibited all of the worst symptoms and care problems. He was incontinent, confused, disoriented to place and time, acting bizarrely, frequently aggressive and violent, particularly when frightened, and, because of his large size, frightening to others. Anne, whose experiences are described in a book by Gail Bernice Holland, *For Sasha, With Love* (1985, Dembner Books) had been caring for her husband for nearly eight years. He had been admitted and then ejected from several nursing homes in just a few months. She was desperate to find a placement, and no organization or government agency seemed able to help.

Jane Ophuls is the kind of woman who never saw a problem that didn't need her. She cannot bear to hear of a tragedy without doing something about it. She would probably cringe at this description because she does not acknowledge her own generosity. But she brought the story of Anne and her husband to an association board meeting. The board suggested that its community assessment committee, chaired by a social worker with lengthy activist credentials, invite Anne to present a summary of her situation.

By all accounts of those present, Anne delivered an impassioned, highly-charged summation of her life, her husband's illness and the failure of anyone to help her. For one member of the committee, Sue Harris, the act of sitting and listening to this story was nearly unbearable. Sue does not speak easily about her own husband's illness and death, even today; but at the time she heard Anne's appeal she was living through a similar tragedy. Her
husband's brain damage was caused by a massive brain hemorrhage from an
aneurysm, anoxia, subsequent surgeries, infection, and hydrocephalus—in
short, a chain reaction of neurological mayhem. The case was particularly
ironic because Dr. Harris had founded and chaired the Psychology Department at
the University of California, San Francisco, Langley-Porter Institute. Thus,
two sophisticated women, one who had worked for nearly 20 years as corporate
secretary to the board of trustees of a major urban hospital and the other the
wife of a leading research and academic psychologist, could not—with all
their contacts and savvy—dislodge the obstacles to their husbands' care and
to their own well-being.

A task force to investigate the problems of irreversibly brain-damaged
adults and their families, particularly those of middle income status, was
formed immediately by the association. By the end of 1976, several family
members, two attorneys, a nurse/discharge coordinator, a psychiatrist, and a
social worker had joined it. Although they initially researched the
inadequacy of nursing facilities, the long list of problems and needs soon
emerged.

With assistance from the association's staff, the group sought publicity
for the problems they uncovered and contacted community and political leaders.
They formed a support group for other family members and held a community
meeting in early 1977 that drew nearly 200 individuals. The task force knew
it had discovered something of far-reaching proportions. After meetings with
state health officials, they wrote and received the grant for which I was
retained. In addition to Steve Thompson's needs assessment study ("Brain
Damage: A Diagnosis of Personal Anguish and Social Neglect," Thompson and
Associates, 1978), the grant provided funds to publish a handbook of legal and
financial information (The Family Survival Handbook), sponsor the family
support group, organize a "network" of family members for mutual emotional support, and conduct a public awareness campaign.

FSP did not succeed overnight, nor were its eventual accomplishments the result of being "in the right place at the right time". The organization was in fact the first catalyst to crystallize the issues, enabling other groups to be in that "right place". Early national media coverage, particularly in the Washington Post and on the PBS network, prompted individuals from throughout the country to contact us. The same advice was given to all who asked what they could do: start a group, we said. Most projects for brain disorders existing at that time were allied with university and medical research programs. FSP was free-standing, and it gave a voice to hundreds who were isolated with a brain-damaged relative.

FSP's ability to respond and achieve a new approach to old problems originated in its earliest actions: the decision to include all brain-impairing conditions within its scope; its partnership with the public sector and elected officials; its identification of the family and caregivers--rather than only the patient--as the target client populations; the insistence that income criteria be eliminated from its model programs; and its unwillingness to invent yet another categorically based service system that would ultimately produce other unserved groups and fragment services further.

Reasons for broad scope: In order to understand the reasons for FSP's decision to focus on all brain disorders, a few social factors that emerged during the last decade should be described. These factors required substantial revision in the conceptions about organically-based brain disorders held by the medical establishment, other professions and social policy makers.

First, new technology and research findings burgeoned in the medical
field in general and in the neurosciences specifically. Ailments or conditions that caused dysfunction due to brain tissue damage were increasingly acknowledged to have far different diagnosis, prognosis and treatment requirements than other mental and physical impairments. The terminology utilized by medical, mental health and social service professionals to describe neurological disorders has yet to match the scientific developments: a vast and confusing array of terms is employed to describe these diseases and conditions; as many as 20 terms—many colloquial—may be used by practitioners for only one disorder. Problems related to nomenclature and diagnosis were among the first identified in Thompson's study.

Second, advanced medical technology and knowledge meant greater numbers of victims of traumatic brain injury, stroke and other forms of brain damage were surviving. At the same time, technology and modern life styles were increasing the incidence of brain injury and other illness. Expanded medical knowledge and improved living standards enable Americans to live longer, thereby facing a higher risk of degenerative neurological disease and dementia.

