

From Senility to Alzheimer's Disease: The Rise of the Alzheimer's Disease Movement

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PUBLIC AWARENESS OF ALZHEIMER'S DISEASE has increased dramatically within the last ten years. The words "Alzheimer's disease" conjure up images of a hideous, debilitating condition that has been referred to as the "disease of the century" (Thomas 1983), the "mind robber" (Froelich 1986), the "never-ending funeral" (Cutler 1986), "a slow death of the mind" (Clark et al. 1984) and one of the gravest problems that elderly persons, researchers, and government must face in the upcoming decades (Cohen 1983a).

In concert with this increased public awareness, the disease has emerged from an obscure, rarely applied medical diagnosis to its characterization as the fourth or fifth leading cause of death in the United States in little more than 12 years. This emergence has resulted from: (1) scientific research causing a shift in the biomedical conceptualization of Alzheimer's disease that resulted in the characterization of the disease as a major social and health problem; (2) the activities of a handful of neuroscientists with interests in promoting the disease; (3) the intersection of the interests of these scientists with the interests of representatives of the National Institute on Aging (NIA); (4) the interaction between scientists, NIA representatives, and care givers of persons with Alzheimer's disease and related dementias in the formation of an advocacy organization—the Alzheimer's Disease and Related Disorders Association (ADRDA)—that formed the basis of a social movement devoted to providing support to care givers and to

advocating increased funding for research into the disease; and (5) the interaction of members of ADRDA and representatives of NIA with patrons, the media, and representatives of Congress to increase awareness of the disease and, from this, an increase in the level of funding available for research into the disease.

Those within the NIA who were involved in the development of Alzheimer's disease research funding creatively forged alliances with individuals and groups that were instrumental in mobilizing resources to support increased biomedical research into the disease. The necessity of raising scientific and public awareness of Alzheimer's disease was based on an understanding of the importance of a categorical disease focus for increasing biomedical research funds from Congress. It was feared that without a disease-specific focus, it would be difficult to develop a solid constituency that would advocate increased funding for Alzheimer's disease-related research.

The aggregation of funds and labor directed toward research on Alzheimer's disease was initially accomplished through increasing research activity within the NIH, and was facilitated by the interests and efforts of biomedical researchers. NIA staff were crucial in promoting the development of a national organization for Alzheimer's disease advocacy efforts that actively encouraged biomedical research resource development. ADRDA provided a framework to sustain the constituency necessary to advocate increased biomedical research funding for the disease from Congress.

The alliances that were formed between scientists, representatives of government agencies, patrons, the media, and members of the general public and Congress were crucial to the ascendancy of Alzheimer's disease. These alliances, however, fundamentally required the development of a unifying construct that provided a focus for political action. This unifying construct was the shift in the biomedical conceptualization of Alzheimer's disease that allowed the inclusion of greater numbers of potential victims by the elimination of age as a primary disease criterion, and countered the popular assumption of the identity between cognitive decline and aging. The elimination of the age criterion was central because it contributed to the transformation of what had been generally considered "senility" into a specific disease with specific pathological characteristics and symptoms. This transformation was central in focusing the interests and activities of a variety of social collectivities with differing but related interests in

that it served as a legitimate framework around which collective action could be mobilized and policies to address the problem of Alzheimer's disease could be developed.

Alzheimer's Disease and Senile Dementia: The Historical Context

Increased public awareness of Alzheimer's disease (U.S. Senate 1980; U.S. House of Representatives Select Committee on Aging 1982, 1983a, 1983b, 1984, 1985a, 1985b, 1986a, 1986b, 1986c, 1986d; Cutler 1986; Kane 1986) must be viewed within the environment of biomedical research that provided the basis for claims that this disease is a critical problem. The work of biomedical researchers set the stage for recasting the disease from a relatively rare phenomenon to the "fourth or fifth most common cause of death in the United States" (Katzman 1976). But to understand fully this definitional transformation, it must be contextualized within the historical development of conceptualizations of dementia associated with old age.

The earliest reference to dementia associated with aging occurs about 500 B.C. The Greek lawmaker Solon revised the practice of dividing an inheritance among family members by allowing the designation of nonfamilial heirs, providing the judgment of the nonfamilial heir not be impaired by old age. Plato (427–347 B.C.) referred to dementia in advanced age as a reasonable excuse for the commission of certain crimes, but Hippocrates (460?–377? B.C.) did not include it among his inventory of mental disorders, most likely because senile dementia was considered a routine part of the aging process (Torack 1983).

In the first century A.D. the Roman medical writer Celsus introduced the terms delirium and dementia in his work *De medicina* (Cohen 1983b). The Roman physician Galen (A.D. 129–199) added "morosis" (dementia) to the list of medical diseases and specified old age as one of the situations in which it occurred. Galen was not wholly translated into Latin until the fourteenth century but by that time the mind was thought to be located in the heart or diaphragm and mental disturbances were thought to be a manifestation of witchcraft (Torack 1983).

In the sixteenth, seventeenth, and eighteenth centuries the writings of medical practitioners noted aspects of what is now called senile

dementia and referred to symptoms such as forgetfulness, dulling of the senses, failing judgment, and return to a child-like state. At the turn of the eighteenth century the clinical recognition of dementia evolved rapidly and in 1797 Pinel coined the term "demence" (Torack 1983). But it was Esquirol, a student of Pinel, who first defined senile dementia in 1838 (Torack 1983).

In the mid-nineteenth century nosologies became based on specific localized disease entities and the belief arose that disease left clearly identifiable traces on body tissue. As part of this nosological trend, physicians began to develop a definition of old age that separated it medically from all other age groups. The belief that diseases would manifest similar symptoms in all persons was supplanted by the notion that diseases would affect people differently according to their stage of life. The work of Schwann and Virchow in 1858 reinforced the notion of tissue degeneration through their examination of cellular structure (Haber 1983). Their work led to the concept that the aged were unable efficiently to replace dying cells, resulting in inevitable deterioration. Because of an inability to explain or deter this cell degeneration, the clinical characterization of the entire stage of senescence began to be viewed as a medical problem. "Growing old was itself the source of inevitable organic alterations that constituted the pathological state known as old age" (Haber 1983).

Until the development of the cell-degeneration theory of senescence, anatomical abnormalities associated with senile dementia remained unrecognized. By 1864 Wilks outlined the first definitive description of brain atrophy associated with senile dementia that subsequently became a regular feature of the pathology of dementia (Torack 1983, 26). In 1868 Binswanger introduced the term "presenile dementia" (Cohen 1983b) and in 1906 the German neuropathologist Alois Alzheimer described a characteristic set of clinical and neuropathological findings that represented the beginnings of the disease known today as Alzheimer's disease.

In Alzheimer's description he reviewed the case of a middle-aged woman whose symptoms began with memory loss and disorientation followed by depression, hallucinations and, within five years, dementia and death. Pathological examination of the brain revealed atrophy and lesions in the area of the cerebral cortex and an unusual clumping and distortion of cortical neurofibrils (Alzheimer 1907). In addition to Alzheimer's original case the Italian neuropathologist Perusini, a

colleague of Alzheimer's at the Laboratory of Anatomy of the Psychiatric and Neurologic Clinic in Munich reported three additional cases of the disease in 1910 (Amaducci, Rocca, and Schoenberg 1986). Between 1907 and 1911 a total of 13 cases were reported (Torack 1978).

Emile Kraepelin, one of the foremost organic psychiatrists of his time, proposed the condition be named after his neuropathologist, Alzheimer (Torack 1978; Braceland 1957). In 1910 Kraepelin introduced the condition "Alzheimer's disease" in the eighth edition of his four-volume classic textbook *Psychiatrie: ein Lehrbuch für Studierende und Ärzte*. Amaducci, Rocca, and Schoenberg (1986) have suggested that Alzheimer initially did not believe that the pathological changes he identified in the brain of the middle-aged woman represented a distinct disease, and that it was Kraepelin who decided to classify the pathological changes as a disease separate from senile dementia. This interpretation loses some of its plausibility when considering the following statement that appeared in Alzheimer's 1907 article, *Über eine eigenartige Erkrankung der Hirnrinde* [On a Peculiar Disease of the Cerebral Cortex], published three years prior to the appearance of Kraepelin's endorsement:

Clinically the patient presented such an unusual picture that the case could not be categorized under any known diseases. Anatomically the findings were different from all other known disease processes. . . . In summary, we are apparently confronted with a distinctive disease process. An increasing number of unusual diseases have been discovered during the past few years. These observations show that we should not be satisfied to take a clinically unclear case and, by making great efforts, fit it into one of the known disease categories.

There is also evidence to suggest that Kraepelin was not convinced that Alzheimer's disease was an entity that was entirely separate from senile dementia. In his discussion of Alzheimer's disease in the eighth edition of *Psychiatrie: ein Lehrbuch für Studierende und Ärzte* Kraepelin (1910) notes:

The clinical significance of Alzheimer's disease is at present still unclear. While the anatomical findings suggest that this condition

deals with an especially severe form of senile dementia, some circumstances speak to a certain extent against this, namely that the disease may arise even at the end of the 5th decade. One would describe such cases at least in terms of "Senium Praecox," if not more preferably that this disease is more or less independent of age.

Alzheimer's viewpoint that the disease was a distinct entity and not an example of the early onset of "senility" was consistent with a process known as "abiotrophy" that was popular in the early nineteenth century. Abiotrophy referred to a process where it was believed that the neural or muscular systems of some people prematurely degenerate because of hereditary defects (Gowers 1902). Alzheimer established a conceptual distinction between senile and presenile forms of dementia that was not evident prior to his work (Torack 1978).

The clinical classification of Alzheimer's disease as an entity distinct from causes of dementia associated with aging was also consistent with the conceptualization of senescence that influenced medical thinking during the late eighteenth and early nineteenth centuries. Growing old was itself considered the source of inevitable organic alterations that constituted the pathological state of senescence. The development of a theory that suggested that a disease constituted the "early" onset of growing old would have been untenable. The importance of this medical conception of senescence is central to an understanding of the acceptance of Alzheimer's claim that the pathological changes he identified constituted evidence of an independent disease entity (Fox 1986; Beach 1987).

The distinction between Alzheimer's disease and senile dementia has historically been the subject of debate (Fuller and Klopp 1912; Schnitzler 1911; Barrett 1913), partially because of differences in the interpretation of the significance of the histological changes (changes in cellular structure or organization) associated with the disease. Alzheimer was the first to describe the characteristic features of the disease, neurofibrillary tangles in the cerebral cortex associated with senile plaques, but there has been contention over whether these findings represented a distinct disease process.

By the end of 1912 more than 45 articles representing examinations of tissue from at least 500 brains appeared in the medical literature reporting senile plaques and neurofibrillary tangles in all forms of

dementing disease (Torack 1978) and similar reports continued well into the twentieth century (Critchley 1933; Boyd 1936; Jervis and Soltz 1936; Marchand 1940; Newton 1948; Sjogren 1952; Green et al. 1952; Thompson 1969; Merritt 1970). Other conditions in which they were found included posttraumatic dementia, cerebral arteriosclerosis, cerebro-cerebellar arteriolar amyloidosis, amyotrophic lateral sclerosis, Down's syndrome, toxic conditions, dementia pugilistica, postencephalitic Parkinsonism, and phenacetin abuse (Bucci 1963; Slaby and Wyatt 1974). Data have also been published from autopsies of patients with the neurofibrillary plaques and tangles who did not exhibit the typical mental deterioration (Gellerstedt 1933).

