

Progress _____ _____ Against Alzheimer's _____ _____ Disease?

We have made some, but the innovation has mostly been in patient care, not biomedical advance—an important lesson that should inform future congressional action.

Alice was diagnosed with Alzheimer's disease in 1987; Bertha just recently. What is different about their experience? Certainly, many more people now know about Alzheimer's disease than did three decades ago. Bertha can now talk about it at Thanksgiving knowing that her family will have some sense of what she's up against; Alice's family had a lot more explaining to do, because few had heard of Alzheimer's disease in the 1980s, when public awareness was scant. The Alzheimer's Association had just been founded in 1979, through a fusion of individual support groups that had sprung up all over the nation; those groups coalesced into a nascent movement that has succeeded in raising awareness. But even in 1987, the movement was small, spotty, and regional; it has since grown into a national presence. And 2018 Bertha's family has many more materials to read, online help aids, options for getting adult day care, and options for assisted living than 1987 Alice. Specialized dementia care units abound, and more people are trained to deliver dementia care. Patients and their families can have more

confidence in the diagnosis at state-of-the-art clinics, which can use molecular biomarkers. And those newly diagnosed can join over a hundred clinical trials (if they qualify) to test drugs that aspire to change the course of disease.

But in many ways—indeed some of the most important ways—the situation has not changed much. Alzheimer's disease is still a plague upon us, and we don't really know what to do about it. Decades of research and tens of billions of dollars have produced mountains of scientific and medical literature. Yet only marginally effective preventive or therapeutic interventions have resulted. In 1987, the neurologist David Drachman observed that “It may be two or three decades before a favorable treatment is available. If this is so, developing increasingly efficient health care delivery grows in importance.” It turns out what seemed unduly pessimistic to many in 1987 was overly optimistic. Those three decades have passed. There is still ample hope, but far less optimism about preventing degeneration, let alone reversing or “curing” the disease, at least in the short run.

Many regard some promising recent clinical trial results as the first glimmers of real hope in years, but that refrain has played before in dozens of boom-and-bust cycles over the decades. Will it be different this time? We still don't actually understand why nerve cells die when people get Alzheimer's disease and the many other neurodegenerative

diseases that cause progressive brain failure (dementia). We don't have effective drugs to prevent or even halt disease progression. Most of the drugs to deal with symptoms are either only weakly effective or quite similar to those already available in the 1980s. So "cure" has not happened; but what about "care?"

On that front, there has been real innovation, triggered in the mid-1980s by a combination of forces, above all patient advocacy groups, Congress, and philanthropy. Here, I want to revisit the sources and benefits of that innovation, in the hope that we can broaden the spectrum of policy tools applied to addressing today's growing Alzheimer's problem. In telling this story I also want to emphasize the critical catalytic role played by an honest broker, the congressional Office of Technology Assessment. OTA, of course, no longer exists, but the story of innovation in Alzheimer's care helps make clear the importance of nonpartisan issue-framing and technical analysis in national policy-making—a lesson all the more resonant in today's hyperpoliticized world.

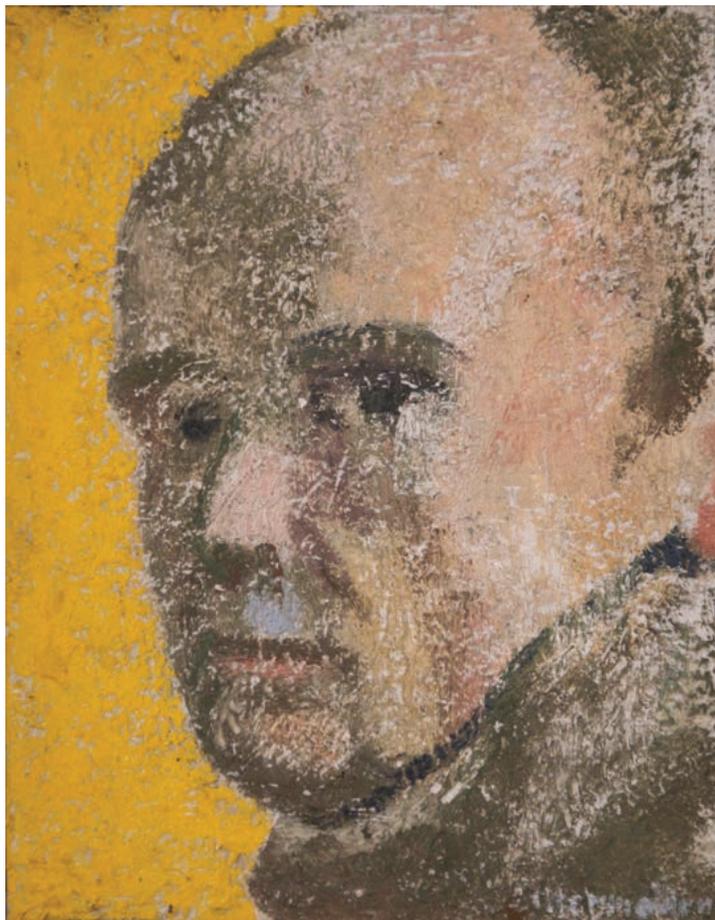
Stasis and progress

Long-term care is still a huge unsolved problem, first for families that have to almost totally spend down a patient's savings to become eligible for Medicaid, at which point financial responsibility moves to states and the federal government. Medicaid is really more than 50 different programs, in each state, the five territories, and the nation's capital. The rules are no less Byzantine and inconsistent among jurisdictions than they were 30 years ago; indeed, the polarized debate over the federal role in health care since the Affordable Care Act passed in 2010 has widened the gap between generous and less-generous states. And the burden still falls on those who care about and care for someone who is unlucky enough to develop dementia. We don't know if it is anyone's fault, and we don't know how to stop it.