The third influence was the trend nationwide to close down large state-run mental institutions in an effort to end the "warehousing" of the mentally ill. As long as confusion over the causes of mental illness, behavior disturbances and personality disorders existed, persons who suffered from an organically based disorder (such as multi-infarct dementia and a variety of other degenerative diseases, alcohol or drug-induced brain damage, and post-trauma, post-anoxia and post-infection impairments) could be treated and housed like other mentally ill persons. With the movement to return mental patients to the community came a growing concern over a lack of
resources in those communities for former hospital patients. These factors had a twofold adverse impact on neurologically impaired mental patients. In order to make better use of limited community and state hospital resources, diagnoses were more carefully scrutinized. Now, adults with neurologically (or organically based) disorders were frequently excluded from hospital and community mental health program admission. Recognition of the inappropriate placement of persons with traumatic brain injury, stroke or dementing illness in psychiatric facilities would have been a blessing had local programs been developed to meet their needs. However, those resources were strained by the release of other mental patients into communities, and while brain-damaged patients were screened out of state hospitals, they also were screened out of local mental health programs because of their organic diagnoses.

The visibility to society of brain-impaired adults was hidden longer because of the large numbers of patients who are middle income; but eventually those with the most bizarre behavior problems or violent manifestations had to go somewhere. Their families turned to a system already glutted by other mentally ill and impoverished or solitary (meaning homeless) patients. That system included no provisions for those with "chronic, organic brain syndrome or damage".

Fourth, several new categorically specific programs and systems had evolved in the United States to meet the needs of other groups: the developmentally disabled, persons over age 60, and the physically disabled joined low-income persons and veterans as groups for whom large service systems were designed. As their needs seemed to be met, at least in theory, other populations (or subgroups) with unmet needs emerged. While advocacy groups for other "special needs" populations made significant gains in federal and state policies and programs, no such voice had developed for the
brain-impaired adult.

Fifth, the United States had concluded ten years of experience with the new federal medical care reimbursement programs for the poor, elderly and disabled. The results for brain-impaired adults were disastrous, perhaps more so than for other persons with chronic illness or disability. Because their needs were most often custodial and non-medical in nature and behavioral in character, patient care was not subsidized by Medicare or private insurance beyond acute hospital stays.

Public and private health insurance programs generally have neglected long-term care needs. They have specifically shunned brain-impaired persons, and the financial and care-providing impacts have been particularly onerous: "chronic brain disorders" are specifically excluded from most health insurance policies; reimbursement of post-acute rehabilitative care is often denied because of the "chronic" or "organic brain syndrome" labels; and brain-impaired patients, especially those with dementia, are often denied admission to long-term care facilities based only on their diagnoses and supervision needs. The federal Medicaid program, following impoverishment of the family or individual, remained as the only resort. But Medicaid reimbursement rates lagged behind care costs, so persons who required intensive non-medical supervision and personal care were excluded from Medicaid facilities, as well. The only real long-term care program was the family itself. In many cases, the streets have picked up the slack.

Finally--and compounding all of these factors--was the medical model of service delivery. Not only did this diagnostically oriented system affect financing, reimbursement and care models, it was inadequate to the task of identifying brain disorders. Most were grouped collectively under a few labels. Today, there is no estimate of the true number of persons who suffer
from organically based brain impairment. Failure to utilize standardized
diagnostic terms and the way "cause of death" data are collected have made it
impossible to determine incidence. With the revelation of brain-impaired
adults as an unserved population case a complex problem: until public
officials can identify the causes and terms for brain damage, no one can
gather accurate statistical data. Without such data, no one can know the
numbers afflicted nor the full extent of the problems to be faced.

In California, the apparent factors that affected brain-impaired persons
were compounded by the existence of an innovative program for individuals who
manifest developmental disabilities prior to their 18th birthday. Called the
"Regional Centers for the Developmentally Disabled", each major community and
geographic region in the State is served by a center that conducts client
evaluations, designs care plans and "purchases" services necessary for the
care and habilitation of persons with certain specified disabilities (mental
retardation, cerebral palsy, autism and similar neurological disorders) that
constitute a "substantial handicap".

However, adults who manifest neurological or other handicapping
conditions after the age of 18 are not eligible for regional center
services. The developmental disability system will be described further in
relationship to program approaches below. Here I want only to point out that
a model for brain-damaged adults existed, and that its existence and
eligibility restrictions helped to exacerbate the anger of those who needed
similar programs.