Alzheimer's disease has historically been conceptualized as a pre-senile form of dementia and its distinction from senile dementia was based upon the age of dementia symptom onset. In the case of presenile dementia of the Alzheimer's type, symptoms can be identified between 40 and 60 years of age while senile dementia was generally used as the diagnostic category if the symptoms appeared after the age of 60 (Roth 1981) or 65 (Katzman and Karasu 1975). As will be described more fully below, the elimination of age of onset as the criterion separating Alzheimer's disease from senile dementia was one of the most crucial developments resulting from increased scientific knowledge regarding the disease.

The suggested elimination of age of onset as the criterion separating Alzheimer's disease from senile dementia was not an example of a paradigm shift in the Kuhnian sense for two reasons. First, there were questions regarding the validity of the distinction beginning from Alzheimer's first characterization of the disease in 1907, and second, subsequent research related to the disease occurred within the confines of "normal science" (Kuhn 1970). Rather, it was primarily due to the application of newly developing technologies, principally the electron microscope, to the study of neurological diseases. More important, the reconceptualization set the stage for the development of a social movement around which awareness of the disease and mechanisms to promote it as an important social and health problem could be developed.

In the next section I will analyze how a social movement was constructed around the phenomenon of Alzheimer's disease. I will utilize McCarthy and Zald's (1987a) notion of "resource mobilization"

to examine the conditions under which Alzheimer's disease emerged from a relatively obscure medical diagnosis to its current characterization as a leading cause of death in the United States.

The Emergence of the Alzheimer's Disease Social Movement

A social movement is "a set of opinions and beliefs in a population representing preferences for changing some elements of the social structure or reward distribution, or both, of a society" (McCarthy and Zald 1987). In the case of those involved in mobilizing the Alzheimer's disease social movement, changes in elements of both social structure and reward distribution were desired. Social structural changes that were, and continue to be, a goal of this social movement include shifts in the allocation of health and social service resources for persons with the disease and their care givers. The goal of changes in reward distribution primarily involve increasing biomedical research funds into areas that are directly related to finding methods to retard or cure the progression of the disease.

McCarthy and Zald (1987) have developed a resource mobilization perspective in an attempt to conceptualize the salient dimensions of social movements. This perspective, in contrast to the influential social psychological orientations of Gurr (1970), Turner and Killian (1957), and Smelser (1963), which assume "that shared grievances and generalized beliefs (loose ideologies) about the causes and possible means of reducing grievances are important preconditions for the emergence of a social movement in a collectivity" (McCarthy and Zald 1987), provides the foreground for the selection of incentives, cost-reducing mechanisms or structures, and career benefits that lead to collective behavior. The former perspective highlights social psychological factors relevant to the emergence of social movements while the latter emphasizes social structural conditions and processes contributing to their emergence. Although I will primarily concentrate on examining social structural conditions that influenced the emergence of the Alzheimer's disease movement, I will also analyze social psychological factors such as shared grievances and generalized beliefs that contributed to the emergence of the movement.

McCarthy and Zald (1987) outline five salient dimensions of re-

source mobilization theory which help to explain the emergence of social movements. These dimensions include: (1) the necessity for the aggregation of money and labor resources; (2) the necessity for some form of organization to obtain the required resources; (3) the necessity of involvement on the part of individuals and organizations from outside the social movement collectivity; (4) an understanding of the movement of resources away from specific social movements and toward other social movements; and (5) a sensitivity to the costs and rewards in explaining individual and organizational involvement in social movement activity.

These dimensions of resource mobilization theory primarily focus upon structural conditions that influence the emergence of social movements. They will be used as guideposts to indicate the salient social structural conditions that influenced the emergence of Alzheimer's disease as a social problem which resulted in the creation of a social movement. Although the work of biomedical scientists that I will discuss in the next section predate the emergence of the Alzheimer's disease movement, their actions provided crucial preconditions that facilitated the emergence of the disease as a social and health problem.

The Seeds of a Social and Health Problem

In the early 1960s Robert Terry, then an associate professor of neuropathology at Albert Einstein College of Medicine, Bronx, New York, was given the task of applying electron microscope technology to the examination of a variety of neurological disorders such as Tay Sachs disease and Pick's disease by Saul Korey, a neurologist and neurochemist then at Einstein. Both Terry and Korey were interested in investigating human diseases of the nervous system, especially those affecting the brain. But the use of an electron microscope required obtaining very fresh tissue which meant that brain biopsies were necessary. The use of brain biopsies was not (and still is not) a common procedure in the United State, but was nonetheless required to obtain the needed tissue samples.

But certain constraints to performing brain biopsies were evident. First, to minimize the possibility of significantly harming a patient, only diseases that were progressive and fatal were selected. Second, the disease had to manifest its characteristics throughout the brain rather than in a focal area. This was required because to do a biopsy

the surgeon had to select an area of the brain that was relatively accessible and in which the loss of a gram of tissue would not affect the patient. Third, the disease had to manifest a structural abnormality that could be conclusively diagnosed (R. Terry personal communication, June 14, 1986).

Few diseases of the brain met these criteria. Certain viral diseases did, but Terry and Korey were not interested in examining those types of disease because they were the province of microbiologists and virologists. Two other major groups of diseases fulfilled these three criteria. One group was the storage diseases—such as Tay Sachs disease—that are inherited disorders in which there is an enzyme deficiency resulting in an inability to metabolize particular lipids. The second group were the dementias such as Alzheimer's disease, considered at the time to be a rare presenile disorder, and Pick's disease.

Terry and Korey began examining the storage diseases, especially Tay Sachs, and their research was progressing well when Korey died unexpectedly. Korey's death resulted in Terry's abandoning the examination of the storage diseases because research into these diseases required expertise in neurochemistry, which Korey had provided. Terry did not have the resources to hire a lipid chemist, so he abandoned his research on storage diseases and concentrated on Alzheimer's disease.

Dr. Terry became aware of an experimental model that could be applied to his research on Alzheimer's disease and this, in conjunction with Saul Korey's untimely death, cemented his research interests:

I was invited to the first Pan American Congress of Neurology in Lima, Peru, in the early 1960s. And . . . a distinguished experimental neuropathologist spoke about a model for the development of vacuolization in neuronal cell bodies. . . . I had just studied and published a few cases of Creutzfeld-Jakob disease . . . and that disease is characterized by vacuoles in the neurons. So I was interested in the model. . . . I tried the technique . . . and at the electron microscopic level they weren't vacuoles at all. They were masses of filaments in the neurons. They looked reminiscent of human neurofibrillary tangles. I had a human disease with an experimental model. I had no competition, and plenty of things to do with it. . . . These are the sorts of stimuli that lock a neuropathologist or an experimentalist into a line of research. I found it so fascinating with so many possibilities to look at that

I gave up all other aspects of research (R. Terry personal communication, June 14, 1986).

As a result of the application of electron microscopy, a perceptibly different understanding of the biological structure of Alzheimer's disease began to develop (Kidd 1963; Terry 1963). The application of this technology occurred within the context of the occupational structure of academic medicine which rewards productive research and publication through various career benefits such as occupational prestige, personal prestige, economic incentives, and economic security (i.e., tenure).

But merely generating knowledge regarding the phenomenon was not sufficient to facilitate the emergence of a social movement. It was not until approximately ten years later, in the early 1970s, that interest in Alzheimer's disease began to develop beyond the relatively limited confines of the group of scientists involved in neuroscience research related to the disease. The development of increased awareness of Alzheimer's disease signalled the beginning of the elevation of the disease to the level of a significant social and health problem.

The spread of interest in the disease beyond the scientific community coincided with the development of a social infrastructure that was critical for the mobilization of the Alzheimer's disease social movement. Social infrastructures within a society (e.g., economic, religious, political, scientific) refer to "preexisting structures of organization and communication that characterize cohesive, on-going, face-to-face groups" (McCarthy and Zald 1987). Preexisting structures of organization and communication can include preexisting ties, communication networks, secondary relations, and indigenous organized strength (McCarthy 1987).

The most notable social infrastructure for the development of the Alzheimer's disease movement was the scientific infrastructure provided by the National Institutes of Health (NIH). With the creation of the NIA a component of the existing scientific infrastructure provided by the NIH was added that provided the economic, labor, and political resources necessary for the characterization of Alzheimer's disease as a social and health problem of significance. A central reason for this was that the leadership within the NIA recognized the importance of a disease-specific or "categorical" approach to increasing funding for biomedical research.

The categorical approach to funding biomedical research has been a strategy effectively developed and used by Mary Lasker and Florence Mahoney in the late 1940s. The efforts of these two women in the post-World War II period were largely responsible for the emergence of the NIH from a relatively obscure division of the Public Health Service, primarily involved in cancer research, to the world's largest medical research center. They introduced modern advertising techniques to fundraising and subsequently developed key allies in Congress who would support biomedical research (Starr 1982). Although mass fund raising for medical research was already an extremely successful tool in the 1940s and biomedical research had emerged as popular cause in the 1930s, Mahoney and Lasker contributed significantly to increasing funding for medical research from Congress, especially for cancer research (Rettig 1977). Their activities were guided by two convictions. First, the American people would actively support increases in funding for medical research when the benefits of such activity were dramatized. Second, the federal government must be a major participant in the on-going support of medical research (Strickland 1972).

The legitimacy of biomedical research in the post-Second World War period was directly related to research successes during the war years such as finding a substitute for quinine in the treatment of malaria (the Japanese had seized the sources of quinine in the Pacific), isolating therapeutically useful derivatives for blood, and improving the strains and media for producing penicillin. But a major postwar research success, and probably the most influential in terms of cementing the public's faith in medical research, was the development of the Salk and Sabin vaccines for polio in the early 1950s (Starr 1982).

It was within this historical environment that support for biomedical research expanded dramatically, reflected in the NIH's rapid budget growth in the 1950s and 1960s. In 1950 the NIH budget was \$46.3 million and by 1960 it had increased to \$400 million (Starr 1982). In the late 1960s the rate of the NIH budget growth began to decline as federal priorities in health were shifted from research to medical training and the delivery of health services (Rettig 1977). The primary exceptions to these reductions in the NIH budget growth during the late 1960s and early 1970s were funds allocated for the National Cancer Institute through the National Cancer Act

of 1971 and funds for the National Heart and Lung Institute through the National Heart, Lung and Blood Act of 1972. The National Cancer Act increased the already-existing pressures toward categorical research appropriations and was the legislation after which the National Heart, Lung and Blood Act of 1972 was patterned (Rettig 1977). By 1984 the NIH budget had grown to \$4.4 billion (U.S. Department of Health and Human Services 1984a).

