La Follette Institute
Case Study Series

The Community Options Program (COP):

A Public Choice for Personal Choice in Long Term Support

Researched and Written by
Jerry Spann
Spring 1987

The Robert M. La Follette Institute of Public Affairs
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I. Introduction

> All . . . [public institutions] in the nature of boarding schools, where the sexes must be separated where there must be boarding in common, and sleeping in congregate dormitories; where there must be routine, and formality, and restraint, and repression of individuality; where the charms and refining influences of the true family cannot be had—all such institutions are unnatural, undesirable, and very liable to abuse. We should have as few of them as possible, and those few should be kept as small as possible.
>
> As much as may be, surround insane and excitable persons with sane people, and ordinary influences; vicious children with virtuous people and virtuous influences; blind children with those who see; mute children with those who speak; and the like.
>
> People run counter to this principle for the sake of economy, and of some other good end, which they suppose cannot be had in any other way . . . . Hence, I begin to consider such establishments as evils which must be borne with, for the time, in order to obviate greater evils. I would take heed, however, against multiplying them unnecessarily. I would keep them small as I could. I would take the most stringent measurements for guarding against those undesirable effects which lessen their usefulness; and for finally dispensing with as many of them as may be possible.
>
> ***Samuel Gridley Howe, 1866***[1]
> (Founder, first American state institution
> for persons with mental retardation)

The Community Options Program (COP) was conceived in Wisconsin's State Department of Health and Social Services and given legislative life in the 1981–83 Biennial Budget Act. By January of 1982, the first phase of COP's long, statewide implementation process was well underway. With only 8 of Wisconsin's 72 counties participating and a biennial budget allocation of only $3.6 million, COP's initial geographic and fiscal scope were quite limited. Its central goals, values and program design were, however, anything but modest. Program authors and advocates sought to do nothing less than successfully challenge the primacy of nursing homes and other institution-based, medical models of long term support for vulnerable elderly and disabled citizens of the state.

Beyond this direct challenge, COP held out the promise of client choice in the selection of alternative modes of long term support. Aimed at honoring the Department's long-standing policy of respecting consumer choice, dignity and self-determination, COP gave many nursing-home-eligible persons the option of electing supportive services provided in the client's home or in home-like settings in the community. In doing so, COP reflected and reinforced a new policy direction for the State Department of Health and Social Services and created a new set of prospects for those persons with serious, chronic conditions, who face the greatest risk of living out their lives in nursing homes and large state centers: the frail elderly, persons with developmental disabilities (autism, cerebral palsy, epilepsy, and mental retardation), persons with mental and physical handicaps, as well as chronic abusers of alcohol and other drugs. Beginning in 1986, a budget amendment granted program eligibility to persons with irreversible dementias.

COP's funding strategy was as ambitious as its policy direction. Capitalizing on an impending crisis, program planners spotlighted rising medicaid costs which were driving the Department of Health and Social Services budget and apparently spiraling out of control: By 1980, these costs neared the billion dollar mark in Wisconsin alone, frightening agency professionals and state legislators. Departmental analysis showed that over 60% of these costs were going to licensed nursing homes. Demographic studies offered even more cause for fiscal concern, projecting a substantial increase in longevity among the aging population in general, and the frail elderly in particular. Wisconsin's current medicaid problems were therefore destined to escalate without an effective counterweight to institutional long term support.

As a corollary to the COP program, Health and Social Services thus proposed and won legislative support for a moratorium on all new nursing home construction. With the moratorium in place, COP could, at least theoretically, be funded out of the state's share (42%) of medicaid expenditures saved by the moratorium. At the client level, this strategy meant that the average cost for each COP-eligible person would amount to no more than the State's contribution to the daily per person rate for nursing home care.

COP promised, in short, to better align the State's long term support values and dollars by funding a program concept that honored client choice and fostered the development of viable community-based services. By linking the nursing home diversion strategy with the moratorium, COP originators set attractive client-centered values into a context of fiscal prudence at a time when the decision-making environment was clouded by growing antagonism to new social programs and irresistible pressures to cut costs.