The bottom line: tens of billions of research dollars over three decades, from both public coffers and private pharmaceutical and biotechnology companies, have not yet produced fully effective drugs. And the

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WILLIAM UTERMOHLEN



Self Portrait, 1990; Oil on board, 18 x 14.5 cm

William Utermohlen was born in south Philadelphia in 1933. He studied art at the Pennsylvania Academy of Fine Arts from 1951 to 1957 and on the G.I. bill at the Ruskin School of Art in Oxford, England, from 1957 to 1958. In 1962 he settled in London, and in 1967 he received his first important London show at the Marlborough Gallery. Depictions of his life and friends in London form intimate themes that thread throughout his body of work.

In 1995 Utermohlen was diagnosed with Alzheimer's disease (AD). Signs of his illness are retrospectively apparent in the work of the early 1990s, notably in the Conversation Pieces, which depict the warmth and happiness of his relationship with his wife, art historian Patricia Redmond, and his rich companionship with friends. But as gallerist and longtime friend Chris Boïcos noted, "Signs of the disease are made apparent in the shifting perceptions of space, objects, and people. They are premonitions of a new world of

silence and sensory deprivation about to close in on the artist.”

Utermohlen's work has become a standard representation of the use of visual imagery to depict internal psychological states of someone with AD. Although he wasn't engaged in art therapy, he did work with UK neuropsychologist Sebastian Crutch, who recognized the value of artistic expression and the arts as windows into mental and psychological processes of which one might not even be conscious. As Crutch noted, “his painting is more eloquent than anything he could have said with words.”

Because Utermohlen was a practicing artist for most of his lifetime, his neural pathways were conditioned to express through brush, paint, and hand. His artwork exhibits a disintegration of form into more affective and primitive symbolic states. His artistic rendering became less complicated and less defended. One can see in his work a progressive loss of identity or sense of self.

Utermohlen's portraits show a deterioration of facial characteristics, which may be indicative of the loss of facial recognition that is often symptomatic of AD. Over time his self-portraits become less cohesive and more abstract, and they show a loss of orientation and specificity, a growing spatial confusion and distortion. Utermohlen gradually integrates less color in his work, which might mean less affect or feelings, and less of a sense of awareness and being in the world, which is typical of people with progressive neurodegenerative disease. Utermohlen's paintings are a powerful representation of a growing health crisis.

Dementia affects 5% of the US population over age 65, and two-third of those people have Alzheimer's disease. Loss of memory is only one of many symptoms. The disease can also erode language capacity and limit patients' ability to articulate what they are experiencing.



Self Portrait, 1996; Mixed media, 45.5 x 32.5 cm

This leads to a deterioration of social connectedness and to feelings of isolation and abandonment. Although William Utermohlen did not formally participate in art therapy, his work suggests that art therapy interventions might be valuable for those with AD.

As a healthcare practitioner and academician whose research interests focus on the neuroscientific basis of creativity and the neurological mechanisms that underscore the intervention strategies in the profession of art therapy, I am famil-

iar with the importance of understanding the relationship between health and disease and its impact on psychological, emotional, and social functioning. Artistic expression, both in the process of creation and in the products that emerge, offers a path of communication and a window into the psyche that may be more effective than words alone.

Individuals suffering from overwhelming stress, neurological problems, trauma, depression, abuse, and mental illness often find it difficult to describe



Conversation Pieces, W9; Oil on canvas, 120 x 120 cm

their experience in words. Painting or drawing provides a channel for patients to express their thoughts and feelings more clearly and directly. Art therapists are trained to understand the art products that are created in the process of psychotherapy, and how the formal elements of artwork are representative of the internal workings of the person. This makes it easier, and faster, for the person to express what is bothering them. Many patients find artistic creations to be less personally threatening than words and are therefore able to be more transparent and objective. The art product stands as a symbol for the self, which allows the person, with the help of the trained therapist, to see themselves

more clearly. And knowing that art can also help others to understand what one is experiencing can help reduce the feelings of isolation and loneliness that accompany AD. As researchers continue their frustrating quest to develop a medical cure or treatment for AD, we must remember that innovations in the care of AD patients can make a difference now.

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Images courtesy of Chris Boïcos Fine Arts





Conversation Pieces, Snow, 1991; Oil on canvas, 193 x 241 cm

“system” of long-term care still largely depends on individual families, many of which are driven to financial ruin. The burden will likely increase as baby boomers reach the ages of highest risk. The one silver lining is some limited—and contested—epidemiological evidence that the incremental risk of Alzheimer's disease may not monotonically rise with age, but may reach a plateau or even decline a bit, so the wave of new cases may eventually crest and break, rather than progressively growing as the populations ages.