Prior to the emergence of the NIA other institutes within the NIH, most notably the National Institute of Neurological and Communicative Disorders and Stroke (NINCDS) and the National Institute of Mental Health (NIMH), served as the social infrastructure that was crucial to the subsequent mobilization of the Alzheimer's disease movement. These were the primary resource (e.g., facilities, funding, and labor) bases scientists initially utilized to increase knowledge of Alzheimer's disease. As I noted earlier, the arena in which much of the research activity occurred was academic medicine and included labor related to obtaining grants, conducting research, and disseminating research findings through conferences and publications. Researchers working in academic medicine subsequently emerged as some of the most avid supporters and directors of the Alzheimer's disease movement.

One of the most notable advocates for Alzheimer's disease research was Dr. Robert Katzman. He was a neurologist, who in the late 1950s, was working with Dr. Korey at Albert Einstein College of Medicine as a postdoctoral fellow. At the time Katzman was involved only peripherally in Alzheimer's disease-related research. In the 1960s Katzman's primary research interest was examining another dementing illness, normal pressure hydrocephalus. (Hydrocephalus is a condition characterized by an abnormal increase in the amount of fluid in the cranium that causes an enlargement of the head, deterioration of the brain, and cognitive impairment. The phenomenon was described by Hakim and Adams (1965) and Adams et al. (1965) and its manifestations include gait disturbance, progressive dementia, and, later, urinary incontinence.) He found, however, that when "we did biopsies on them [patients with suspected normal pressure hydrocephalus] . . . it turned out that a lot of them really didn't . . . have normal pressure hydrocephalus, they had Alzheimer's disease" (R. Katzman personal communication, November 12, 1985).

These findings stimulated Katzman's interest in studying Alz-

heimer's disease, and in the early 1970s he began to work clinically with Dr. Terry on Alzheimer's patients. In addition to scientific curiosity and the desire to further his career through research, his mother-in-law had been diagnosed as having the disease. This was a major motivating factor behind both his scientific and personal involvement in this area.

In 1974 Katzman was also attempting to organize an Alzheimer's lay organization in New York City that would expand interest in the disease beyond the handful of scientists working in the area. At the time he was unsuccessful in establishing the organization because of the lack of interest on the part of individuals whose involvement was crucial for the development of an organizational structure that could procure financial and labor resources to mobilize the Alzheimer's disease social movement.

In 1974, because of his interest in dementia generally and Alzheimer's disease specifically, Katzman prepared a paper for presentation at the Houston Neurological Symposium sponsored by the University of Texas Health Science Center in Houston. In that paper Katzman discussed the general topic of the differential diagnosis of dementia:

And as I started to think about it I looked up some of the epidemiological information about dementias and I knew from the pathologic data that was coming out that about 50 to 60 percent of the cases had Alzheimer's disease. And I did some simple projections and started to make some estimates (R. Katzman personal communication, November 12, 1985).

In the paper that Katzman had prepared in conjunction with Toksoz Karasu (1975), two suggestions were made that emerged as crucial in altering the biomedical conceptualization of Alzheimer's disease by recommending the elimination of the historical distinction between Alzheimer's disease and senile dementia. The first suggestion, which Katzman estimated from existing epidemiological data, was that "senile dementia" was the fourth leading cause of death in the United States. The second suggestion, based on the work of Ralph Terry and other researchers, was that senile dementia and Alzheimer's disease were the same entity: "We should like to make the suggestion, simplistic as it may be, that we should drop the term 'senile dementia' and include these cases under the diagnosis of Alzheimer's disease" (Katzman and Karasu 1975, 106).

In that same year the National Institute on Aging was established by the Research on Aging Act of 1974 (Public Law 92-296) to develop "a plan for a research program on aging designed to coordinate and promote research into the biological, medical, psychological, social, educational, and economic aspects of aging." The advocates and supporters of an institute devoted to aging research, including Florence Mahoney, had encountered numerous obstacles to the creation of an aging institute. In the 1960s and 1970s opponents of a separate institute for aging research claimed that there were inadequate numbers of competent investigators interested in aging research, that too many institutes were proliferating, and that the NIH was already supporting an adequate aging research effort (Lockett 1983).

Although Florence Mahoney supported the idea of an aging institute, she could not interest Mary Lasker in the idea, primarily because Mrs. Lasker felt that solving the problems of cancer and heart disease would solve the problems of aging. There were also conflicts among the groups that supported the creation of an institute devoted to research in aging. Florence Mahoney felt strongly that the new institute should focus solely on biomedical research because to devote resources to psychosocial and behavioral research would dilute resources available for biomedical research. Mrs. Mahoney's position was in direct opposition to many of those involved in gerontological issues and research who favored a broader focus for the institute that would include the examination of all aspects of the aging process (Lockett 1983).

A compromise was reached between those supporting a narrowly defined focus on biomedical research and those supporting a broader mission including psychosocial and behavioral research. The final bill that was passed by Congress (H.R. 14424) retained the language of the Senate version of the bill calling for biomedical, social, and behavioral research. President Nixon vetoed the bill, however, in his interest to reduce the size and complexity of the federal government. In 1973 the bill was reintroduced essentially unchanged and was again passed by Congress in 1974. The bill was sent to President Nixon's desk slightly less than two months before he would leave office as a result of Watergate. Not wanting to further alienate a Congress that was involved in considering his impeachment, Nixon signed P.L. 93-296 on May 31, 1974 (Lockett 1983).

Two years after the passage of the legislation that created the NIA

an editorial written by Katzman appeared in the April 1976 *Archives of Neurology*. In this editorial he reiterated his projections that Alzheimer's disease ranked as the fourth or fifth most common cause of death in the United States:

Essentially what I was doing in this editorial was taking things to their logical conclusion. . . . All I did was say if, in fact, half of the cases of senile dementia are due to Alzheimer's disease, and if you project the number of cases of senile dementia on the basis of community studies to our population of over 65 today, then it becomes a major public health problem and we have to start dealing with it. . . . I was simply making a logical extension. . . . People were sort of aware of it, but . . . hadn't done that simple logical extension at that time. And so I was excited about the importance of it (R. Katzman personal communication, November 12, 1985).

These relatively simple projections would be echoed in subsequent political activities and, tied to estimates of long-term care costs for the institutionalized elderly, would emerge as one of the primary justifications for increasing federal support for Alzheimer's disease research. The importance of this editorial in focusing attention on the problem of Alzheimer's disease was stressed by Katzman: "I think there's no question that that's my major contribution. Of the 115 papers I've written, that two-page editorial is clearly the most important" (R. Katzman personal communication, November 12, 1985).

By suggesting an identity between senile dementia and Alzheimer's disease, Katzman was able to increase by many times the number of potential cases of Alzheimer's disease in the general population. This suggestion also challenged the assumption of inevitable cognitive decline associated with growing old. "Senility" became tied to a specific disease (i.e., Alzheimer's disease) and was disassociated from the commonly held belief that growing old itself caused dementia. These projections formed the catalyst both for subsequent efforts to define the disease as a major social and health problem, and to mobilize resources to address the defined problem. Katzman was the first "issue entrepreneur" (McCarthy and Zald 1987) for the Alzheimer's disease cause.

In that same year a director for the NIA was hired, but finding a director for the new institute proved to be a difficult task. Florence Mahoney and NIH officials were seeking a biomedical scientist for

the director position but no suitable candidates were willing to take the job. Frustrated by this state of affairs, Mrs. Mahoney began to consider other possibilities. Dr. Robert N. Butler, a practicing clinical psychiatrist and gerontologist, was on the early list of possible candidates for the director position but had not made the final list. After reading his Pulitzer Prize-winning book *Why Survive? Being Old in America* (1975), Mrs. Mahoney met with him and was impressed by his wide range of interests and knowledge. She recommended him for the position to NIH officials and with the backing of Arthur Flemming, an influential Department of Health, Education and Welfare insider, he became director of the NIA on May 1, 1976 (Lockett 1983).

As the first director of the NIA, Robert Butler was interested in the importance of countering public misconceptions about "senility." He had been a practicing psychiatrist and brought with him an interest in correcting public misconceptions that not every elderly person is functionally and cognitively disabled, and that there are many conditions that lead to dementing disorders or memory loss which are not necessarily natural aspects of aging. It was also his desire to correct the misconception that all such problems were irreversible.

Butler was interested in the nervous system and felt that research in the areas of neuroscience and neurobiology were essential if progress was to be made in understanding abnormal cognitive changes associated with old age. Because the NIA did not have the resources to support significant research in this area at the time, Butler saw that these goals could potentially be attained through collaborative efforts with the NIMH and the NINCDS. Both institutes had programs concerned with examining central nervous system functions and aging and had funded research over the years that was related to Alzheimer's disease. At the time Butler's interest

. . . began not so much with the name Alzheimer's disease, but the question of central nervous system functioning and aging back in 1953 and 1954 and 1955. I had occasion to work with the National Institute of Mental Health . . . [in] measuring blood flow oxygen consumption. . . . We looked at the normal, healthy aged in state hospital populations. . . . It was intriguing that normal, healthy people, out of keeping with the expectations, [showed] no dramatic changes. In fact, blood flow and oxygen consumption were essentially the same in younger people.

[Subsequently] I . . . personally became interested in nursing homes and the character of the people in them, and it was very obvious, in both mental hospitals and nursing homes, that there were a huge number of elderly people with brain disease. So it didn't take much for me to get interested in Alzheimer's disease (R. Butler personal communication, May 23, 1986).

When established, the NIA was struggling to identify an area into which it could direct research efforts. In the initial stages the NIA was

. . . attempting to define the scope of the institute's research agenda . . . and began to develop a major program plan entitled: "Our Future Selves." The planning process started as soon as the NIA was created. In fact, the process was already in place before Butler came on board. . .

In the early years, one of the many problems the NIA faced was a lack of focus in its research agenda. The institute tried to stimulate too many initiatives at the same time. At one time, it had as many as 12 research priorities. This shotgun approach to program development did not work well (Z. Khachaturian personal communication, April 16, 1986).

As has historically been the case for other institutes within the NIH, it was important for the NIA to develop areas of research specialization. From the beginning the NIH resisted a separate institute for aging research for a number of reasons. First of all, the NIH argued against duplication of administrative services and costs, and was against the proliferation of research. Second, the NIH was skeptical of the possibilities of major breakthroughs in understanding the complex process of aging. Third, opposition to the development of a separate institute for the study of aging was evident from the wider scientific community. In addition to the conservatism of scientists in general, and the categorical disease orientation of biomedical researchers, there was fear that funds for aging research would divert funds from other established research areas. This intensified the opposition from the scientific community at large (Lockett 1983).

The National Institutes of Health and Alzheimer's Disease

After the publication of his editorial in 1976 Katzman and Terry corresponded with Dr. Donald Tower, then director of the National

Institute of Neurological and Communicative Disorders and Stroke (NINCDS). He had also known Tower from previous neuroscience projects in which he was involved that had been funded by the NINCDS and had collaborated with Tower in writing a textbook of neurochemistry in 1969. NINCDS funding supported Dr. Terry's early work which resulted in the application of the electron microscope to the study of degenerative neurological diseases, and he had received a project grant specifically to study Alzheimer's disease in 1977.