COP's large cast of characters will be familiar to participants and observers of high-level state decision-making: cabinet secretaries, agency professionals, governors, interest groups, advocates, county political leaders and social service workers, program recipients, lobbyists, state legislators and members of the press. All those involved in COP's creation had to confront, from very different perspectives, compelling need, competing interests and contracting dollars. The decisions they made, the compromises they struck, the legislative strategies they devised and their public statements offer valuable lessons to public sector managers from a variety of government service areas.

II. Decision Making: The External Forces

While COP was innovative in design, it was also a response to the political, social and fiscal forces of its time, as well as a reaction against Wisconsin's historical reliance on large, medically-oriented institutions of long term care. Chapter II sketches in broad-brush fashion several major trends that directly affected the development of COP. Chief among these were (A) the state's rapid expansion of nursing home capacity between 1950 and 1980; (B) national and local critiques of institutional care in the 1970s and (C) the status of Wisconsin's community services by 1980.

A. The Institutional Romance

Economic prosperity and the best of intentions cooperated to provide for a massive expansion of nursing homes, hospitals and colonies for the developmentally disabled, beginning shortly after World War II. This boom began in 1947 after the release of a shocking report prepared by a legislative-appointed committee charged with investigating overcrowding and abuse at State Colonies (now "Centers") for persons with developmental disabilities, during the war years.[2] In response to the ensuing scandal, the State Legislature spent some $31 million over a 10-year period toward the rehabilitation and enlargement of the colony system. Old colonies were refurbished, given new staff and physical facilities, and Central Wisconsin Colony and Training School was built in Madison. The Department of Public Welfare's noble goal was to offer the best care to the widest possible client population "in modern, well-staffed institutions," modeled after conventional medical facilities.[3]

A decade later, state and federal legislatures were similarly generous in the area of nursing home construction, which received a huge impetus with the 1965 enactment of Title XIX of the Social Security Act (Medicaid). Created to establish a "minimal level of health care for the poor,"[4] medicaid offered a valuable, sum-sufficient match (58%) to states for the purpose of upgrading patient care in large institutions and nursing homes.[5] This new source of funding had a massive impact on the direction of long term care policy in Wisconsin and elsewhere, both because the federal resources were so enormous and because they were tied to institutional care.

Medicaid dollars offered a bonanza to states inclined to seize an immediate opportunity to shift the huge fiscal burdens of long term care away from their own budgets and onto the federal budget.[6] Counties began to "transform" their hospitals into licensed nursing homes. Medicaid funds also became a major source of new revenue to support the maintenance of the Centers and the buildup of private nursing homes. Without malice aforethought, Wisconsin's enthusiastic embrace of Medicaid funds served to anchor and reinforce "for years to come the bias in favor of segregated," institutional care for people with chronic disabling conditions.[7]

During the 1960s and 1970s, the State was approving the construction of new nursing homes throughout Wisconsin. It also imposed new regulations in an effort to end abuses and ensure quality care. Community after community asked for and received a spanking-new nursing home facility for its aged and disabled residents. "Ma and Pa" operations, widely thought to be antiquated and inefficient, were typically replaced by much larger facilities designed to achieve medical sophistication and economies of scale. These new facilities were typically located on the outskirts of towns or in rural areas, away from population centers and easy access. By 1980, uncontrolled growth was contributing to an extraordinary use of nursing-home beds. In fact, studies showed Wisconsin to be the number two state in the country in nursing home use, with a utilization rate almost twice that of the national average.[8]

B. The Call For Change

There were, however, forces at work that would shift the climate of opinion dramatically during the 1970s. The successful civil rights advocacy of the previous decade had sensitized the whole country to the rights of oppressed minorities and the social evils of segregation. The resulting cultural changes paved the way for an assault on institutions that stereotyped, isolated and abused the elderly and persons with mental, physical and development disabilities. Anti-institutional feelings were reflected in and fueled by national and local media exposés that focused public opinion on gross forms of abuse and neglect. Many such scandals appeared first as sensational front-page news stories and later as class-action suits filed in federal district courts across the country.