In 1978, I suggested to FSP's steering committee that it could pursue two
approaches as an organization to address its already identified generic scope.
It could follow the "single disease" approach and become a "Disease of the
Month" type group, concentrating on the term "brain damage" or on one or two
disorders. Or, FSP could look to the developmental disabilities system and
the programs established under the Older Americans Act for examples of broadly
based, generically oriented organizations. The steering committee agreed to
the broader model primarily because they believed that diagnostic
categorization was at the root of the problems they were addressing. Our
scope was reinforced by the many state and national public officials who
pointed out their frustrations at being "hit up" daily by innumerable causes.
They urged us to adopt a pragmatic approach that would represent the largest
possible target group.

The fragmentation of services, the categorical approach to service
eligibility and delivery, and the problems associated with diagnosis and
patient assessment for disorders causing dementia are now well documented.
Obviously, categorical program models are major contributors to the
fragmentation that causes severe inequities for some patients. The way in
which funds are cycled into programs is an insidious aspect of service
character. Government funding follows fashionable trends in much the same way
as does television network programming. Programs begin to receive government
support long after the public grasps the problem to be addressed or knows of
the popularity of a given program solution. Grant-making that respects,
first, competent grant writing and, second, the reputation of the applicant
seems to contribute greatly to the uneven distribution of services, research
and system components. These projects follow existing categorical models,
and recipient financing observes the same models. If FSP could circumvent the
more common funding cycles and break the trends of grant giving, then whatever
programs were developed for brain-impaired adults might not suffer from the
same fragmentation. Government could perhaps be persuaded to respond at the
same time as the community.
We examined the results achieved by various disease education and research groups. Their gains were remarkable, but largely within research, treatment, education and creation of specific service units, such as dialysis. The long-term results were a piecemeal service system and continuation of service policy based on elements of the medical model. Concentration on a single disease group, such as dementia, might result in little overall systems change or policy. The most significant factor in FSP's mission was our acknowledgement of the commonality with other chronic illnesses and disabilities in terms of long-term care development and provision.

We were, of course, forced to re-examine the scope of the organization every time a segment of the adult population began to organize. But the arguments in favor of the larger population always outweighed those of focusing on a smaller segment. We felt that every popular disease eventually peaks in the public's mind. We decided to start at the place where we must end up. We decided to be an organization that addresses the social policies that cause fragmentation, categorical eligibility, and service gaps; that addresses a heretofore unrecognized client, the family; and that seeks to avoid the pitfalls of other public advocates during a period of economic austerity and social realignment. By mid-1979, FSP had adopted an ambitious agenda:

To establish a network of families of brain-damaged adults for mutual emotional support.

To educate the public about the problems that result from brain damage in adulthood and about the service needs of families and patients.

To develop and obtain funding and support for a model of comprehensive, coordinated and affordable services.
To encourage development of services by other groups, policy makers and communities and to change policies that impeded service development.

To establish a data base, possibly the first ever, of information about brain-impaired adults, their families and caregivers, brain disorders, service needs, and service costs.

To train service professionals, the legal profession, paid caregivers and others about aspects pertinent to the care or supportive assistance of patients and families.

To provide a clearinghouse of information and research on brain disorders and service alternatives and theories.

To link up with other allied organizations and professionals, with key involvement by family members, toward broad policy, education and service development goals. "Allied groups" included other health and disease education and research organizations, particularly concerning chronic illness and disability, rehabilitation programs, nursing homes, home health agencies, and senior programs.

**Approaches undertaken:** The Thompson study suggested a model of service that included centralized diagnostic and evaluation services, information and referral, counseling, legal advice, in-home supportive services, adult day care, and inpatient care. The options for establishing these services included single-agency delivery, such as by a medical center; a pilot project in a community agency with service provider subcontracts; and integration of policies for brain-impaired adults and their families into the agencies responsible for providing or financing each type of service. Thompson proposed legislation that would establish the community agency pilot project, and eventually we incorporated all three approaches.

The first legislation we sponsored was AB 1043, authored by California Assemblyman Art Agnos in 1979. According to his staff, Mr. Agnos analyzed the bill's chances for passage before agreeing to introduce it. He concluded that the bill might not pass in the first year but it would attract support for later approval. FSP reasoned differently. Art Agnos was chairman of the State Assembly's Democratic Majority Caucus, which made him a potent legislator. Before his election he was consultant to the Assembly Select
Committee on Aging. He was also a former social worker and could understand and--more importantly--articulate our cause.

The bill passed each hurdle, with negotiations occurring only over the appropriation. We sought $1.1 million to establish the service components proposed by Thompson, but the Assembly Ways and Means Committee asked us to come up with a program for $250,000, or rather, we were asked what we could do with that amount of money. This action typifies the public policy process where program "designs" are tailored to fiscal expedients.