The brightest ray of hope comes from innovation that few people think of when they use the word: real progress in the practical work of taking care of people who develop dementia. The diversity, availability, and expertise in dementia care have grown, most notably through strengthened support groups, day and respite care, assisted living, and specialized dementia services. The national Alzheimer's movement created demand for services that have expanded and improved. There is, of course, ample room for improvement in both quality and fair access. State-of-the-art care is not available everywhere. The best services are available only to those who can pay for them. And we are a very long way from finding a fair way to distribute the financial burden. But there is solace in knowing the care has improved and can continue to do so.

Thirty-one years ago in *Issues*, Peter Whitehouse and I characterized a “looming crisis” facing the nation because of Alzheimer's disease and other dementias. We got the looming part right. But it was not a crisis. Ebola is a crisis, and flu is a crisis some years; AIDS was a crisis until it became a chronic illness with better drug treatments. Dementing conditions presented problems that have continued to fester, growing incrementally year by year. It is more like cancer, but without the remarkable advances in cellular and molecular biology and understanding of immune function and public health interventions that have begun to tame some forms of cancer. So “looming crisis” was the wrong policy frame. Peter Whitehouse was then a budding neurologist from Johns Hopkins whose work on acetylcholine neural pathways in the brain helped limn a possible pathway to treatment. Indeed, some drugs were developed. The first such drug was tacrine, which gave way to donepezil, which is still in use; but these drugs and a later addition, memantine, have at best a very modest clinical impact. The search for newer and better drugs was even then shifting to explore different biological targets: the “amyloid cascade” and “tau hypothesis.” Amyloid and tau are two hallmarks of Alzheimer's disease, known from its first description over a century ago.

The emerging scourge

In 1906, the German psychiatrist Alois Alzheimer described the combination of symptoms—decline of memory and cognition—that when observed in those with the anatomical brain changes (plaques and tangles) became the definition of the disease named after him. Alzheimer first encountered

51-year-old Auguste Deter in Frankfurt, Germany, in his medical practice. Her short-term memory and cognition were failing disastrously. Years later, when she died, Alzheimer was invited to perform an autopsy and examine her brain. He correlated the symptoms of dementia with the microscopic plaques and tangles he observed in her brain. Amyloid is a glob of proteins that accumulates outside nerve cells; tau is another fibrous protein that gets tangled inside nerve cells. A great deal of science has endeavored to understand the causal network that results in plaques, tangles, and broken brains. But after more than a century of research, we still don't know if plaques and tangles are causes of dysfunction or results of cellular destruction—or a bit of both through intricate interactions in a complex causal network.

When Alzheimer first presented the case of Auguste D. to his colleagues, there was almost no discussion, and he came away from that 1906 presentation disappointed. No one was really listening, and indeed “Alzheimer's disease” remained a relative backwater of neurology and psychiatry until Robert Katzman changed diagnostic practice in a famous 1976 article, “The Prevalence and Malignancy of Alzheimer Disease: A Major Killer.” Katzman, a pioneering neurologist at the University of California, San Diego, argued that “Alzheimer disease,” a term reserved for those developing dementia before age 65, was the same as the much more common “senile dementia” later in life. Alzheimer's disease was thus a hugely significant cause of death and disability—the fourth or fifth most common cause of death. Moreover, it was going to become much more common as the population aged.

As diagnostic practice adopted Katzman's terminology, making apparent the magnitude of devastation, support groups began to pop up all over the nation. They were unified in their concern about the burdens of care, in building networks of people who could help one another cope and understand, and in hope that more research might produce a technical fix. People facing common problems found one another and founded associations, the distinctively American phenomenon de Toqueville was so impressed with in *Democracy in America* a century and a half earlier. Katzman's unified diagnostic category strengthened and broadened the nascent social network of families contending with the ravages of dementia.

In parallel, the National Institute on Aging (NIA) began to consider Alzheimer's disease a major research priority. The National Institute on Neurological and Communicative Disorders and Stroke (NINCDS) and the National Institute of Mental Health (NIMH) had long-standing but modest research programs on Alzheimer's disease and other dementias. NIMH was the mainstay of psychiatric research and NINCDS for neurological conditions. The National Institute on Aging was a new kid on the block, having become an institute in 1974. NIA leaders flagged Alzheimer's as