At Alabama's Partlow State School and Hospital (for persons with mental illness), several deaths due to "understaffing, inadequate supervision and brutality were widely reported."[9] General physical abuse, rape, grotesquely unsanitary conditions and lack of minimal care and treatment were charged in a national media exposé of the Pennhurst School and Hospital (for persons with mental retardation) in Spring City, Pennsylvania; a similar story emerged around conditions at the Willowbrook State School in Staten Island, New York.[10]

While in some of these cases federal judges merely ordered corrective action in the form of new staff and institutional appropriations, others determined that the offending institutions were beyond repair. Conclusions of this kind led to deinstitutionalization orders and new public policies ensuring the patient's right to adequate and effective treatment in the least restrictive environment possible. At the same time, rapid advances in rehabilitation medicine and the growing sophistication and use of psychotropic drugs made noninstitutional care a practical possibility for large numbers of persons who were previously thought unable to live beyond institutional walls. The actual results of federally mandated deinstitutionalization taught new lessons, as well. Only a few years after federal orders had been put in force, 5,150 of Willowbrook's 5,400 retarded residents had been relocated to community settings.

Since the 1930s, Wisconsin's Centers had suffered sporadic investigations and embarrassing media attention related to charges of overcrowding, inadequate staff and insufficient programming.[11] Beginning in the early 1970s, the Centers also experienced periodic difficulties meeting the technical and substantive requirements of medicaid standards. The lessons of these problems, as well as more dramatic examples like Pennhurst and Willowbrook, were not lost on the Wisconsin State Department of Health and Social Services.

A small but significant number of the Centers' more capable residents had in fact been moved into small group homes by the early 1970s. By the same time, hundreds of less capable residents had been transferred to licensed, medicaid-eligible nursing homes. Clearly the motives for these actions were mixed. Deinstitutionalization saved millions of state dollars by capturing federal medicaid funds. The agency could, however, also argue that nursing homes represented the lesser of two evils, because they were smaller and less subject to overcrowding.

Many advocates and rehabilitation professionals questioned the nursing-home placement initiatives, citing lack of specific standards for the care and treatment of non-elderly disability groups.[12] More radical critiques asked why young persons with mental retardation and adolescents with non-acute, medically-controlled mental illness were being placed in nursing homes designed and staffed for the frail, and often gravely ill, elderly.

The 1970s were also a time of new and aggressive advocacy on behalf of persons with physical disabilities. In 1973 Governor Patrick Lucey established the Governor's Task Force on Problems of People with Physical Handicaps to study the special social and educational problems faced by this group and to make recommendations designed to address barriers and ensure the achievement of full civil rights. A year and a half after its founding, the Task Force submitted its *Final Report* to the Governor.

Early sections of the report noted that the number of persons with physical disabilities was steadily increasing due to Viet Nam War casualties, highway accidents and industrial mishaps, coupled with medical advances that were achieving unprecedented survival rates. The report also argued that "the delivery of health care services, however, continues to be geared to the infectious diseases with far too few resources allocated for the rehabilitation of the ever-increasing number of persons with chronic physical disabilities."[13] Commission members also deplored civil rights failures and social practices that ". . . labelled, segregated, isolated and sometimes institutionalized . . . persons with disabilities."[14] The report's wide-ranging recommendations urged initiatives designed to further "opportunities for self-determination and independent living. . . ."[15]

One of the strongest and most consistent calls for change came from Lieutenant Governor Martin Schreiber's Nursing Home Ombudsman Program. Between 1972 and 1979, the program generated a steady stream of news releases and articles exposing nursing-home treatment scandals, decrying the state's inadequate regulation record and illuminating the need for and the difficulties associated with reform. Exhibit 1 is a representative example of the Ombudsman Program's concerns, reflecting its commitment, energy and growing skepticism about regulation as a solution to client abuse and neglect. Schreiber's continuing interest and support, in addition to the activities of the Ombudsman Program, led to increased public discussion among aging groups about alternatives to nursing-home care. These discussions eventually inspired the development of the Community Care Organization (CCO), to be discussed later in this chapter.