Jane Uitti, the consultant retained to "work" the bill, and I sat down in a coffee shop with two FSP steering committee members, Frances Morain and Bernard Peeters. We scratched off diagnostic services (too expensive and also usually reimbursable by private and public insurance programs), inpatient services (too expensive and too vast a problem, i.e., in what type of facility and what type of program?), and adult day care (California and the Older Americans Act were providing funds for adult day care in many communities). We then asked ourselves, "what are the greatest problems identified by families surveyed in the Thompson study, our support groups and telephone calls, and documented by such researchers as Carl Eisedorfer, M.D.?" They were the lack of organized, accurate information and advice, the need for emotional support, and the need for home care for middle income persons or those ineligible for county (Title XX) home care and Medi-Cal.

We proposed amendments to Assemblyman Agnos that would establish a pilot program for information, advice and referral, case coordination, legal counseling and in-home supportive services; a nonprofit agency with family members representing all types of brain damage on its governing board, would administer the project. The bill passed and went to the Senate where it passed easily.
We had to overcome three problems to achieve the signature of governor Edmund G. "Jerry" Brown, Jr. One was the inability to find a generic state agency that would agree to oversee the project. We wanted the Office of Statewide Health Planning to take the program, but its director did not believe the office had enough project management capability. The director of the Department of Rehabilitation offered to take it if no one else would, but the state's vocational rehabilitation programs reached only a small percentage of the brain-injured population. No other department including Aging and Health Services, was interested. The Department of Mental Health, which had administered our first grant was the only appropriate state agency that wanted the new project, and that's where AB 1043 was placed. The second problem was the State Department of Finance position of opposition which was based on the erroneous belief that the bill duplicated other state efforts. The Finance Department stated that these clients were served in the Department of Developmental Services; we succeeded in describing the distinction between brain-damaged adults and developmentally disabled clients. Our final obstacle was the governor who was in the middle of his "era of limits" administration. Brown was opposing all new programs that would require new general fund appropriations. However, one of his legislative aides was married to a man who had suffered aphasia due to a brain injury. She convinced the governor of the very great need for our program. When he then countered that the proposed project was too small, she persuaded him that anything, even a pilot project, was a necessary start.

FSP's legislative efforts at this time faced incredible odds in 1979. About 1,300 family members and providers were on our mailing list, and most were in Northern California. Few proposals can succeed in California without the large voting block in the south. I studied state legislative district
maps and compared cities where legislative votes were needed to the addresses in our card files. We wrote letters, and in the evenings the steering committee and other volunteer called family members in targeted cities. We asked support group participants to contact their relatives in other parts of California. The Senator from Whittier, a Republican, supported our Democrat-sponsored bill; he heard from two constituents and a hospital administrator in his district; he was convinced of the need for such a project in his home territory. He did not know that the constituents were the mothers of FSP's secretary and a steering committee member; the hospital was the facility where another steering committee member had placed his wife who was comatose. Creative grassroots lobbying.

Five years later, when in 1984 we sponsored AB 2913 to establish the statewide program of regional resource centers, more than 200 organizations wrote letters of support. Assemblyman Agnos, who again authored the legislation for us, said that he had never received as much mail on any issue as he did in support of AB 2913—and he had just authored a controversial gay employment rights bill which was vetoed by the governor after several days of deliberation, front page coverage and heavy lobbying by groups on both sides.

Why, then, were we able to pull the rabbit out of the hat in 1979? The Alzheimer's Disease and Related Disorders Association (ADRDA) had not yet formed (FSP would join others in proposing its formation later that year). Alzheimer's was not even a common diagnostic term in California in 1979 and would not be until at least 1983. The Spivak family had not yet established the National Head Injury Foundation. The national organizations for other neurological disorders were targeting research, education and client independence. They were not focusing on the difficult, severely cognitively impaired patients yet. Worst of all, without concrete data available about
the incidence and prevalence of brain damage in the United States or California, there was no way to document who was and was not receiving services and how much those services cost or would cost.

By calling on every pivotal vote-maker in the State Capitol, however, with a small, presentable and articulate group of family members, we were able to convince enough legislators and staff members that one small pilot project for one year would not hurt and just might help. We did not send busloads of constituents to the Capitol, avoiding the risk of angering already overworked legislators. Our message appealed to both parties and to fiscal liberals and conservatives. We were not trying to throw a lot of money at a problem, and we did not propose that the state be responsible for every brain-damaged person (which would have created an entitlement and open-ended program).

Most importantly to FSP, we could give some immediate assistance to those who contacted us and could begin our most critical strategy: the building of a public voice for future wider efforts. Successful sponsorship of state legislation also gave FSP public recognition, credibility with other advocacy groups and professionals, connections in state agencies and the Capitol (very helpful whenever state payments on our grant were delayed), and heightened visibility among the state's service proponents.