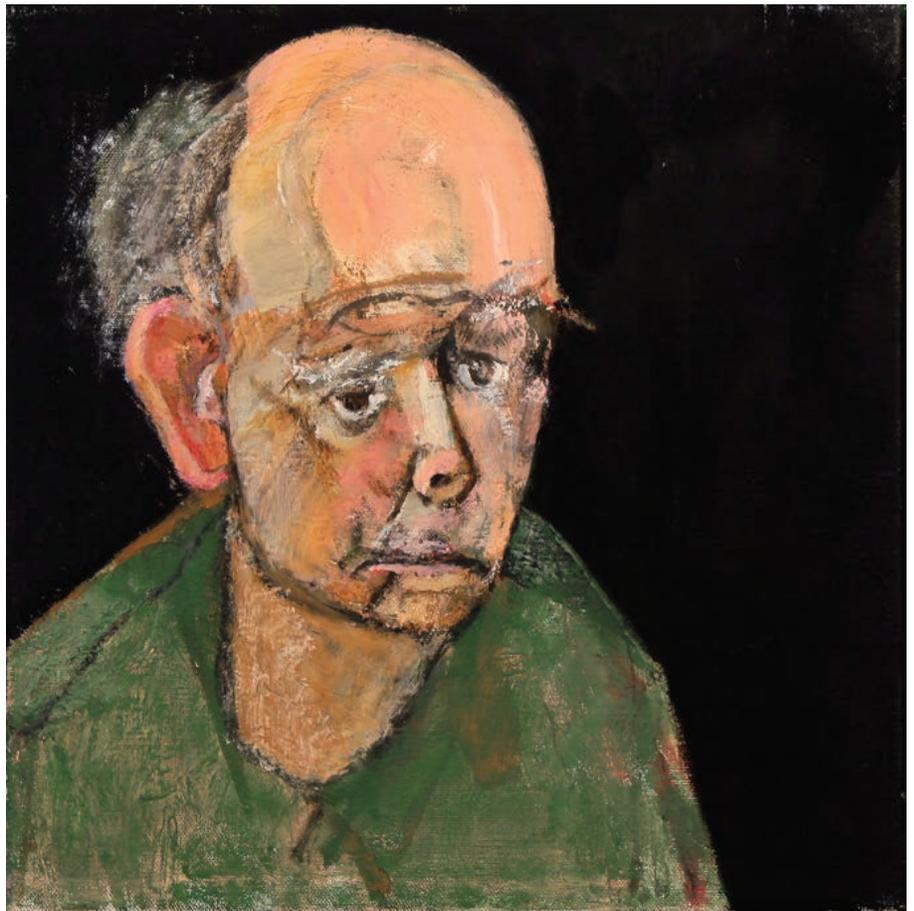
a flagship initiative, a decision that fostered healthy cooperation and competition among the three federal research institutes, as attention turned to Alzheimer's. The "coopetition" so common in science itself can also take place in the funding organizations, as it did here. Thus by the mid-1980s, the stage was set for a movement: research was increasing, NIA had established 10 centers of excellence for Alzheimer's research, the Alzheimer's Association was finding its footing in advocacy, and clinicians were recognizing dementia as a large and growing problem. The service sector followed to fill a newfound demand.

Congress began to pay attention. Alzheimer's disease became the subject of many hearings, and interest that began in the Committees on Aging in the House and Senate spilled over to the authorization committees concerned with health (Labor and Human Resources in the Senate and Energy and Commerce in the House) and the committees dealing with financing and organization of health care (Senate Finance and House Ways and Means). House and Senate committees on Veterans Affairs worried about what could be done for the increasing number of veterans developing dementia. The appropriation committees had been increasing research budgets for dementia, from \$4 million in 1976 to \$65 million in 1987. Yet dementia research was still funded at levels tenfold less than cancer or heart disease.

The number of publications on Alzheimer's disease in the medical and scientific literature in 1972 totaled 72. When I started studying Alzheimer's disease as a medical student in 1976, I could read every article that came out, and review all the past literature as a summer project. In 1985 the number of publications reached 548; no one person could keep up with all Alzheimer's research. Today specialization and proliferation of scientific research have grown by another order of magnitude. Indeed, the proposed federal Alzheimer's research budget for 2019 is \$2.3 billion, a sum we could never have imagined in 1987.