The need for alternatives to nursing-home care was also dramatically set forth in a 1980 report entitled *Life in Limbo*, published by the Wisconsin Coalition

Exhibit 1. "Nursing home abuses revealed." *Capital Times*, Madison, Wis., January 24, 1977

Nursing home abuses revealed

Schreiber report describes casualties of behavior control

By RON McCREA
Of The Capital Times Staff

Some Wisconsin nursing home residents have been subjected to "blatant abuse" because of the uncontrolled use of behavior modification therapy, according to a report released today by Lieutenant Governor Martin Schreiber.

The report, prepared by Schreiber's Nursing Home Ombudsman Program, details cases of elderly residents being strapped to wheelchairs and confined in isolation for hours, receiving repeated cold showers, being deprived of meals or solid food and being threatened with the loss of family contacts, privacy and access to worship services.

The report also details two cases in which death was associated with the behavior control programs. In one of the deaths, the report accuses state regulatory agencies and the Wisconsin Medical Society of deliberately ignoring a criminal abuse because a doctor had authorized it. **(See accompanying story.)**

A recurring theme in the report is that orders written by doctors and social workers seem to carry more weight in nursing homes than laws written by the Legislature to protect patients. The study says:

"Because of the unique status of health professionals in our society, they are given almost free reign to design programs and treatment.

"Unless responsibility can be set for the treatment of nursing home residents and an effective system can be designed to review the treatment, there will be no limit to what health professionals can order done to, or for, nursing home residents."

The report discloses that "even in the least restrictive programs, such things as telephone privileges and social visits are granted only at the discretion of the therapist. And, in more restrictive programs, basic needs and rights — the right to sleep in one's bed, eat three daily meals, be treated with dignity and respect — are at stake."

Such abuses are outlawed in state statutes, administrative codes and professional guidelines, the study says, but because the abuses are built into "therapy programs," nursing home personnel tend to regard them as legitimate and regulatory agencies are reluctant to interfere.

"It makes you want to wring somebody's neck," Schreiber commented.

Among the cases described in the report are these:

- A 79-year-old man who shouted frequently was restrained in a wheelchair in a shower anteroom for periods of up to 12 hours. Throughout a month of these lengthy isolations, he was suffering from painful bone injuries. He died within weeks after the injuries were discovered and treated.
- A resident with multiple sclerosis was ordered tied in bed for half a day for running into another resident with a wheelchair.
- A woman was scalded to death in a shower during a period of isolation for being noisy.
- A man was given cold showers for bed-wetting. One day he received two cold showers for refusing to sit in the dayroom. Another day, he received three cold showers for refusing to get dressed.
- A woman was denied solid food for three consecutive weeks because she wouldn't dress herself.

"In these cases, the concept of behavior modification as therapy has been completely perverted," the study says.

"Behavior modification" is the label applied to a family of techniques which seek to teach constructive habits and eliminate undesirable ones by bringing positive or negative consequences to bear on conduct.

"Positive reinforcement" therapy

(Continued on Page 4, Col. 1)

Tied to chair in isolation, he wanted to die—and did

By RON McCREA
Of The Capital Times Staff

In the case of one Wisconsin nursing home resident, the aftermath of a "behavior modification" program was a dramatic behavior change: he died.

Today's report of the lieutenant governor's Nursing Home Ombudsman Program does not identify the man or the nursing home, but state documents and correspondence obtained by The Capital Times say the incident occurred at the Portage County Home at Stevens Point.

According to the Ombudsman report, a 79-year-old man with a history of psychosis was repeatedly restrained in a wheelchair fastened to the wall of a shower anteroom and left isolated for periods up to 12 hours during the month of June, 1975.