In 1980 we received the contract to implement the pilot program, and we would return to the Legislature in 1981 and 1982 to continue and augment its funding. By then, the Department of Mental Health had incorporated the project into its base program and given us additional funds to set up a statewide information and training clearinghouse. The funds were token, hardly enough to buy file cabinets to house our information; but the gesture sanctioned the time we spent helping families and groups outside the San Francisco Bay Area.
We operated the pilot project for five years, until June 30, 1985, feeling our way to develop the best program possible. Although we fine-tuned and revised components of the program during that time, the essential model remained the same. Along the way, other new efforts came to our attention and we began to develop "colleagues." A few of the efforts we tried and their outcomes included:

A consultant for families: Our original project design established a "program coordinator" and "social worker" for in-home supportive services to work collaboratively with families. Outreach would be conducted by our program assistant (a permanent staff position), and overall management would be provided by FSP's executive director. However, FSP was at that time still a special program of the Mental Health Association and was in the process of setting up a separate corporation. The hiatus made it difficult for the new FSP board to raise money to fund other activities, and so the pilot project was organized to run itself. The program coordinator was turned into a project manager; the social worker handled only home care cases. Kathy Kelly, the project assistant, filled in with support groups, training and outreach; I turned my attention to grant writing and organizational development. A committee of the board, headed by Sue Harris, held everything together.

By the end of the first year, the board asked me to take over management of the project, and the staff identified the original component—someone to be the ongoing contact and planner with families—as being a critical need, the glue, so to speak. Families needed to call frequently and talk with someone familiar with brain damage and its complexities. Also, we were learning that the family situations were ever-changing, meaning that either the patient's status, or the caregivers' status, or other ingredients, were rarely the same from one month to the next. FSP had to be become the family's resource during
all its crises and help to forestall emergencies whenever possible.

We invented a new position, the "family consultant". The consultant would work as a professional planner and problem solver with families. FSP's involvement was important to many of the families we helped, even after the brain-damaged patient was placed in a facility or died. Our role was to teach caregivers and other family members to become their own case managers, to support them with information and reassurance, to be a sounding board. Our staff members would help identify problems, recommend possible solutions, and research community resources and publications. The family members would carry out their own plans. When needed, the family consultant would confer with other professionals and mediate on behalf of a caregiver or patient. But never would FSP's services supplant the family or be delivered against a patient's wishes.

Examples of the mediation role are numerous. In one case, the family consultant brought a family physician, neurologist and psychiatrist together to meet with family members when the three practitioners were recommending counter-productive treatments for a dementia patient. In another case, the family consultant persuaded a northern California hospital administrator not to release a semi-comatose accident victim until the family, who lived in southern California, could locate a convalescent facility. When a stroke patient's brother appealed to FSP to help prevent his brother's further physical decline due to cessation of Medi-Cal reimbursed physical therapy visits, FSP staff persuaded the nursing home's administrator to permit an aide to supervise simple physical therapy exercises at no additional expense.

Until 1983, the family consultation process was limited to three sessions because of limited funds and staff. The arrival of a licensed clinical social worker on staff and the doubling of intake each year (from 200 in year
one to 2000 in year five) caused us to make consultation services more flexible, ranging from long-term care planning to individual counseling.

Professionals were also in danger of "burning out" in their attempts to help patients and families. One memorable case brought to us by the State Department of Mental Health involved a hospital discharge planner who worked for five months, contacting hundreds of facilities and programs, in her unsuccessful efforts to place a severely brain-damaged woman in a skilled nursing facility. The woman required total care and was verbally loud and disruptive. She was on Medi-Cal and her only living relatives were in Canada. The hospital administrator was pressuring the discharge coordinator to get the patient out of the hospital. The coordinator was as emotionally exhausted as many relatives. Our education programs were soon tailored to help paid caregivers as well.

IHSS...it works, but is it too costly? In the first year of the pilot project, we provided in-home supportive services to 52 San Francisco families for an average monthly cost to the state of $745. More than 70 percent of our IHSS patients had a disorder causing dementia or other progressive disease, 36 percent had suffered strokes or other types of vascular accident, and 40 percent had at least two neurological diagnoses. Our social worker conducted a home assessment, worked with several home health agencies under contract to FSP and arranged for the appropriate services in the homes. Home health aides, 24-hour attendants and transportation were used the most. The program was a great success. Families and home health providers agreed that the program kept patients out of facilities and eliminated unnecessary acute hospitalization. Several assumptions about home care for brain-damaged adults proved wrong: behaviorally disturbed, combative adults could be cared for at home if aides received training in patient and behavior management. Very few
cases required skilled nursing care--personal care was adequate for home maintenance.

But for a few severely impaired patients the program was costly when compared to some skilled nursing facility placements, costing FSP more than $2000 a month for 24-hour attendent care. Although we believe that the cost of a program should not be the deciding factor in home care and facility placement, we did believe that these costs were too high for the limited funds provided under our pilot project. But little cost-of-care information was available. We were asked frequently by state officials to compare our home care costs to other traditional settings. The only method available to us, via a hand calculator, was to determine where our patients would be placed without IHSS and who would pay, e.g., the family, Medi-Cal, etc. Our calculations showed that in less than three years, the state would pay nearly $300,000 more for these patients than our program would cost. The cost computations were so rough, though, that I'm embarrassed when officials quote the results.