Enter OTA

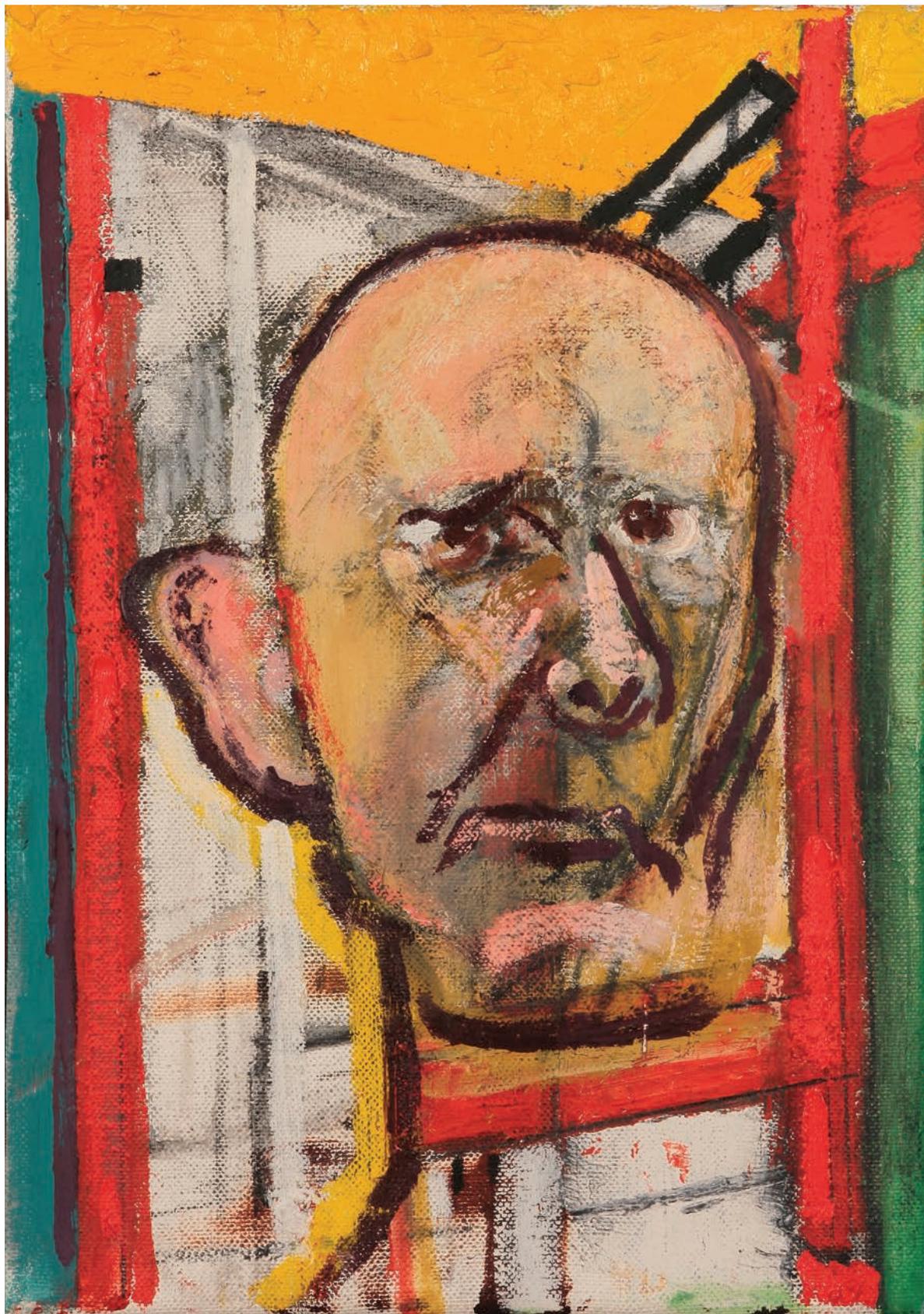
In the face of intensifying concern about Alzheimer's disease and dementia in many committees dealing with diverse issues, Congress turned to its Office of Technology Assessment



Self Portrait, 1997; Oil on canvas, 35.5 x 35.5 cm

for advice. OTA (which Congress killed in 1995) was at the time just over a decade old: "Congress's own think tank," as Peter Blair, an assistant director of the OTA, once dubbed it, studying policies touching on science, technology, and medicine. OTA had just completed a 1985 report, *Technology and Aging in America*, that described chronic conditions of aging, leading off with "Dementia: Social Problem, Medical Enigma and Federal Burden," as well as a chapter on long-term care that expanded on the immense care needs attributable to dementia that would relentlessly grow in coming decades. OTA's role was not to make policy, but to gather and sift evidence and arguments for those in Congress who had to solve problems and make the policy decisions. OTA presented policy options and arguments, but did not make recommendations.

As the *Technology and Aging in America* report was nearing completion, OTA staff met with both Republicans and Democrats on 16 committees and subcommittees (sometimes together, sometimes separately, depending on the micropolitics of staff relations). I organized these meetings, building on the network from the project just completed. We asked Hill staff in the trenches what policy questions were



Self Portrait, 1998; Oil on canvas, 35.5 x 25 cm

looming on the horizon. We went in with a list of a dozen possible topics. Dementia and Alzheimer's disease were not on the list, except as subordinate topics under several items. OTA's 1985 "fact sheet" on Alzheimer's disease had garnered a great deal of congressional attention, but it did not occur to us to frame a technology assessment around it.

In one of the early meetings, David Sundwall, a family physician and health legislative aide to Senator Orrin Hatch (R-UT), looked at the list and said that if OTA really wanted to be helpful, it should tackle Alzheimer's disease and dementia. Congressional staff were hearing about it everywhere. The idea of a report on Alzheimer's disease quickly rose to the top of the list in subsequent meetings with other members of Congress and their staffs. Thus was born the OTA project that produced *Losing a Million Minds* in April 1987, a 538-page compendium of information and policy options for Congress to consider in confronting Alzheimer's disease and other diseases causing dementia. Note that the idea came not from OTA staff or its network of experts or a formal horizon-scanning exercise of futurists, but rather from Hill staff immersed in the messy business of answering constituent calls, holding hearings, and helping draft legislation—democracy in action.

The article Peter Whitehouse and I wrote for *Issues* was a summary of the OTA report, published two months after its completion. More than three decades later, that report still feels as though it is the most important work I have ever done in a career working at the intersection of science, technology, medicine, and public policy. The main reason is that it actually informed legislation, it helped Congress think through the policies emerging from a national movement at just the right time, and most important, it became a touchstone for those designing real-world services for dementia care. It made clear that innovation in care-giving was important, and raised the profile of a neglected field.