He was put there to stop him from screaming all the time. One of the things he screamed for was X-rays and medical treatment. The psychiatric social worker and psychiatrist who designed his isolation "treatment" thought he was just screaming to get attention. Only later did they learn that he was suffering from a broken hip and fractured ribs.

While the man sat strapped to his chair with his broken bones during

(Continued on Page 4, Col. 1)

Carter moving quickly to reduce nuclear arms

By HELEN THOMAS

WASHINGTON (UPI) — President Carter plans to seek a worldwide reduction of arms sales and will move "quickly and aggressively" to reach

he did not contemplate a moratorium on U.S. weapons sales, because that would be "abrupt."

But he said Secretary of State Cyrus Vance will be "much more heistant in

Photo by Ron Brayer

Baraboo home destroyed

Two persons escaped injury, but lost all of their possessions early Sunday in a blaze that destroyed their home on Highway C, about five miles north of Baraboo. Baraboo Fire Chief Ronald Federman said the home of the Daniel Holzman family was entirely engulfed in flames when firemen arrived. The Holzmans fled barefoot into the snow clad only in their nightclothes. Federman said the blaze may have started from a wood burning stove.

Nebraska's unicameral Legislature:

Efficient and inexpensive

By ED BARK
Of The Capital Times Staff

No one benefits more from Nebraska's unicameral Legislature than the taxpayers who voted it into existence 40 years ago.

For starters, Nebraska has fewer legislators (49) than any other state, although it is ranked 35th in population, according to the 1970 census. Before scrapping their traditional bicameral Legislature for a streamlined, one-house body, Nebraskans paid the salaries of 133 lawmakers, one more than the current number of senators and representatives in Wisconsin.

By removing nearly two-thirds of their legislators, the voters also freed a sizable chunk of tax dollars to be spent elsewhere — or not at all.

"Just about everything you do is going to be cheaper," said Vincent Brown, who has been clerk of the Nebraska Legislature since 1969.

The statistics bear him out.

According to the Nebraska Blue Book, the last bicameral Legislature met in 1935 for a total of 134 days at a cost of $233,363.01. The first unicameral Legislature convened for 98 days in 1937. The bill to the taxpayer was $103,445.38, and that included a salary increase provision attached to the unicameral constitutional amendment which gave each legislator a raise from $800 to about $1,750 per two-year term of office. (Terms have since been increased to four years.) The cost of running a regular session of the unicameral Legislature remained below $200,000 until 1957, when Nebraska's lawmakers met for 115 days at a cost of $202,811.93.

A study of the unicameral Legislature by the University of Nebraska concluded that costs probably would be from two to three times higher under a bicameral system in 1957 — which applies to today.

The cost of running the unicameral has in fact skyrocketed in recent years, largely due to a steady increase in the number of legislative staffers that has been typical in most states. But the bill to Nebraska's taxpayers remains a drop in the bucket compared to what Wis-

(Continued on Page 4, Col. 1)

Exhibit 1, *continued*

• Old man wanted to die—and did

(Continued from Page 1)

his isolation periods, he was often threatened with no food. According to the report, some meals actually were withheld. Another feature of the "treatment" forced him to sit in his excrement.

His isolations or "time outs" became so lengthy that he developed the equivalent of bedsores from sitting in the wheelchair. Periods of four and five hours in isolation were charted. On one day he was in the shower room twice for a total of six hours. And on June 23, 1975, he was isolated from 8:30 a.m. to 8:20 p.m. without lunch. He refused his supper.

"At no time do records indicate that the shouting abated in response to the treatments," the report notes.

Finally he was admitted to a hospital and examined. His fractures and other injures were discovered and treated. Then he was sent back to the County Home. From there it was all downhill.

He was described as "hostile and uncooperative" when he returned and his nursing charts said he often expressed the wish "to starve" and "to die."

Four weeks later he was sent to the hospital in "unresponsive, poor condition."

Then he died.