In a letter that was sent to Tower on April 20, 1976, a copy of Katzman's editorial was enclosed along with the suggestion that a conference be held to discuss the problem of dementia. The letter outlined gaps in knowledge that currently existed in relation to Alzheimer's disease. Also of importance was the following statement: "Specific congressional interest in research in such areas as stroke and head injury has been successful in developing centers of investigations; perhaps the same techniques should be applied to Alzheimer and related diseases" (letter from R. Katzman and R. Terry to D. Tower, April 20, 1976).

A disease-specific orientation had been instrumental in the creation of the National Cancer Institute (Strickland 1972; Rettig 1977) as well as in the creation of other institutes within the NIH. For the emerging problem of Alzheimer's disease, the NINCDS had in Tower a director who evidenced a concern with the scientific and public health problems that Katzman had outlined. Even more important, the neurology institute (as well as the NIA and the NIMH) provided the social infrastructure to facilitate the interaction of scientists for the purpose of discussing and defining problems with their current understanding of the disease. Less than ten years after Katzman and Terry sent their letter to Tower to organize this conference, Alzheimer's Disease Research Centers were established under NIA sponsorship.

Tower agreed that dementia was a public health problem and suggested that Katzman and Terry organize a conference to bring "appropriate authorities from around the world" to present the status of current research in this area and to identify areas where research, information, and resources were needed (letter from D. Tower to R. Katzman, May 6, 1976). In Tower's view the conference (which was subsequently expanded into two conferences) was to serve two purposes. First, to provide the NINCDS with information for "program-

ming and allocation of resources” and, second, to stimulate the interests of program participants as well as others in this problem. A copy of the letter was sent by Tower to Robert Butler in order to “coordinate their interests (NIA) and ours both in the program of the conference as well as the subsequent courses of action arising from the conference” (letter from D. Tower to R. Katzman, May 6, 1976).

The conference, entitled “Alzheimer’s disease—senile dementia and related disorders” was held in June 1977, was cosponsored by the NINCDS, the National Institute for Mental Health (NIMH), and the NIA, and focused on biomedical research (U.S. Senate Special Committee on Aging, 1979). This conference stimulated “new research on the causes and prevalence of senile dementia as well as the options for research on treatment approaches” (U.S. Department of Health and Human Services 1981; Katzman, Terry, and Bick 1978).

These were the first of a number of subsequent collaborative conference efforts between the NINCDS, the NIMH, and the NIA that focused on biomedical research issues related to dementia (U.S. Department of Health and Human Services 1981). These and similar conferences were important aspects of the scientific infrastructure provided by the NIH in that they provided an arena in which participants could explore research problems and cement mutual interests in furthering dementia-related research. The increasing involvement of the National Institutes of Health in the area of Alzheimer’s disease research was crucial for the subsequent success of the Alzheimer’s disease movement because it provided a preexisting arena in which the aggregation of money and labor could be mobilized to support further investigation into the characteristics of the disease.

One of the most important outcomes of the June 1977 conference for the incipient Alzheimer’s movement was the urging by Robert Butler of the formation of a “voluntary health organization devoted to Alzheimer’s disease and related disorders” (letter from R. Katzman to J. Stone, May 23, 1979). This connection with the NIA was subsequently to emerge as a critical factor in mobilizing economic, political, and labor resources to create an organizational structure to obtain the necessary resources to mobilize the incipient Alzheimer’s disease movement. The creation of an Alzheimer’s disease movement was also important for increasing the legitimacy of the NIA within the NIH. This was because of the need for a social collectivity that could organize to advocate for increasing funding for a disease that

the NIA could call its own. The disease-specific approach had worked for other institutes within the NIH and it was possible that it could work once again. Although the NIA would provide the necessary organizational structure for biomedical research development, it was not the structure necessary to sustain a constituency to advocate for increased Alzheimer's disease research funding. The creation of an organization that could mobilize and sustain such a constituency for advocacy purposes was crucial if Alzheimer's disease research efforts were to multiply.

*The National Institute on Aging and Alzheimer's Disease:
Categorical Funding and Alliances for Dread Disease*

While Dr. Butler helped to facilitate the cooperation of other institutes within the NIA around activities related to Alzheimer's disease, he was also aware of the need for the NIA to develop a disease-based research focus. To this end, Zaven Khachaturian was hired by Butler in 1977 to establish the Neurobiology of Aging program. Khachaturian was a neurobiologist with a long-standing interest in the neurochemistry of the brain, and was acutely aware of the importance of increasing NIA visibility within the NIH, as well as providing a more directed approach for NIA research activities. He began to focus efforts on research concerned with cognitive changes associated with aging "because there was a vacuum, not much was being done, no one else was focusing on them" (Z. Khachaturian personal communication, April 16, 1986).

By 1978 the Neurobiology of Aging program was underway with a focus on the biological basis of cognitive changes in normal aging. In an attempt to establish the credibility of the program, Khachaturian designated as his task convincing scientists who were well known in their respective fields to submit proposals to the NIA for projects related to the biological basis of cognitive changes in normal aging. As no special funds were allocated for research into Alzheimer's disease or neurobiology at the time, the burden was on Khachaturian to convince Butler that these were areas worth investigating:

The only way I could develop a viable program was by increasing the number of approved projects that could compete successfully against other more established programs. The way to accomplish

that goal was to work with the scientific community and attract them to be interested in the problems associated with the aging nervous system. So the principal task was to find good scientists who could be turned on by neurobiology of aging and Alzheimer's disease research (Z. Khachaturian personal communication, April 16, 1986).

While Khachaturian facilitated the involvement of the biomedical research community in Alzheimer's disease, Butler primarily focused his efforts on representing the NIA to Congress and in developing a public constituency to be an advocate for the Alzheimer's disease research cause. Butler was aware of the existence of a number of grassroots organizations devoted to addressing issues associated with caring for brain-impaired persons. But the organizations were geographically dispersed and were primarily focusing activity in their local areas. What was needed was a catalyst to bring their individual group efforts into focused collective action.

In the late 1970s the lay organization Katzman had attempted to organize in 1974 materialized as he was finally able to obtain the legal assistance that he had failed to secure earlier. The creation of this organization was instrumental in providing the structure needed to facilitate resource (i.e., labor and money) aggregation for the Alzheimer's disease movement. In December of 1978 the Alzheimer's Disease Society, which Katzman had begun in conjunction with Mr. Lonnie Wollin, a New York City attorney, received its tax exempt status notification. Katzman had approached Wollin in 1974 to assist in establishing the society, but as Wollin remarks:

Though I was legally able to, and had the legal knowledge to do so, I just did not go ahead with it. It wasn't until the third member of my family died of Alzheimer's that . . . we proceeded to form the Alzheimer's Disease Society (L. Wollin personal communication, June 6, 1986).

In February of 1979 Katzman requested and obtained \$3,000 from Dr. Jack Wilder, a professor of psychiatry at the Albert Einstein College of Medicine and a colleague of Katzman's, to begin the activities of the Alzheimer's Disease Society.

The next step was to organize a board of directors for the society. Katzman's colleague, Robert Terry, asked Jerome Stone, a successful

Chicago businessman, if he would be willing to sit on the Lay Board of Directors for the organization (letter from R. Terry to J. Stone, March 15, 1979). A number of years earlier Terry had met Stone, whose wife had been diagnosed as having the disease, and at that time the two had discussed the need for a society dedicated to Alzheimer's disease. Stone was interested in such an organization because of the difficulties he experienced in obtaining accurate information concerning his wife's illness:

Frankly, we didn't know what this thing was, we just went around from our family doctor who then said, well, sounds like this could be a little bit of depression. I think maybe she could use some counseling, psychotherapy and, you know, just give her a lot of loving and affection and everything will be all right. Common, he says, in women whose children have left the nest, post-menopausal and so on. So you see, we found that regular family physicians, internists, really did not know what Alzheimer's disease was. . . .

There was no literature on Alzheimer's disease, certainly no literature for the layman, there was no technical training for doctors, neurologists, anything. There were no nursing aides for Alzheimer's and, consequently, we were in a vacuum (J. Stone personal communication, October 30, 1986).

Terry outlined the goals of the society (i.e., information dissemination to physicians and families and encouragement and support of research) and, in addition to requesting that Stone be on the society's Lay Board, asked for his assistance in "getting this Alzheimer's Disease Society started toward an effective role in this country" (letter from R. Terry to J. Stone, March 15, 1979). Stone subsequently agreed to be on the Lay Board (letter from R. Katzman to J. Stone, May 23, 1979) and in May of 1979 Katzman expanded upon the two goals of the society briefly mentioned in Terry's earlier letter. The central focus of the society was the support of biomedical research in the area of Alzheimer's disease. As Katzman noted:

The goals of the Alzheimer's Disease Society are to provide education to the public and information to the medical profession. . . . The major objective of the Society, however, is to support research in Alzheimer's disease and related disorders both by giving direct research support to scientists and by using whatever leverage may be developed to help increase the [funds from the] National In-

stitutes of Health for this disease (letter from R. Katzman to J. Stone, May 23, 1979).

At the same time Katzman, at the suggestion of Robert Butler, requested Florence Mahoney to join the Lay Board of the society "in response both to Dr. Butler's statement [made at the 1977 international research conference] and to the urging of relatives of patients and interested physicians" (letter from R. Katzman to F. Mahoney, March 26, 1979). As noted earlier, Mrs. Mahoney was instrumental in hiring Butler as the director of the NIA and she had a long-standing interest in health issues, including birth control, mental health, and biomedical research. Another connection that supported Katzman's request for Florence Mahoney's assistance was through Dr. F. Marott Sinex, a biochemist at Boston University, who was involved with the society as a member of the Medical and Scientific Advisory Board. Sinex had long been involved in aging research and had been a strong advocate for creating the NIA and for increased federal funding for aging research. He had a continuing association with Florence Mahoney in their related activities which ultimately led to the creation of the NIA (Lockett, 1983). To increase awareness of the scientific community in the newly formed society, Katzman was able to have an announcement published in the journal *Neurology* which noted that "the interest of the neurological community in this organization would be greatly appreciated" (letter from R. Katzman to L. Rowland, May 14, 1979).

There were a number of similar "grassroots" groups organized in diverse geographical regions of the United States that were also focusing on problems associated with brain-impaired persons. In addition to Katzman's group (Alzheimer's Disease Society) in New York, there were organizations in California (Family Survival Project), Washington (Alzheimer's Support Information Service Team [ASIST]), Pennsylvania (Chronic Organic Brain Syndrome Society [COBSS]), Ohio (Alzheimer's Disease Association), Massachusetts (Massachusetts Society against Dementia), and Minnesota (Association for Alzheimer's and Related Diseases [AARD]).