One of the frequent complaints about both OTA and the National Academies of Sciences, Engineering, and Medicine is that their reports are too long, too slow, and poorly attuned to the policy needs and schedule of Congress. Those criticisms are often true, but a final report is only one—often partial and inadequate—measure of utility. As *Losing a Million Minds* was being prepared, more than 20 contractor reports were prepared and a half dozen hearings took place. OTA staff were tapped by the various committees to help identify witnesses, frame the purpose of hearings, and prepare questions. We were consulted by both parties in both houses about policy ideas that turned into bills. Most bills died—which is always the case when issues emerge and lots of new ideas are on the table—but several became law in late 1986, near the end of the 99th Congress. The report itself did not come out until April 1987. But the process of developing the report contributed directly to the development of three different bills. One was the Alzheimer's Disease and Related

Dementias Services Research Act, which authorized health services research, passed as one of the last gasps of the 99th Congress. The budget reconciliation and appropriation bills also included provisions to address the problems of dementia.

I'll come back to the importance of this legislation; but first, I want to emphasize OTA's contribution. OTA was only one of many elements that led to new laws; indeed the OTA project was a result, not a cause, of the same movement perceived by Congress—that something needed to be done about Alzheimer's disease. But if OTA did not launch the voyage, it helped navigate. Staff expertise, contractor reports, and expert networks were shared throughout the OTA process, and became resources for Congress, shared with congressional staff as legislation was developed, through OTA's persistent engagement with many House and Senate committees. *Losing a Million Minds* is best seen as an archival reference document that compiled and synthesized what was learned—and extracted policy-relevant lessons—but the report itself was not OTA's main contribution.

Not just nostalgia

The OTA process was systematically bipartisan. In today's Congress, an information broker such as OTA might find itself in an unremitting political crossfire. But in 1985-87 it was not so. There were many bipartisan bills. Howard Metzenbaum (D-OH), one of the most liberal members of the Senate, worked closely with Chuck Grassley (R-IA), one of the Senate's staunch conservatives. Many of the hearings and the planning sessions involved staffers working across the aisle. One of these, Evelyn Bonder, had lost her husband to Alzheimer's disease. Senator Metzenbaum hired her to work in Washington, after she testified about her husband's dementia at a field hearing in Cleveland. Senators Hatch and Ted Kennedy (D-MA), despite their very stark conservative-liberal and Republican-Democrat differences, worked closely with Henry Waxman (D-CA) and John Dingell (D-MI) in the House to incorporate a long-term care demonstration under Medicare into that year's budget bill. And their committees authorized a program of health services research to improve dementia care, because such research was funded at a level thirtyfold less than biomedical research in molecular and cellular biology and neuroscience. And funding even for that biomedical research—to reduce the gap between research on dementia and research on cancer, AIDS, and heart disease—was strongly supported, and completely bipartisan.

OTA is the only place I have ever worked that actually did problem-oriented interdisciplinary research. At OTA, drawing on many types of expertise came naturally; OTA's proximity to congressional members and staff on the Hill who were trying to address problems while managing national politics drove the agenda in a way that only rarely happens in universities or at the National Academies.

The two most important members of the OTA staff were

not PhD researchers, but former service providers with a talent for analysis and writing. Katie Maslow was a social worker, one of the most gifted policy analysts I have ever worked with. She went on to do a follow-up OTA study, *Confused Minds, Burdened Families*, released in 1990, then joined the Alzheimer's Association and eventually the National Academies. Nancy Mace had written *The 36-Hour Day*, the most widely used book about dementia care, touted as life-saving by many going through the experience. It is a best-seller to this day. Maslow's and Mace's importance was clear at the time, but even more apparent in retrospect. Their hands-on experience addressed the policy domain where most progress has been made: how to take care of people who develop dementia. It was not the scientists and clinicians who proved most important.

We have learned a great deal about the basic biology of dementing conditions. That knowledge has not yet translated to prevention or cure, but there is no reason to abandon hope.

OTA did, however, draw on considerable technical expertise too, both on staff and by commissioning reports from internationally recognized experts. The staff included two social workers, a budding health services researcher, a practicing attorney, an economist, a PhD biologist, and an MD. The advisory committee was chaired by a moral philosopher. The other members of the OTA advisory panel were household words in the nascent Alzheimer's disease movement. I emphasize the breadth and diversity of the staff because assembling such research teams was standard for OTA, but is very difficult to accomplish in universities and the National Academies, where the PhD credential, and related evidence of individual disciplinary scholarship, are the dominant indicators of expertise and intellectual legitimacy. OTA's breadth of staff expertise was essential. But even that was not sufficient. OTA solicited over 20 contract reports that fed into the process. These reports were written by luminaries in their respective fields, selected because of expertise on OTA's advisory panel, its staff, and its rich network of expert communities. The reports were shared with congressional staff as they were completed, and the expert network that nucleated around the OTA project became linked to the congressional staff drafting bills and holding hearings.

Of all the background documents—most of which summarized and interpreted policy-relevant evidence—the most useful were “reports from the field” of those pioneering innovations in dementia care. These were the emerging national experts in the emerging field of dementia care. The authors of those reports were selected mainly by Nancy Mace and Katie Maslow, in consultation with the OTA advisory panel and its national network of experts. OTA drew on programs that could serve as models at a time when there were few day and respite care services.