A Nursing Home Ombudsman Program investigator uncovered the incident in November, 1975, and the program staff immediately pressed for action. But they ran into a solid wall of bureaucratic refusal and medical arrogance. Their report states:

"By any common sense definition, the extended isolation of an injured 79-year-old man is abuse. Yet when the Ombudsman Program referred the case to state regulatory agencies, the district attorney and professional societies, the response was uniform: no one was willing to initiate action. When confronted with the details of the case, some of the groups refused to recognize that abuse had even occurred."

From the responses included in the report, it is plain that a major reason for this refusal was that a licensed physician had authorized the procedure.

The Division of Health, which regulates nursing homes, looked into the case and concluded that the man had received "good nursing care during (his) entire stay in the facility." The report notes that "because a physician's orders were signed for the program, the division was satisfied that proper care was given, even though abuse as defined in the nursing home code had occurred."

The Division of Nurses told the Ombudsman Program that too much time had elapsed for them to take any action.

The Portage County district attorney said that no jury would convict the psychiatrist who ordered the procedure for negligence because at least one "recognized psychiatric textbook" approved of long confinements.

The Wisconsin Medical Society sent the Ombudsman Program "a point-by-point rationalization of all aspects of the (behavior modification) program, including disregard for the man's injuries." Among the Medical Society's points were these:

- In spite of physical evidence of injury, it would have been wrong to stop the behavior program on the basis of a known liar's complaints.
- Although the program had not worked for four weeks, its continuation was warranted because "one of the necessary requisites in order for it to work at all is consistency."
- Because there are disagreements among experts, it would be "presumptive to pass judgment on who is and who is not a candidate for this kind of therapy."

The State Medical Examining Board agreed to investigate the incident in January, 1976. "Yet, one year later, the agency has yet to take action on the matter," the report says.

Finally, in December, 1976, the Division of Health reconsidered its position and referred the case to the attorney general for possible prosecution.

"This decision came only after the Ombudsman had collected substantial testimony from psychiatrists, medical doctors and social workers to support its contention that abuse had occurred," the report says. "Without this pressure, it may reasonably be assumed that the case would have lapsed into obscurity.

"It remains to be seen whether or not the responsible professionals will actually be held accountable."

• Nursing home abuses revealed

(Continued from Page 1)

tries to achieve change by systematically rewarding proper behavior. "Aversive therapy" tries to eliminate improper behavior by punishing it systematically.

Schreiber's report calls the Wisconsin practice "abusive therapy" and blames it on three flawed situations:

- Therapy programs are being applied to inappropriate individuals.
- Effective programs have degenerated into abuse because of understaffing and lack of professional oversight.
- Techniques of behavior modification have been used piecemeal and "perverted by application with no pretense of treatment; instead, these techniques have been applied merely to 'control' or 'punish' problem patients."

The report notes that "problem patients" are increasing in numbers because of the emphasis on community-based treatment of mental disorders.

But it also says that nursing homes are training their own residents to be "problem patients" by being short-staffed: "In a setting where the number of staff hired is often only minimally adequate, those residents who receive the most attention are those who disrupt the daily regimen."

"If the incontinence, screaming, disrobing and hostile language which are common behaviors among disturbed residents are an expression of the need for attention and normal stimulation, then their environment should be enriched and their social contacts increased," the report suggests.

Unfortunately, "behavior modification programs developed for residents are frequently designed to deprive or isolate."

The State Division of Mental Hygiene is belatedly developing guidelines to regulate behavior modification programs in long-term care facilities, the report says. But it expresses grave doubts that guidelines will be useful:

"In four years of observing the failure of existing state statutes and professional guidelines to prevent abuse, the Ombudsman Program has grown skeptical of the adequacy of such measures.

"Given the inertia of governmental regulatory agencies, the self-protective character of health professionals and the difficulty of actually establishing accountability for what goes on, a mere set of guidelines, no matter how explicit, will not prevent abuse."

Schreiber's study suggests that community involvement in monitoring nursing homes might help, but notes pessimistically that lay people and family members "commonly assume that the specialized knowledge of the professional is not subject to human failings."

for Advocacy, the State's official protection and advocacy agency for persons with developmental disabilities. Although the report focused attention on a single disability group, it painted a picture of life in nursing homes that was so vivid and disturbing that its message got widespread attention and substantial play in the press.