Three of these groups were started by scientists who were present at the 1977 conference organized by Katzman and Robert Terry at which Robert Butler urged the formation of a voluntary organization dedicated to Alzheimer's disease and related disorders. The others

were started by family members whose relatives had Alzheimer's disease or a related disorder and who had repeatedly experienced difficulties in obtaining accurate diagnoses as well as financial, emotional, medical, and social support. Such experiences were a common motivating force behind the development of these local organizations. These experiences represented the "shared grievances" and deprivation that was a primary social psychological motivation behind family members' willingness to form an organization to mobilize collectively to address the problems they were facing. Many of the family members had been so devastated emotionally and financially by having to care for a loved one with the disease that the benefits of organized action outweighed the costs associated with such action.

Robert Butler was instrumental in bringing these groups together because in his view they had to organize into a national group to be effective. He was also interested in claiming Alzheimer's disease as one of the major research areas for the NIA so that funding for research into this disease would be channeled through his newly formed organization:

I decided that we had to make it [Alzheimer's disease] a household word. And the reason I felt that, is that's how the pieces get identified as a national priority. And I call it the health politics of anguish. People don't die from basic research, they don't suffer from basic research. They suffer from specific diseases (R. Butler personal communication, May 23, 1986).

Butler was implementing what he knew was an appropriate strategy to secure budgetary increases for the NIA. Targeting a specific disease for research efforts had historically been an effective technique to secure public support and funding for the NIH.

On October 29, 1979, Butler, in conjunction with Donald Tower at the NINCDS, persuaded representatives from these groups to come to Washington for a meeting. Butler had arranged for representatives of the Epilepsy Foundation to attend the meeting to emphasize the importance of combining into a single national organization to be effective. It was at this meeting that the foundation for a national Alzheimer's disease advocacy organization (later known as the Alzheimer's Disease and Related Disorders Association [ADRDA] and then the Alzheimer's Association) was laid.

A point of contention emerged at this first meeting which would

subsequently threaten the stability of the organization and would re-emerge as a critical issue throughout the formative stages of the movement's development. As Martha Fenchak Bell, representing the Organic Brain Syndrome Society of Pittsburgh at the time, notes:

we had . . . two . . . agendas coming to this national meeting, the medical community and the consumers. And both had very specific agendas that they wanted addressed and obviously the medical community, because of their interest, wanted very much to have a cure, a treatment, and medications developed for the disease to be halted. And as consumers . . . my group came from a background of grassroots needs and concerns of the family which is there's no money out there for reimbursement of this illness, everyone is going bankrupt, there are no services, and we've got to change this. . . .

And there was a great deal of suspicion on both sides that each agenda wouldn't be dealt with appropriately. . . . Even though everybody had these very strong concerns about what we wanted, we all felt . . . that this would be our best chance of dealing with all the problems (M. Fenchak Bell personal communication, October 30, 1986).

This meeting resulted in the passage of several resolutions that would ultimately have great impact in determining the subsequent development of the organization. In addition to the creation of the organization's name, it was agreed that a subsequent national board meeting be held where one representative from each of the seven organizations would attend and bring "the name of a public figure from their geographic area whose stature could be used as a drawing card for the national association" (memo from L. Wollin to ADRDA board members, December 29, 1979). This was crucial because public figures could facilitate both financial and labor resource aggregation. Jerome Stone and Florence Mahoney were designated as public members of the board and Katzman and Dr. Carl Eisdorfer, then professor and chair of the Department of Psychiatry at the University of Washington and associated with the Alzheimer Support, Information and Service Team from Seattle, were to be invited to attend the board meeting as nonvoting advisors (memo from L. Wollin to ADRDA board members, December 29, 1979).

The first National Board meeting was held on December 4, 1979, in Chicago. The meeting resulted in the designation of the organi-

zation's board members; Jerome Stone was elected president of the board and representatives from the original seven organizations that had attended the NIA-sponsored meeting two months earlier constituted the first ADRDA Board of Directors. The broad goals for the national organization had been outlined at the initial meeting in Washington and included coordination, education, family support, research for disease prevention, public policy, advocacy, organizational development, and fundraising.

The promotion of biomedical research by the newly formed organization emerged as one of the primary interests of Dr. Katzman. A Medical and Scientific Advisory Board was established and was co-chaired by Katzman and Eisdorfer, both of whom were also appointed as voting members of the organization's Executive Committee. The function of the advisory board was to review and recommend funding for research starter grants that could be given by ADRDA (minutes of the meeting of the ADRDA Board of Directors, December 4, 1979).

A Public Policy and Advocacy Committee was also formed with Dr. Sinex and Mrs. Mahoney as cochairpersons but no action was taken at that time. It was noted, however, that "by contacting a few members of the House and Senate Appropriations Committee, funds could be obtained. But it was stated that care must be taken because Congress is not receptive to a 'Disease of the Month' concept" (minutes of the meeting of the ADRDA Board of Directors, December 4, 1979).

Organizational development slowed when internal disagreements regarding ADRDAs structure and purposes emerged during attempts to develop and ratify by-laws. The conflict, which was originally voiced by representatives from the Family Survival Project in San Francisco, revolved around the difficulty in accepting the narrow focus of Alzheimer's disease for the lion's share of the organization's efforts.

Robert Katzman, as a member of ADRDAs Medical Advisory Panel, recommended that the major efforts of ADRDA in the areas of public information and research be targeted toward Alzheimer's disease. This reflected the fact that, from a medical point of view, there were a wide variety of diseases that could cause dementia and that "to cover all these disorders in terms of public information or research would dissipate any potential resources we might accumulate" (letter from R. Katzman to J. Stone, May 28, 1980). The dissipation of resources

was a central issue because of the desire to focus advocacy efforts on increasing biomedical research funding for Alzheimer's disease.

Katzman's viewpoint was that the services of ADRDA-sponsored family support groups should be made available to anyone, regardless of disease. Public education and scientific research, however, was a different matter. His view was that these activities should focus only on Alzheimer's disease and a limited number of researchable related disorders which might illuminate the characteristics of the disease.

This disagreement emerged from the differing interests from which each party approached the functions and responsibilities of such an organization. Similar disagreements had occurred in the 1979 meeting in Washington. As a researcher, Katzman was an advocate for targeting scarce resources that would benefit the cause of biomedical research to a specific disease entity that could be studied scientifically. But other participants in the social movement were advocating for a broader focus because of personal experiences of caring for relatives with cognitive disabilities and a desire to obtain assistance for people with brain impairments and their care givers.

The organizational focus on funding biomedical research projects was again raised during a subsequent meeting of the ADRDA board held in Chicago on June 5, 1980. Anne Bashkiroff, representing San Francisco's Family Survival Project, "stated that her group would not want the national organization to issue direct grants [for research] but to advocate others to allocate funds" (minutes of the meeting of the ADRDA Board of Directors, June 5, 1980) again reflecting the interests of care givers in focusing the movement's efforts toward obtaining needed assistance to care for a brain-impaired person. Although the goals of the organization formally accommodated a wide variety of interests, it was clear that biomedical research support and advocacy were primary.

But the issue of expanding the organization's efforts beyond Alzheimer's disease remained the most troublesome problem for the Pittsburgh, Seattle, and San Francisco groups. It was clear that Alzheimer's disease was to be the primary focus of the newly formed organization. John Mitchell, an ADRDA board member from Scottsdale, Arizona, stated the importance of this narrow focus: "The name of the game is 'Alzheimer' and if they [Seattle, San Francisco, and Pittsburgh] do not want to play let's call them out of order and request their withdrawal. You can sell Alzheimer but you can't sell alcoholism under

the title of Alzheimer and it should not be attempted" (letter from J. Mitchell to R. Katzman, July 15, 1980).

Conflicts regarding the disease-specific focus of the organization were not resolved for the San Francisco-based Family Survival Project or the Seattle-based ASIST group and they formally withdrew from ADRDA in 1980 (minutes of the meeting of the ADRDA Board of Directors, August 25, 1980; November 8, 1980). In resource mobilization terms, the conflicts which resulted in a number of the original family support groups breaking away from ADRDA reflected concern that limited resources would be spread too thin (i.e., toward services for patients with a variety of brain impairments and their care givers and away from biomedical research for Alzheimer's disease) if the organization did not specifically focus on one disease for advocacy efforts. To avoid such occurrences and to retain tighter control over chapters' activities, the National Board subsequently determined that all requests for local chapters be forwarded to the National Program Development and Membership Committee (minutes of the meeting of the ADRDA Board of Directors, August 25, 1980).

Interest in the newly formed organization began to explode after a letter from a family member of an Alzheimer's disease victim that outlined the problems inherent in dealing with someone with the disease was published in October 1980 in the nationally syndicated newspaper column *Dear Abby*. Marian Emr of the NIA Information Office had been contacted by Abigail Van Buren's staff for information regarding where a family member could obtain assistance and information. She responded to the request by providing the name and address of ADRDA. The media coverage gave much greater visibility to the emerging organization and resulted in tremendous response from the public:

They [ADRDA] had this little office and they had these boxes full of mail containing thousands and thousands of letters because it was just untapped. And that really set the thing up. They still didn't have very much money, but it just set things off (R. Katzman personal communication, November 12, 1985).

The organization received between 30,000 and 40,000 letters in response to the *Dear Abby* column. The publication of this letter was a turning point in terms of increasing the level of public interest in

the disease. It also reflected the potential resource base that could be drawn upon to support the movement's activities. The letters that were received provided the fledgling organization with a convenient mailing list from which to solicit contributions (minutes of the meeting of the ADRDA Board of Directors, November 8, 1980). The dissemination of knowledge of the existence of ADRDA provided an explicit focus to direct appeals for assistance from members of the public at large. In resource mobilization terms, the public response from the publication of the letter in the syndicated column signalled the involvement of yet other individuals and organizations outside of the Alzheimer's disease movement that were crucial for the success of the enterprise. This event highlighted the importance of involving the media in the movement's activities.

During this period of ADRDAs development (1979–1980), the number of projects within the NIA grew and by 1981 the Physiology of Aging Branch, of which Khachaturian was chief, accounted for 41 percent of the NIA's extramural, training, contracts, and intra/interagency agreement funds (the greatest proportion of such funds ever received by any one NIA program and/or branch/cluster in the period of 1978 to 1984) (U.S. Department of Health and Human Services 1986). Khachaturian's lobbying efforts resulted in increases in the number of Alzheimer's disease-related research proposals being submitted for NIH peer review.

The reputation of the scientists and the quality of the proposals resulted in increasing numbers of NIA proposals being funded. NIA funding had increased an average of 39 percent per year in the period of 1976 to 1980 (from \$19.3 million to \$70 million) (U.S. Department of Health and Human Services 1984a). This was very important for the new institute because it was the basis upon which its credibility and legitimacy grew both within the NIH and Congress. A research area had been identified for the Neurobiology of Aging program, but the work of attracting key researchers was crucial

because the first question that . . . the Congressional staff asked us was whether we had the scientific manpower to do the work. . . . In '78-'79 I could not, without hesitation, say yes, there are many scientists waiting to work on good scientific leads. We had to have a number of productive investigators working on promising leads to convince Congress that an investment in Alzheimer's disease would produce viable results and that this area of science could

make reasonable progress. . . . The key elements in building a successful national program of research was the presence of a critical mass of scientists interested in this area and the possibility that a credible scientific story would emerge (Z. Khachaturian personal communication, April 16, 1986).