Another problem with the IHSS program was it's availability only to San Francisco County, due to limited funds; all of our other services were offered in six counties. Somehow we needed to help the many caregivers in those areas who needed relief. In 1982, I proposed to the board that we change our in-home supportive services program to a "respite brokerage". Our IHSS findings showed that families believed 10 hours of assistance per week was enough relief to keep the patient at home. This became the foundation for our respite program.

Respite Program - band aid for caregivers: We initiated the respite program as a subsidy, with family copayments based on income. It was important not to limit the length of time for participation (duration), but we
could not risk running out of funds in mid-year, either. We capped the subsidy at a level that would pay 10 hours of home care weekly ($7,500/month in 1982, $425/month in 1986). On average, the families contribute about 23% of the cost. We also instituted contracts with day care centers to provide out-of-home programs for those families who preferred them and whose patients functioned highly enough; our vouchers can provide two to four days a week in day care. Transportation was available to take patients and caregivers to out-of-home activities. The focus of the service is the caregiver, not just the patient, as a service recipient. We can now serve more than 100 families annually, but the need is greater and inexpensive options are needed. We are developing other types of respite: volunteers, inpatient beds, home-aide-hiring registries, and so on. This year, we are beginning to reimburse family members who hire aides privately. We also refer to attendant programs in other community agencies such as Independent Living Programs and Catholic Charities.

**Real attorneys for real problems:** After patient care, families had always identified legal and financial help as the most significant need. Not only did they want advice, however, they wanted competent advice. Finding attorneys who could provide competent counsel on estate planning, taxes, probates and other private issues was difficult enough; finding attorneys that would work "cheap", were willing to forego fee generation from cases, and were confident enough in their own skills to confer with a variety of other legal and social service professionals was nearly impossible. We failed at attracting interest from county bar societies; the state bar would not let us charge fees for legal services; legal aid services were unfamiliar with the legal concerns of middle-income families. Finally, at the suggestion of a foundation director, we asked a group of attorneys and social workers who
specialized in financial management to form a planning committee. They helped us establish subcontracts with attorneys to provide screening consultations with families; we established a list of specialists to whom the attorneys could refer for follow-up work, and we continued to include legal and financial workshops in all family and professional educational activities. A key component was to establish one of our social workers as a screener for concerns, particularly related to public benefits and insurance. The primary goal of our legal consultation program, in concert with our social worker, is to help families conserve resources and plan for the legal and financial consequences of long-term care.

**FSP as social change agent:** The last important aspect of our pilot program was our work as social change agent: public policy development, service coordination, technical assistance and community organizing activity. More than any other aspect of FSP, these activities make it unique. All of our efforts were designed and carried out to encourage the development of programs by other organizations. For example, we participated in the formation of ADRDA (regrettably, our mission to serve those with other brain impairments prevented FSP from becoming a chapter), and we helped develop local Alzheimer's respite centers, an Alzheimer's family support program sponsored jointly with a local hospital, the Brain Damage Coalition of California, more than 100 support groups and numerous service programs.

The concept of mutual effort and collaboration is the concept behind AB 2913 (Chapter 1658 of 1984). The new law establishes regionally based resource centers to assist families of brain-impaired adults and professionals statewide. Modeled after our pilot program, flexibility is built in to allow each region to develop its own services based on community needs. The right community fit is assured by placement of the centers in nonprofit agencies and
requiring project advisory councils. The centers' goals are three-fold:

1. To obtain comprehensive, coordinated public policy for adults with brain impairments;

2. to ensure the existence of an array of appropriate programs and services for brain-impaired adults and their families; and

3. to place a high priority on utilizing community resources in creating opportunities for families to maintain a brain-impaired adult at home when possible and in other community-based alternatives when necessary.

To achieve these goals, Regional Resource Centers must carry out the objectives specified in Chapter 1658:

a. Provide directly or assist families in securing information, advice, and referral services, legal services and financial consultation, planning and problem solving consultation, family support services, and respite care services;

b. Provide centralized access to information about, and referrals to, local, state, and federal services and programs in order to assure a comprehensive approach for brain-impaired adults, their families, and caregivers;

c. Assist in the identification and documentation of services needs and the development of necessary programs and services to meet the needs of brain-impaired adults in the geographic area;

d. Cooperate with the Statewide Resources Consultant and the Director of Mental Health in any activities which they deem necessary for the proper implementation of Chapter 1658; and

e. Work closely and coordinate with organizations serving brain-impaired adults, their families, and caregivers in order to ensure, consistent with requirements for quality of services, that the greatest number of persons are served and that the optional number of organizations participate.