Another kind of innovation

Innovation is often equated with translating from molecular and cellular science to clinical application, from lab to bedside. The innovation in dementia care, however, was not molecular and cellular biology begetting drugs, but rather new ways of delivering care, and addressing the specific problems of those with dementia and trying to meet the needs of those caring for afflicted family members. Institutions were experimenting with day care centers, adult in-home care, and specialized units within nursing homes. Many doubted that those suffering from dementia could be safely taken care of in day care facilities or in short-term respite care. Some experiments worked; others did not, but pooling the experiences fostered learning and improvement.

Did any of this matter? No review of the three main bodies of law that the 99th Congress passed to address Alzheimer's disease and dementia can be comprehensive or entirely objective. But looking back 30 years later, it's clear that there has been more improvement in the range and quality of “care” services than drugs or prevention.

On the biomedical research front, we have learned a great deal about the basic biology of dementing conditions. That knowledge has not yet translated to prevention or cure, but there is no reason to abandon hope. Three decades of unrequited research is not evidence of failure, but a foundation for future work, and an indication that the biology of dementia is much more complicated than we thought it was 30 years ago. We knew these diseases were hard nuts to crack, but few people would have guessed how many failures in drug discovery and development would stack up. It is thus fortunate that Congress did not put all its eggs in the research-to-cure and research-to-prevent baskets. Those are still running bets. The fact is that we don't know—and cannot know in advance—if there will ever be a technical fix for Alzheimer's disease. We made this point in the OTA report, and argued that innovation in dementia care and improvement in coordination of care and financing would be important policies to address. Supporting biomedical research on Alzheimer's disease was already a mainstay of federal Alzheimer's policy before the OTA report, but the report reinforced it, and there were several waves of further expansion since—through both Republican and Democratic administrations, and



Self Portrait, 1999; Oil on canvas, 45.5 x 35.5 cm

when different parties controlled houses of Congress. But effective prevention or treatment is still a dream, and could remain so for some time; it depends what we discover.

The other major thrust of national policy on dementia is taking care of those who develop it. Those policies include financing and delivery of services, the “care not cure” policies to address the needs of people who develop dementia until and unless prevention or treatment improve dramatically. The financing of care has not changed much in three decades, and remains a pressing problem. The range and quality of services, however, have expanded significantly, and innovation on that front is the most dramatic change.

The federal role in policies to improve dementia care is a mixed bag. Policies include those that arose through legislation in 1986 and 1987. The Medicare demonstration of long-term dementia care that Congress mandated in 1986 became largely focused on whether case management and community care could reduce or substitute for nursing home placement and save money for Medicare (and Medicaid). In my personal view, the demonstration that many hoped might explore new pathways of care instead focused on cost-offsets that never materialized. Those who got services through those demonstration programs no doubt received the \$40 million worth of services stipulated by the law, but the nation got very little useful information about taking care of people with dementia. The demonstration was framed primarily as a way to save money, not to improve services. Other Medicare set-asides in the bills established diagnostic centers and funded a respite care demonstration in New Jersey. But the Medicare demonstrations were not a major source of innovation.

The real innovation took root mainly outside government, linked to the OTA process in Congress through the expert network that emerged. The emergence of day care, respite care, and other alternatives to nursing homes was the source of truly significant innovation. At the time, it was an open question whether day and respite care could adequately meet the needs of those with dementia and their families. Skepticism that anything short of nursing home care would be safe was in the air. Yet new centers for adult day care and respite care began to appear in the 1980s, and dramatically expanded through the growing national advocacy movement. With interest from Congress and private payers, health services innovators could test new ideas, drawing on the newly augmented resources, both public and private. Congressional support came mainly via the Alzheimer's Disease and Related Dementias Services Research Act.

The power of nonprofits

The most powerful impetus for day care and respite care came not from government, however, but from the nonprofit Robert Wood Johnson Foundation (RWJF). RWJF staff had been turning their attention to dementia care, and were

enthusiastic partners and participants in the OTA process. They attended congressional hearings and OTA panel meetings and workshops, and were in regular contact with OTA staff. In 1987 and into 1988, RWJF teamed up with the federal Administration on Aging and the Alzheimer's Association to sponsor a grants program, the \$5.1 million Dementia Care and Respite Services Program, in my view the single most important innovation in dementia care. RWJF, which funded the lion's share, and its program staff proposed an unusual framework: four-year grants that started with full funding, but tapered down, with the expectation that a funded project would become self-sustaining. I was deeply skeptical of the financial model, thinking that these services would never survive on their own financially, and that it was unrealistic and unfair to expect them to. And I was wrong.

The initial program funded 17 projects in 13 states between 1988 and 1992. The grants required a marketing plan and a credible business plan for continuation after the grant ended. Experimentation was encouraged. When the question of transportation to and from day care and respite care facilities was requested as a budget item, for example, senior RWJF officials were initially skeptical. Was paying for transportation really a legitimate health expense? But the RWJF program staff persuaded senior managers at the foundation to allow it on a pilot basis, and it proved essential. The step-down grants proved viable, and centers for day and respite care sprouted throughout the nation, inspired and informed by the model programs. They pooled diverse funding sources and brought a business sense to the delivery of long-term care services.