The development of this scientific credibility was essential. As I noted earlier, in the history of the political struggle that led to the creation of the NIA, the paucity of researchers in the field was repeatedly used as a rationale to deny the need for a separate institute concerned with research on aging (Lockett 1983).

Members of ADRDA from the scientific community were also acutely aware of the need for increased scientific interest in the disease. Dr. F. Marott Sinex, an experienced advisor in gerontology to the extramural program of the NIH stressed this fact to Jerome Stone, the president of ADRDA:

Funding within the National Institutes of Health while subject to some restrictions would not seem to be the major barrier for research support of Alzheimer's disease. The problem is to get more good proposals to the Council with good priority scores! We must increase the awareness of study section members without making them feel that their particular fields are threatened by this particular categorical research. Scientists are also reached by the national media. We should support the overall budgets of the National Institutes of Health particularly the National Institute on Aging, Neurological Disease and Blindness and Mental Health, specifically their programs in Alzheimer's disease. Difficulty in funding is more likely to arise because of overall funding restrictions rather than any specific problems with the funding of Alzheimer's disease (letter from F. M. Sinex to J. Stone, November 7, 1980).

By this time study of the disease was yielding promising scientific results. Research was beginning to provide the basis for discoveries of neurochemical changes associated with the disease which made it more intriguing scientifically because:

That made it a disease you could work on. It was a specific, it wasn't general aging, age-related deterioration of the brain. It was a specific neurological disease. So these two things [including the pathologic research by Terry, 1963 and Kidd, 1963] absolutely revolutionized studies of Alzheimer's disease. It was not aging. This

was a disease. This was not senility. It was a disease with a name and a specific chemistry and that . . . meant scientists were interested, not just neuropathologists (P. Davies personal communication, November 5, 1986).

NIA staff were acutely aware of the importance of involving the media in the cause of Alzheimer's disease and continued efforts were made to get the press interested enough in the NIA-sponsored research to publish the results. Working through the NIA information office Khachaturian would see to it that whenever an interesting finding about Alzheimer's disease was discovered, it was reported to the press. Researchers would submit their findings to the NIA prior to being published in a scientific journal and when the article was approved for publication, the findings were distributed to the press.

It was never a sure thing that the article would be published in the press, however. It generally depended on whether the reported research made an interesting story that provided evidence which countered popular beliefs regarding some phenomenon. But the publication of such findings was extremely important because

. . . around here [in Washington] Congress tends to pay more attention to popular media than scientific journals. . . Part of the strategy was to inform the public, using the media, about major scientific accomplishments in Alzheimer's disease research and the implications of the scientific findings in terms that lay people could understand (Z. Khachaturian personal communication, April 16, 1986).

As noted earlier, these activities were crucial because they attracted the attention and interest of individuals and organizations outside of the Alzheimer's disease social movement collectivity.

In addition to seeking out well-established research scientists and convincing them to become interested in Alzheimer's disease research, Khachaturian's efforts were also directed toward placing the disease on research agendas that went beyond those of the NIA. In 1979–1980, Joseph Califano, then the director of the Department of Health, Education and Welfare (DHEW), wanted to implement a rational method to develop the DHEW agenda and, in particular, the research agenda for the NIH. The NIH went through a formal exercise to identify research areas around which the NIH would develop its budget

requests, and *Health Research Activities* emerged from this process (U.S. Department of Health, Education and Welfare 1979). Eleven priority areas were identified in this document, and one of those was the area of research into Alzheimer's disease and related dementias. Other priority areas included issues such as smoking and health, maternal health, and recombinant DNA research, which involved research topics that cut across many institutes at the NIH.

NIA staff introduced the concept that Alzheimer's disease and the dementias of aging should be one of the priority areas for research within the NIH because it had major public policy implications and, more important, was a scientifically promising research area:

It got on the agenda because we could demonstrate that there were some scientific opportunities (and) that we had the scientific manpower to pull it through. . . . Of course, we got a lot of support from the outside scientific community to get Alzheimer's disease research on the NIH agenda (Z. Khachaturian personal communication, April 16, 1986).

One of the seven proposed elements of the Alzheimer's disease and the dementias of aging initiative was the development of "centers for training and excellence in the study of chronic dementia to provide continuing leadership and innovation" (U.S. Department of Health, Education and Welfare 1979, 124). The possibility of creating such centers had been noted by Donald Tower three years earlier. Such centers would become an extremely important mechanism for developing the sites, facilities, research teams, and training programs necessary for increased biomedical research on the disease. To achieve the goals set out in the initiative, the need for significant increases in funding for Alzheimer-related research was outlined. The initiative projected that by 1984 more than double the amount of resources allocated for Alzheimer-related research in 1979 would be needed.

The importance of the *Health Research Activities* was that it signaled the first time that the issue of Alzheimer's disease and related dementias was placed on a formal NIH agenda. But the *Activities* did not play a major role in identifying the area of senile dementia as a focal point for budget development and no significant resources were committed to this research area as a result of being placed on that agenda. The *Activities* attempted to create the concept that the NIH needed 5,000 new projects as a minimum baseline for budget de-

velopment. Ironically, in subsequent years that minimum level was converted into a ceiling in yet another attempt to stem the growth of federal spending (Z. Khachaturian personal communication, April 16, 1986).

By the early 1980s ADRDA had emerged as a visible and viable advocacy organization. ADRDA committee members were very effective in increasing public and congressional awareness of the problems of patients and care givers, as well as the need for increased funding for research. Primarily as a result of ADRDA-initiated activities to increase public awareness, a plethora of hearings documenting the devastating effects of Alzheimer's disease, as well as the need for increased research funds, were conducted beginning in 1980 (U.S. Senate 1980; U.S. House of Representatives 1982, 1983a, 1983b, 1984, 1985a, 1985b, 1986a, 1986b, 1986c, 1986d). In addition to the news releases the NIA supplied to the press regarding advances in Alzheimer's disease research, ADRDA began more actively to disseminate and promote human-interest stories regarding the devastating effects of the disease on family members (Alzheimer's Disease and Related Disorders Association 1985). These activities were essential for the mobilization of the Alzheimer's disease movement because they kept the issue of Alzheimer's disease in the public consciousness and helped to recruit new allies to the cause and new members into the organization.

In 1982 in an effort to increase visibility in Washington, ADRDA hired a consulting firm, CR Associates, at the suggestion of Florence Mahoney (L. Wollin personal communication, June 6, 1986). This lobbying activity was in concert with the continuing advocacy efforts of members of the organization's Lay Board and local ADRDA chapters. Jerome Stone, the founding president of ADRDA, played an important role in obtaining congressional support for Alzheimer's disease-related research because of personal connections to a number of members Congress and the administration (R. Katzman personal communication, August 23, 1988). In addition, members of the ADRDA Medical Advisory Board were in frequent contact with the NIA regarding research and funding opportunities. As Katzman noted:

Those of us on the medical side on the Advisory Board frequently talked to Zaven [Khachaturian]. By that time I was on the council

requests, and *Health Research Activities* emerged from this process (U.S. Department of Health, Education and Welfare 1979). Eleven priority areas were identified in this document, and one of those was the area of research into Alzheimer's disease and related dementias. Other priority areas included issues such as smoking and health, maternal health, and recombinant DNA research, which involved research topics that cut across many institutes at the NIH.

NIA staff introduced the concept that Alzheimer's disease and the dementias of aging should be one of the priority areas for research within the NIH because it had major public policy implications and, more important, was a scientifically promising research area:

It got on the agenda because we could demonstrate that there were some scientific opportunities (and) that we had the scientific manpower to pull it through. . . . Of course, we got a lot of support from the outside scientific community to get Alzheimer's disease research on the NIH agenda (Z. Khachaturian personal communication, April 16, 1986).

One of the seven proposed elements of the Alzheimer's disease and the dementias of aging initiative was the development of "centers for training and excellence in the study of chronic dementia to provide continuing leadership and innovation" (U.S. Department of Health, Education and Welfare 1979, 124). The possibility of creating such centers had been noted by Donald Tower three years earlier. Such centers would become an extremely important mechanism for developing the sites, facilities, research teams, and training programs necessary for increased biomedical research on the disease. To achieve the goals set out in the initiative, the need for significant increases in funding for Alzheimer-related research was outlined. The initiative projected that by 1984 more than double the amount of resources allocated for Alzheimer-related research in 1979 would be needed.

The importance of the *Health Research Activities* was that it signaled the first time that the issue of Alzheimer's disease and related dementias was placed on a formal NIH agenda. But the *Activities* did not play a major role in identifying the area of senile dementia as a focal point for budget development and no significant resources were committed to this research area as a result of being placed on that agenda. The *Activities* attempted to create the concept that the NIH needed 5,000 new projects as a minimum baseline for budget de-

velopment. Ironically, in subsequent years that minimum level was converted into a ceiling in yet another attempt to stem the growth of federal spending (Z. Khachaturian personal communication, April 16, 1986).

By the early 1980s ADRDA had emerged as a visible and viable advocacy organization. ADRDA committee members were very effective in increasing public and congressional awareness of the problems of patients and care givers, as well as the need for increased funding for research. Primarily as a result of ADRDA-initiated activities to increase public awareness, a plethora of hearings documenting the devastating effects of Alzheimer's disease, as well as the need for increased research funds, were conducted beginning in 1980 (U.S. Senate 1980; U.S. House of Representatives 1982, 1983a, 1983b, 1984, 1985a, 1985b, 1986a, 1986b, 1986c, 1986d). In addition to the news releases the NIA supplied to the press regarding advances in Alzheimer's disease research, ADRDA began more actively to disseminate and promote human-interest stories regarding the devastating effects of the disease on family members (Alzheimer's Disease and Related Disorders Association 1985). These activities were essential for the mobilization of the Alzheimer's disease movement because they kept the issue of Alzheimer's disease in the public consciousness and helped to recruit new allies to the cause and new members into the organization.

In 1982 in an effort to increase visibility in Washington, ADRDA hired a consulting firm, CR Associates, at the suggestion of Florence Mahoney (L. Wollin personal communication, June 6, 1986). This lobbying activity was in concert with the continuing advocacy efforts of members of the organization's Lay Board and local ADRDA chapters. Jerome Stone, the founding president of ADRDA, played an important role in obtaining congressional support for Alzheimer's disease-related research because of personal connections to a number of members Congress and the administration (R. Katzman personal communication, August 23, 1988). In addition, members of the ADRDA Medical Advisory Board were in frequent contact with the NIA regarding research and funding opportunities. As Katzman noted:

Those of us on the medical side on the Advisory Board frequently talked to Zaven [Khachaturian]. By that time I was on the council

of the NIA and knew what the NIA was doing so I knew what the interest was on the federal level. . . .

So in a sense there was both the Alzheimer's association [ADRDA] and the people who were interested at the federal level at the NIH [who] were sort of helping each other in this regard (R. Katzman personal communication, November 12, 1985).