Chapter 1658 placed responsibility for coordinating services to brain-impaired adults and their families, and relevant programs for professionals, in the Department of Mental Health. Statewide coordination of several functions is to be undertaken by a nonprofit agency as the "Statewide Resources Consultant" under the Department. In 1985, FSP's service program was designated the first Regional Resource Center serving six counties in the San Francisco Bay Area. FSP also became the Statewide Resources Consultant to the State of California. As the consultant, FSP:
develops and coordinates statewide information, technical assistance
and training about brain damage, the problems it causes and services
needed;

helps plan and set up the Regional Resource Centers throughout the state to
provide services to brain-impaired adults and their families, and to
assist these Centers in building additional local resources;

helps secure greater federal and private participation in financing
of services;

conducts research on the extent and consequences of brain disorders
and needed public policy reforms, aids in designing a classification
system and nomenclature, and makes recommendations for population and
epidemiological studies.

The law defines "brain impairment" as "significant destruction of brain tissue
with resultant loss of brain function". Both injury to the brain and
degenerative brain diseases are included in the definition. Examples given in
the statute include: Alzheimer's disease, multi-infarct disease, Parkinson's
disease, Huntington's disease, stroke, traumatic brain injury, post-anoxia and
post-infection damage, tumors and hydrocephalus.

Under Chapter 1658 service eligibility cannot be based on a client's
income. Persons who are eligible for Department of Developmental Services and
other public programs cannot receive the same types of services through
Regional Resource Centers, although Resource Centers can help clients find
those programs.

Chapter 1658 appropriated $1.1 million from the state general fund to the
Department to begin implementation of the law in the first year. The
Department and the Statewide Consultant are required to coordinate their
efforts with those of the California's Torres-Felando Long-Term Care Reform
Act and Linkages programs and with other legislative mandates in the aging and
long-term care field, as well as with other state agencies to ensure that
services are not duplicated.

Comparison to other statewide and regional programs: FSP studied
several program models before developing the approach taken in Chapter 1658.
Most notable were the previously described Regional Centers for the Developmentally Disabled, the Area Agencies on Aging under the Older Americans Act, the Protection and Advocacy Agency for Developmental Disabilities, and Health Systems Agencies. The Regional Resource Centers for Brain-Impaired Adults and Their Families are most like the Regional Centers for the Developmentally Disabled in that they are central resources, located in nonprofit agencies, where clients and providers can receive a variety of services and assistance.

California's State Department of Developmental Services manages funds for the Regional Centers for the Developmentally Disabled; a statewide council advises on matters pertaining to the system and to program development; a network of regional Area Boards reviews programs locally and provides technical assistance. Several communities also sponsor local citizen advisory groups on developmental disabilities. The Protection and Advocacy, Inc., program provides representation for those persons denied services and appeals system policies.

While the Developmental Disability program provided a model for delivering an array of services to the older, brain-impaired population, there were problems in the approach that we sought to avoid. The Regional Centers are entitlement programs that provide case management services to individual clients, utilizing open-ended purchase of service from "vendors". The costs are high and growing, and critics question whether the parents' roles have been supplanted. California's diagnostic eligibility definition—which differs from the federal functional definition and results in denial of service to some who suffer brain damage before age 18—is also challenged.

Assemblyman Agnos and FSP adopted the client needs review and planning model, utilized vendor selection methods and copied the technical assistance
role of the developmental disabilities service system. But we capped the cost of our program, made our centers' services those of resource information and counseling rather than entitlements, emphasized that other public programs must be employed first, and continued with our case coordination—rather than management—concept.

The Regional Resource Centers for Brain-Impaired Adults and Their Families are like the Area Agencies on Aging and Health Systems Agencies in their citizen advisory, planning and needs assessment roles. They are not grant-making or monitoring agencies. Protection and Advocacy, Inc. provided a valuable example of a nonprofit agency established by government to manage a program. However, legal representation of clients was specifically excluded from Chapter 1658 at the request of legislators.

Reasons for success and obstacles: Comments on factors that contributed to FSP's success and some obstacles have been included above when relevant. In summary, I think the reasons for our success include:

1. Emphasis on the family, in addition to the patient, as a target for services. Also, our ambiguous definition of "family" to include neighbors, friends, distant relatives and "significant others" has made the program adaptable to California's varied population groups.

2. The motto "to support the family, not supplant it", carried out in our programs by avoiding case management as a service has made the program palatable to family members and public officials. Simply stated, it makes people feel less anxious about our intent.

3. Our recognition of cost limitations and the need to build cheap
solutions makes FSP popular in the state Capitol. One legislator has frequently said that "FSP is a good buy". Our organization—and other groups seeking our help—have felt the stress of our financial limits. But few state-funded programs can boast of doubling intake annually, reaching more than 25,000 individuals through education programs, and sponsoring two landmark bills while increasing our public funds budget by only 12% over five years.