The initial 1988-1992 program was followed by a smaller \$2.5 million effort, Partners in Caregiving: The Dementia Services Program. That helped 50 centers in 30 states and Washington, DC, with smaller grants between 1992 and 1996. Although “dementia” was retained in the program title, in fact most of the centers were not dementia-specific. The program was becoming a national resource for day and respite care more generally, not just for dementia care. The follow-on program also tested the concept that programs might not need direct grant support for operations, but just technical support. Half the associated centers got grants that included funds for operations, while the other half got only technical support, drawing on the financial advice and care-delivery expertise of the burgeoning network of centers. The third and final RWJF program, the \$1.9 million Partners in Caregiving: The Adult Day Services Program, entirely removed the specificity for dementia and focused on disseminating the technical support, rather than grants for providing direct services. This was another distinctive feature of the RWJF programs: the National Program Office transformed from grant-giving into a hub of technical assistance supporting a thriving national network of long-term care services and became

a wellspring of expertise in how to deliver long-term care outside nursing homes. Staff involved in the program became nationally recognized experts in a growing field devoted to improving the variety and quality of long-term care.

Building on what has worked

So, as Congress begins to pour new money into Alzheimer's research, what lessons can we draw to help guide the next generation of public investments? First, there was a time when Congress could address national problems across the partisan divide. Solving problems could trump partisan tribalism. Our system of government can work, but it is not automatic; it requires commitment to civil discourse and common interests in solving problems. Today that sounds naïve, but 30 years ago it was reality—and it was a key ingredient to making important progress on Alzheimer's care. It can happen again.

Second, innovation is not just about molecules and machines. It is also about organizing care, learning how to render care more efficiently, more effectively, and with greater compassion and expertise. Innovation may come from business models and knocking down practical problems one at a time, not just by discovering drugs. People who know about delivering care, behavioral science, social work, coordination of programs, and health services research are important, and they can make progress even when science does not produce effective treatment or prevention.

Third, nonprofits are an important part of the innovation system. Arguably the most innovative policies that developed in the wake of the 1987 OTA report were supported through an alliance crafted by a major nonprofit foundation, the Robert Wood Johnson Foundation, whose staff integrated fully into the nascent Alzheimer's support movement and teamed up with a federal agency to foster alternative ways to deliver daily care to those with dementia. The national Alzheimer's Association became a potent force that led the Alzheimer's movement.

Fourth and finally, Congress can use some help in addressing policies affected by science, technology, and medicine. The early congressional efforts to deal with Alzheimer's disease were aided by the analysis and the expert network that nucleated around OTA as a resource. It was valuable to have a project focused on the emerging national Alzheimer's movement. OTA's report was more the result than the cause of a nascent national movement, but OTA caught the wave and enabled many players to make progress that might not otherwise have happened as quickly or effectively. It was a combination of Hill staff noticing an emerging cluster of problems, asking for the evidence pertinent to the problems to be gathered and synthesized, and bringing that knowledge into the political arena in a way that could be integrated into the congressional schedule and process.

Congress can, of course, function without a center for evidence-sifting in science, technology, and medicine; it

has done without OTA for over two decades. But Congress does not function as well. The absence of technical capacity in Congress is apparent in the cluelessness of its members trying to understand cyberthreats, or to regulate Facebook, or to deal with public concerns about genome editing. Medicine and biotechnology are issues for both Republicans and Democrats. Beyond biology, science and technology pervade most domains of policy, and will for the foreseeable future. Science, technology, and medicine are involved in many, if not most, decisions that Congress faces. Congress hobbled itself in 1995 when it stopped funding OTA. The songwriter Joni Mitchell told us, “you don't know what you've got till it's gone.” The story of innovation in dementia care—a story of citizens, philanthropy, and the political process working together to ease human suffering—helps make clear what has been lost. There are many ways for Congress to tap expertise in science, technology, and medicine, and Congress would work better if it turned attention to building that capacity.

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Recommended reading

- Peter Blair, *Congress's Own Think Tank: Learning from the Legacy of the Office of Technology Assessment (1972-1995)* (New York, NY: Palgrave Macmillan, 2013).
- Jeffrey Cummings, Garam Lee, Aaron Ritter, and Kate Zhong, “Alzheimer's disease drug development pipeline: 2018,” *Alzheimer's & Dementia: Translational Research & Clinical Interventions* 4 (2018): 195-214.
- Aaron Fluitt and Alexandra Givens, “Improving the Tech Expertise in Congress: Time to Revive the OTA?” Institute for Technology, Law & Policy, Georgetown University (2018).
- Zach Graves and Kevin Kosar, “Bring in the Nerds: Reviving the Office of Technology Assessment,” R Street Policy Study no. 128 (January 2018).
- Nancy L. Mace and Peter V. Rabins, *The 36-Hour Day: A Family Guide to Caring for People Who Have Alzheimer's Disease, Related Dementias, and Memory Loss*, 5th ed. (Baltimore, MD: Johns Hopkins University Press, 2011).
- US Congress, Office of Technology Assessment, *Confused Minds, Burdened Families: Finding Help for People with Alzheimer's and Other Dementias* (Washington, DC: US Government Printing Office, 1990).
- US Congress, Office of Technology Assessment, *Losing a Million Minds: Confronting the Tragedy of Alzheimer's Disease and Other Dementias* (Washington, DC: US Government Printing Office, 1987).

This article is supplemented by additional online material about the Office of Technology Assessment and Robert Wood Johnson Foundation work on Alzheimer's care.