ADRDA and the NIA were working closely to advance the cause of Alzheimer's disease research, but it was through the efforts of ADRDA's Washington lobbyist that increased access to representatives and senators was realized (R. Katzman personal communication, November 12, 1985; J. Stone personal communication, October 30, 1986). ADRDA developed a two-pronged public awareness campaign aimed at local communities and government leaders (Ruscio and Cavarocchi 1984). Through its chapters and affiliates (which covered 15 states in 1979 and which in 1986 consisted of 125 chapters and affiliates in 44 states that utilized between 25,000 and 35,000 volunteers) (U.S. Senate 1980; Alzheimer's Disease and Related Disorders Association 1985; J. Stone personal communication, October 30, 1986), ADRDA members were instrumental in contacting senators and representatives advocating support of Alzheimer's disease-related legislation (J. Glenner personal communication, May 13, 1986). The development of a "public culture" of Alzheimer's disease resulted from these efforts, which has been instrumental in the elevation of the disease to a greater level of public awareness (Gubrium 1986). But in spite of increasing success in congressional and public advocacy efforts, bureaucratic forces within the NIH were moving to counteract the perception that research on Alzheimer's disease was underfunded.

Keeping the Lid On: The NIA in the Context of the NIH

The success of the NIA in increasing funding for Alzheimer's disease research was due to a recognition and implementation of strategies that had worked to increase funding for other institutes within the NIH. The NIA's success was also due to the ability of scientists working on NIA-sponsored research projects to make progress in understanding the disease. Although much of the biomedical research technology was already in existence before the NIA was established, mainly due to over 30 years of research activities in such institutes

as the NINCDS and the NIMH, it took an institute like the NIA to focus that technology in this specific area:

The whole story on neuro-chemistry of Alzheimer's disease could have been unraveled 12 or 15 years before 1976 when the first papers came out detailing the specific chemical deficit. That work could have actually been done in the early sixties but it wasn't, because who cared about Alzheimer's disease then. . . . It was really the application of existing technology to a new problem that was the result of increased interest in the disease. The technology was all there. It was just a matter of applying it. It's still surprising to me that there are actually a couple of papers in 1964 which hinted at some of the neurochemical abnormalities that we later reported in 1976, but nobody'd really picked up on the idea (P. Davies personal communication, November 5, 1986).

Before 1982 the NINCDS was the major funding agency for the study of Alzheimer's disease. During the years from 1978 to 1984 the Physiology of Aging Branch, which during that time was primarily responsible for Alzheimer's disease research activities within the NIA, had received the greatest proportion of NIA extramural research, training, contract, and intra/interagency agreement funds (averaging 36.7 percent per year) (U.S. Department of Health and Human Services 1986).

But the addition of resources was always managed within a context of the larger bureaucratic goals of the NIH, which at times did not correspond to Butler's goal of expanding the resource base of the NIA. This was made clear at the end of Butler's tenure as director of the NIA during a 1983 House Select Committee on Aging hearing on dementia which was chaired by Representative Edward Roybal of California. In the question-and-answer period following the presentation of testimony, Roybal asked Butler, William Mayer (Administrator of the Alcohol Drug Abuse and Mental Health Administration ([ADAMHA]), and James Wyngaarden (Director of the NIH) for their recommendations for Alzheimer-related funding.

Butler began by noting that "it is essential as an investment that we make major new additions to research. And I know that there is probably nothing magical about the thought of doubling the amount but I have come to that figure with some, I hope, rationality" (U.S. House of Representatives 1983a, 88). He went on to state that there

should be at least 10 centers of excellence to study Alzheimer's disease distributed throughout the United States at a cost of approximately \$15 million. This recommendation was in addition to increasing NIA funds for investigator-initiated research by \$10 million to a total of approximately \$25 million, as well as increasing the intramural programs of the NIH and the ADAMHA by "about several additional million dollars" (U.S. House of Representatives 1983a, 89).

Mayer was the next to respond to Congressman Roybal's question, indicating that "at this time we don't feel that simply an additional infusion of money into our research enterprise is going to significantly alter what we are doing as our part of this undertaking" (U.S. House of Representatives 1983a, 89). Wyngaarden echoed Mayer's sentiments: "Within the priorities for all the activities that we must support, we feel that research on Alzheimer's disease and other dementias of the aged is adequately addressed" (U.S. House of Representatives 1983a, 90).

Roybal was obviously not pleased with the responses of Mayer or Wyngaarden:

I remember making an amendment increasing the appropriation for research of cancer that amounted to \$1 billion; \$17 million is nothing in comparison. Either the disease is so serious that we need more work in the field or it is not. I am surprised that your answer seems to be that we have enough money to take care of the problem.

. . . Are you telling me that insofar as the National Institute of Health is concerned, that funding is sufficient? Is that correct? (U.S. House of Representatives 1983a, 90).

Wyngaarden reiterated his stance and Roybal again asked Butler his opinion. Butler responded by stating: "I think the collective judgment of many in the scientific community and certainly the judgment of those who suffer from this disease is that we are simply not, repeat not, devoting adequate resources to unraveling the mystery of it" (U.S. House of Representatives 1983a, 91).

In spite of such disagreements the NIA had, by 1985, established 10 Alzheimer's Disease Research Centers across the country to coordinate basic, clinical, social, and behavioral studies on Alzheimer's disease, create national standards for diagnosis, and establish a well-defined clinical population for future studies. The centers were es-

tablished as a result of the passage of the Health Research Extension Act of 1985 (Public Law 99-158). This act also authorized the director of the NIA to make grants specifically to conduct Alzheimer's disease-related research—the first such mandate in public health law—and authorized the creation of an Alzheimer's disease patient registry. In response to this law, the NIA established the Office of Alzheimer's Disease Research to coordinate various NIA activities related to Alzheimer's disease (Z. Khachaturian personal communication, June 10, 1988). The NIA had also collaborated with a number of international organizations, including the World Health Organization, to sponsor a planning meeting to develop international standards and research criteria for the diagnosis of Alzheimer's disease (U.S. Department of Health and Human Services 1986).

The following year, the Alzheimer's Disease and Related Dementias Services Research Act of 1986 (Public Law 99-660), was passed. This act authorized the creation of a Council on Alzheimer's Disease, an Advisory Panel on Alzheimer's Disease, Awards for Leadership and Excellence in Alzheimer's Disease and Related Dementias (LEAD), research related to services, a clearinghouse on Alzheimer's Disease, and also authorized Alzheimer's disease-related educational activity. Also of significance was an amendment to Title III of the Older American Act of 1987 (Public Law 100-175) that authorized Alzheimer's disease clinical trials research (Z. Khachaturian personal communication, June 10, 1988).

In 1976 the NIA was spending approximately \$4 million on research into Alzheimer's disease, which grew to an estimated \$80 million in 1989. The 1989 NIA Alzheimer's disease-related research budget is approximately 800 times larger than it was in 1979 (table 1). Increases in NIA funding for research on Alzheimer's disease and the passage of legislation related to the disease largely represented the results of concerted efforts by members of, and those allied with, the Alzheimer's disease movement. The efforts of those involved either directly or peripherally in the movement resulted in increased congressional and public awareness of the disease which was crucial for mobilizing additional resources to address the "disease of the century."

TABLE 1
 Total NIA Budget and Percentage Allocated for Research on Alzheimer's Disease and Related Disorders: 1976-1989
 (dollars in millions)

	1976	1977	1978	1979	1980	1981	1982	1983	1984	1985	1986	1987	1988	1989
Total NIA budget	19.3	30.0	37.3	56.9	70.0	75.6	81.9	94.0	114.9	143.0	150.9	177.4	194.6	222.6
% incr. from previous year	—	55.5	24.3	52.5	23.0	8.0	8.3	14.8	22.2	24.5	5.5	17.6	10.0	14.4
% allocated for AD-related research	4.4	5.0	5.3	7.3	6.0	6.9	9.8	12.6	16.0	20.2	21.8	23.7	24.5	35.9
Actual dollars for AD-related research	0.8	1.5	2.0	4.2	4.2	5.2	8.0	11.8	18.4	28.9	32.9	42.0	47.7	80.0
% annual increase	—	87.5	33.3	100.1	0.0	23.8	53.8	47.5	55.9	57.1	13.8	27.7	13.6	67.8

Sources: NIH Data Book. U.S. Department of Health and Human Services, June 1984a, 1984b, 1989.

Conclusion

The mobilization of resources to advance and organize what eventually resulted in the Alzheimer's disease social movement occurred within the context of social structural and social psychological conditions that contributed to the creation of the movement. Alzheimer's disease was elevated to the level of a significant social and health problem through the efforts and interests of a handful of neuroscientists concerned with furthering research goals, the organizational focus of NIA leaders to develop and promote a categorical disease emphasis to establish legitimacy within the NIH, and the creation of ADRDA as a focal point for advocacy efforts and for the aggregation of resources (e. g., labor and money) to support the Alzheimer's disease movement.

The NIH was central to the development of the movement because it provided a preexisting social infrastructure that facilitated the aggregation of scientific, political, and public resources for the development of a social movement. ADRDA emerged through the support of this infrastructure and was crucial to the success of the movement because it facilitated the creation of a social collectivity that was mobilized to attract the interest of the media and Congress in diverting resources primarily to support biomedical research on the disease.

Central to the emergence of this movement was the claim by researchers involved in investigating the disease that the historical distinction that had been made between senile dementia and Alzheimer's disease was not warranted on scientific grounds and therefore should be abandoned. The elimination of this distinction dramatically increased the number of potential cases of Alzheimer's disease by allowing the inclusion of cases of senile dementia associated with persons over 60 years of age. It also added further weight to the recognition that cognitive decline was not an inevitable aspect of growing older but was rather due to the effects of specific diseases.

This reconceptualization of Alzheimer's disease led to its perception as a significant social and health problem around which collective action could be mobilized to search for solutions to problems engendered by its existence. This transformation focused the activities of a variety of persons with different, but related, interests in that it served as a legitimate framework around which collective action could be mobilized, and policies to address the problem of Alzheimer's disease could be developed.