4. The integrity not to publicize our services when waiting lists existed limited the potential to anger those in need of help.

5. Understanding that brain impairments were part of a bigger picture in long-term care provision and financing, we can one day wind down. Few nonprofit agencies have the goal in mind.

6. Lack of fear of others. FSP is rarely accused of committing some sins believed to be common in the nonprofit community. Understanding that brain impairments are part of a bigger picture in long-term care provision and financing, FSP strives to understand other local groups and communities and to minimize turf battles. Rather than attempting to provide all needed services, we urge other groups to develop programs. We say in our literature that the complex problems caused by brain damage require creative solutions, which means that we must work with others to stretch limited funds and opportunities.

7. The board of directors. During the first four years of its existence, Family Survival Project was comprised of a dozen
hardworking family members, professionals and community activists. Paid staff was limited to part-time assistance from the association until the Project's first grant enabled the hiring of two employees. All decisions were made by or with the steering committee. Members devoted long hours as office volunteers, led the support group, testified in the Capitol, called family members in the evening to offer emotional support, and argued over policy decisions. Even with the growth in funds and staff, the overall direction and program decisions of FSP remain the province of the board.

But numerous obstacles were encountered.

1. The professional community at first was disinterested. We found the medical profession's disinterest to be foremost, but not unique. Brain-damaged adults were viewed as an impossible patient population. In fairness, many other needy groups (the homeless mentally ill, juvenile criminals, etc.) were highly visible. The problem was so great that I still remember vividly the first neurologist who invited us to speak to his staff and the first general practice physician who referred a family. Hospital discharge planners, county home care workers, community geriatric mental health workers and rehabilitation specialists were the ones who helped break down professional apathy. They knew as well as, probably better than, families where services broke down.

2. Public officials feared (and still fear) the so-called "tip of the ic. oerg". One analyst even used that language in a memorandum to the
state director of health services. The lack of incidence data and service cost data intensifies rather than allays these fears. In 1986, fiscal analysts in Sacramento are still asking for needs projections "before we're spending millions on this population and it's too late to get out."

3. Our complex messages and lower local visibility during times of heightened state or national focus also posed problems. We do not offer many pithy slogans. "Experts on brain damage and all its ramifications" doesn't make good copy. A two-year public relations campaign and AB 2913 are addressing this problem, however. Doing so is important to our ability to raise private funds for programs and to provide valuable help for those in need. We've been in business long enough to see changes in attitudes—"caregiver" replaced "caretaker" and "Alzheimer's" replaced "senility". Patience and persistence will pay off.

4. Lack of affiliation with a University or Medical Center. Ironically, FSP was created because no university or medical center in Northern California was filling this role. However, without an affiliation with such an institution, FSP did not have the credentials to obtain research grants or gain access to professional journals to publish results. To remedy this situation, funds through AB 2913 and other grants now enable us to undertake joint projects with the University of California, San Francisco, the Northern California Alzheimer's Disease Center, Mt. Zion Hospital and Medical Center, and faculty of the University of Southern California.
Challenges for the Future: FSP and other programs serving adults with dementia are presented with many challenges in the future. The principal issues will be the inclusion of our client populations in long-term care programs, the financing of that care, and the ethical and legal questions concerning termination of life, patient management, and rights of the cognitively impaired adult.

FSP's immediate challenges involve the implementation of AB 2913. We have until 1987 to set up the Resource Centers and must negotiate annually with the state for budget augmentations to meet the growing caseloads and work of each center. The requirement to establish uniform standards and procedures for our programs can result in a difficult period for those who have worked under flexible, innovative guidelines. This is a problem for all professionals working with those related to a patient with a disorder causing dementia. As we succeed in reaching our lofty goals, both in the realm of research and that of service delivery, we confront pressure to become more routinized and adopt professional standards.

The topics of professional standards and systematic service provision always raise the traditional conflicts between "direct service personnel", "policy makers" and "administrators/planners". At FSP, these dynamics are being closely watched: half of our staff are currently employed in the family service program and half in statewide clearinghouse, policy and development activities or administration. The tension between each group is palpable when discussions over goals and resource utilization occur. We strive to make each recognize its need for the other. The confusion over roles among participants occurred once before, when the organization's volunteers and board members first felt less needed as the agency's staff and programs grew. Actually, a different type of involvement was required, but for a while it felt to them
that they might lose touch with their own organization.

We must also work to balance the government's desire to lower or limit costs with our knowledge of this population's unmet needs. To date, FSP has been able to convince the State of California that we are not taking on the whole world (i.e., all brain-impaired persons and their caregivers). Rather, our programs help individuals, families and other private and public agencies create options that government has not provided. The fact remains, however, that costs will occur if these patients are to be fully served, and those costs will be higher than most public officials are currently willing to support. We hope that California's Regional Resource Centers will contribute to the growing effort to change their minds.
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 \_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.