References

- Alzheimer, A. 1907. Über eine eigenartige Erkrankung der Hirnrinde. *Allgemeine Zeitschrift für Psychiatrie* 64:146–48.
- Adams, R.D., C.M. Fisher, S. Hakim, R.G. Ojemann, and W.H. Sweet. 1965. Symptomatic Occult Hydrocephalus with “Normal” Cerebrospinal-Fluid Pressure. *New England Journal of Medicine* 273:117. (Also cited in Katzman and Karasu 1975.)
- Alzheimer’s Disease and Related Disorders Association. 1985. Alzheimer’s No Longer a Silent Epidemic. *Newsletter* 5(1):1.
- Amaducci, L.A., W.A. Rocca, and B.S. Schoenberg. 1986. Origin of the Distinction between Alzheimer’s Disease and Senile Dementia: How History Can Clarify Nosology. *Neurology* 36:1497–99.
- Barrett, A.M. 1913. A Case of Alzheimer’s Disease with Unusual Neurological Disturbances. *Journal of Nervous and Mental Disorders* 40:361–74. (Also cited in Beach 1987.)
- Beach, T.G. 1987. The History of Alzheimer’s Disease: Three Debates. *Journal of the History of Medicine and Allied Sciences* 42:327–49.
- Boyd, D. 1936. A Contribution to the Psychopathology of Alzheimer’s Disease. *American Journal of Psychiatry* 93:155–75.
- Braceland, F.J. 1957. Kraepelin, His System and His Influence. *American Journal of Psychiatry* 114:871–76. (Also cited in Torack 1978.)
- Bucci, L. 1963. A Familial Organic Psychosis of Alzheimer Type in Six Kinship of Three Generations. *American Journal of Psychiatry* 119:863–66.
- Butler, R. 1975. *Why Survive?: Being Old in America*. New York: Harper and Row.
- Clark, M., M. Gosnell, D. Witherspoon, J. Huck, M. Hager, D. Junkin, P. King, A. Wallace, and T. Robinson. 1984. A Slow Death of the Mind. *Newsweek*, December 3, 56–62.
- Cohen, G. 1983a. Luncheon address presented at the fall training conference of the Western Gerontological Society, San Francisco, November 18.
- . 1983b. Historical Views and Evolution of Concepts. In *Alzheimer’s Disease: The Standard Reference*, ed. B. Reisberg, 29–33. New York: Free Press.
- Critchley, M. 1933. Discussion on the Mental and Physical Symptoms of the Presenile Dementias. *Proceedings of the Royal Society of Medicine* 26:1077–80.
- Cutler, N. 1986. Public Response: The National Politics of Alz-

- heimer's Disease. In *The Dementias: Policy and Management*, ed. M. Gilhooly, S. Zarit, and J. Birren, 161–89. Englewood Cliffs, N.J.: Prentice Hall.
- Fox, P.J. 1986. Alzheimer's Disease: An Historical Overview. *American Journal of Alzheimer's Care* 1 (Fall):18–24.
- Froelich, W. 1986. Family's Fate Turns on a Biological Roll of the Dice. *San Diego Union*, June 23.
- Fuller, S.C., and H.I. Klopp. 1912. Further Observations on Alzheimer's Disease. *American Journal of Insanity* 69:17–29. (Also cited in Beach 1987.)
- Gellerstedt, N. 1933. Zur Kenntnis der Hirnveränderungen bei der normalen Alterinsvolution. *Upsala läkareförenings förhandlingar* 38:193–408. (Also cited in Beach 1987.)
- Green, M.A., L.D. Stevenson, J.E. da Fonseca, and S.B. Wortis. 1952. Cerebral Biopsy in Patients with Presenile Dementia. *Disturbances of the Nervous System* 13:303–7.
- Gowers, W.B. 1902. Abiotrophy. *Lancet* 1:1003–7. (Also cited in Beach 1987.)
- Gubrium, J. 1986. *Oldtimers and Alzheimer's: The Descriptive Organization of Senility*. Greenwich, Conn.: JAI Press.
- Gurr, T.R. 1970. *Why Men Rebel*. Princeton: Princeton University Press. (Also cited in Zald and McCarthy 1987.)
- Haber, C. 1983. *Beyond Sixty-Five: The Dilemma of Old Age in America's Past*. New York: Cambridge University Press.
- Hakim, S., and R. D. Adams. 1965. The Special Clinical Problem of Symptomatic Hydrocephalus with Normal Cerebrospinal Fluid Pressure: Observations on Cerebrospinal Fluid Hydrodynamics. *Journal of Neurological Science* 2:307. (Also cited in Katzman and Karasu 1975.)
- Jervis, G.A., and S.E. Soltz. 1936. Alzheimer's Disease—The So-called Juvenile Type. *American Journal of Psychiatry* 93:39–56. (Also cited in Beach 1987.)
- Kahn, E. 1959. The Emil Kraepelin Memorial Lecture. In *Epidemiology of Mental Disorder*, ed. B. Pasamanick, 1–38. Washington: American Association for the Advancement of Science.
- Kane, R. 1986. Senile Dementia and Public Policy. In *The Dementias: Policy and Management*, ed. M. Gilhooly, S. Zarit, and J. Birren, 190–214. Englewood Cliffs, N.J.: Prentice-Hall.
- Katzman, R., R. Terry, and K. Bick. 1978. *Alzheimer's Disease: Senile Dementia and Related Disorders*. New York: Raven Press.
- Katzman, R. 1976. The Prevalence and Malignancy of Alzheimer Disease. *Archives of Neurology* 33:217–18.
- Katzman, R., and T. Karasu. 1975. Differential Diagnosis of De-

- mentia. In *Neurological and Sensory Disorders in the Elderly*, ed. W. Fields, 103–34. New York: Stratton Intercontinental Medical Book Corp.
- Kidd, M. 1963. Paired Helical Filaments in Electron Microscopy of Alzheimer's Disease. *Nature* 197:192–93.
- Kraepelin, E. 1910. *Psychiatrie: ein Lehrbuch für Studierende und Ärzte*. Leipzig: Barth.
- Kuhn, T. 1970. *The Structure of Scientific Revolutions*. Chicago: University of Chicago Press.
- Lockett, B. 1983. *Aging, Politics, and Research: Setting the Federal Agenda for Research on Aging*. New York: Springer.
- Marchand, L. 1940. De la maladie d'Alzheimer et de la maladie de Pick dans leur rapports avec la demence senile. *Medicine* 21:115–20. (Also cited by Slaby and Wyatt 1974.)
- McCarthy, J.D. 1987. Pro-Life and Pro-Choice Mobilization: Infrastructure Deficits and New Technologies. In Zald, M.N. and McCarthy, J.D. 1987. *Social Movements in Organizational Society*, ed. M.N. Zald and J.D. McCarthy, 49–66. New Brunswick, N.J.: Transaction Books.
- McCarthy, J.D., and M.N. Zald. 1987. Resource Mobilization and Social Movements: A Partial Theory. In *Social Movements in Organizational Society*, ed. M.N. Zald and J.D. McCarthy, 15–42. New Brunswick, N.J.: Transaction Books.
- Merritt, H.H. 1970. *A Textbook of Neurology*. Philadelphia: Lea and Febiger.
- Newton, R.D. 1948. The Identity of Alzheimer's Disease and Senile Dementia and Their Relationship to Senility. *Journal of Mental Science* 94:225–49.
- Rettig, R.A. 1977. *Cancer Crusade: The Story of the National Cancer Act of 1971*. Princeton: Princeton University Press.
- Roth, M. 1981. The Diagnosis of Dementia in Late and Middle Life. In *The Epidemiology of Dementia*, ed. J. Mortimer and L. Schurman, 24–61. New York: Oxford University Press.
- Ruscio, D., and N. Cavarocchi. 1984. Getting on the Political Agenda. *Generations* 9:12–15.
- Schnitzler, J.G. 1911. Zur Abgrenzung der sogenannten Alzheimerschen Erkrankung. *Zeitschrift für die gesamte Neurologie und Psychiatrie* 7:34–37. (Also cited in Beach 1987.)
- Sinex, F.M. Letter to Jerome Stone, President Alzheimer's Disease and Related Disorders Association, New York, New York. November 7, 1980.
- Sjogren, H. 1952. Clinical Analysis of Morbus Alzheimer and Morbus Pick. *Acta Psychiat. Neurol. Scand.* (Supplement 82):67–115.

- Slaby, A.E., and R.J. Wyatt. 1974. *Dementia in the Presenium*. Springfield, Ill.: Charles C. Thomas.
- Smelser, N.J. 1963. *Theory of Collective Behavior*. New York: Free Press. (Also cited in Zald and McCarthy 1987.)
- Starr, P. 1982. *The Social Transformation of American Medicine*. New York: Basic Books.
- Strickland, S.P. 1972. *Politics, Science and Dread Disease*. Cambridge: Harvard University Press.
- Terry, R. 1963. The Fine Structure of Neurofibrillary Tangles in Alzheimer's Disease. *Journal of Neuropathology and Experimental Neurology* 22:629-42.
- Thomas, L. 1983. [Quote appearing in Alzheimer's Disease and Related Disorders Association advertisement.] *New York Times*, June 21.
- Thompson, A.F. 1969. Sinotomalogia neurologica de las enfermedades de Pick y Alzheimer. *Archivos de la Fundacion Roux-Ocefa* 3:185-93. (Also cited by Slaby and Wyatt 1974.)
- . 1983. The Early History of Dementia. In *Alzheimer's Disease: The Standard Reference*, ed. Barry Reisberg, 23-28. New York: Free Press.
- Torack, R.M. 1978. *The Pathologic Physiology of Dementia*. New York: Springer-Verlag.
- Turner, R.H., and L. Killian. 1957. *Collective Behavior*. Englewood Cliffs, N.J.: Prentice-Hall. (Also cited in Zald and McCarthy 1987.)
- U.S. Department of Health and Human Services. 1989. *Moger Material*. Washington. (Unpublished data.)
- . 1986. *Report of the Director National Institute on Aging*. Washington.
- . 1984a. *NIH Data Book*. National Institutes of Health pub. no. 84-1261. Washington.
- . 1984b. *Progress Report on Alzheimer's Disease: Volume II*. National Institutes of Health pub. no. 84-2500. Washington.
- U.S. Department of Health and Human Services. 1981. *Progress Report on Senile Dementia of the Alzheimer's Type*. National Institutes of Health pub. no. 81-2343. Washington.
- U.S. Department of Health, Education and Welfare. 1979. *Health Research Activities of the Department of Health, Education and Welfare: Current Efforts and Proposed Initiatives*. Washington.
- . 1986a. *Setting a Federal Agenda for Alzheimer's Disease*. 99th Congress pub. no. 99-569. Washington.
- . 1986b. *Alzheimer's Disease and Related Disorders: The Government's Response*. 99th Congress pub. no. 99-588. Washington.

- . 1986c. *Alzheimer's Disease: Burdens and Problems for Victims and their Families*. 99th Congress pub. no. 99-542. Washington.
- . 1986d. *Alzheimer's Disease: Pennsylvania Perspective*. 99th Congress pub. no. 99-548. Washington.
- . 1985a. *Alzheimer's Disease: A Florida Perspective*. 98th Congress pub. no. 98-476. Washington.
- . 1985b. *Caring for Our Nation's Alzheimer's Victims*. 99th Congress pub. no. 99-521. Washington.
- . 1984. *The Politicization of the 1981 White House Conference on Aging*. 98th Congress pub. no. 98-458. Washington.
- . 1983a. *Senility: The Last Stereotype*. 98th Congress pub. no. 98-390. Washington.
- . 1983b. *Alzheimer's Disease: Is There an Acid Rain Connection?* 98th Congress pub. no. 98-400. Washington.
- . 1982. *Oversight Conference on Aging: A Preconference Assessment*. 97th Congress pub. no. 97-320. October 21, 1981. Washington.
- U.S. Senate, Subcommittee on Aging of the Committee on Labor and Human Resources and U.S. House of Representatives, Subcommittee on Labor, Health, Education and Welfare of the Committee on Appropriations. 1980. 96th Congress. Washington.
- U.S. Senate, Special Committee on Aging. 1979. *Development in Aging: 1978. Part 1*. Washington.

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