The report's authors, Judy Zitske and Betty Hallgren, chose a sample of 23 state nursing homes (with developmentally disabled residents), representing a broad range of sizes, locations, and types, as well as licensure and ownership categories. Each establishment was visited and observed for approximately 12 hours to develop a portrait of typical physical environments, relative restrictiveness, patient groupings, activities, relationships and the like. What the observers saw and reported characterized the nursing homes sampled as isolated, impersonal businesses, organized for staff convenience around bureaucratic and medical routines at the expense of residents' needs and rights. The report asserted that different disability groups were not only segregated from the community, but often totally segregated from each other, or, alternatively, mixed in completely irrational groups that served no useful educational or social purpose. The staffs, typically inadequate in size and training, often distanced themselves from the residents or treated them as dependent children. A majority of the residents sampled had no meaningful relationship in or outside their institutional "homes." The recommendations and conclusions of *Life in Limbo* were stark and unequivocal.

> The use of nursing homes as residences for people with developmental disabilities should be immediately discontinued. No new admissions should be permitted. For people who are so ill as to literally require 24 hour/day hospital-like care, generic hospitals or one of the three state centers for people with development disabilities should be used.
>
> Furthermore, the individual residential and community support needs of *all* people with disabilities already in nursing homes should be assessed by multi-disciplinary teams of competent developmental specialists. Planning should begin immediately for the true reintegration of these people into the community.
>
> Re-integration, in this sense, means movement into small, dispersed and culturally typical residences which are in close physical proximity to population clusters, family and community resources.[16]

The report went on to argue that Wisconsin's decision to "deinstitutionalize" thousands of developmentally disabled citizens through the use of nursing homes amounted to "massive involuntary confinement of people without due process."[17]

It is important to note that *Life in Limbo* and the many companion social critiques of the period differed in one very important respect from the Partlow and Pennhurst media exposés. Rather than spotlight isolated, lurid abuses, they sought to show—as Samuel Gridley Howe had 120 years before—that institutions were inherently flawed because they isolated people from normal formative relationships and experiences, because they were dominated by routine and standardization at the expense of individual dignity and choice, and because they stood as ugly, reinforcing symbols of society's decision to segregate those labeled as disturbing and different.[18]

A new theoretical and ideological basis for these critiques was to be found in the teachings and writing of Dr. Wolf Wolfensberger, an expert in the field of the treatment of persons with developmental disabilities. His work in Scandinavia, Canada, and the U.S. had spawned a professional movement with a large following, which, by the late 1970s, included many local advocates and Department of Health and Social Services professionals representing a number of different disability groups. Wolfensberger's work argued that persons perceived as different are systematically devalued by rejection, segregation, reduced autonomy, poverty of experience and stereotyping.[19] The guiding principle of his theories, "normalization," held that growth and achievement of full potential could only occur when such persons were systematically interpreted by society as "human, healthy, contributing, belonging and growing individuals."[20] The principal means of normalizing lay in "increasing the physical presences and valued participation of handicapped people within the community" through placement in homes, consistent social contact with valued members of society, individualized learning programs and the like.[21] In this view, nursing homes—however well-intentioned and well-managed—could never foster the goals of normalization.

C. The Status of Wisconsin's Community Services in 1980

By the fall of 1980, the principles of normalization and the state's past and recent history with regard to institutional and noninstitutional forms of long term support were being scrutinized within the Department of Health and Social Services, with an eye toward major new policy and program development. Certainly the fiscal facts of the matter were indisputable and could easily be illustrated in graphic terms. In any comparison of state and federal expenditures for long term support, it was clear that community-based support was a stepchild to its institutional counterpart, as Exhibits 2 and 3 demonstrate. Further,

Exhibit 2. State and Federal Funding for Community and Institutional Services, 1976 versus 1981.

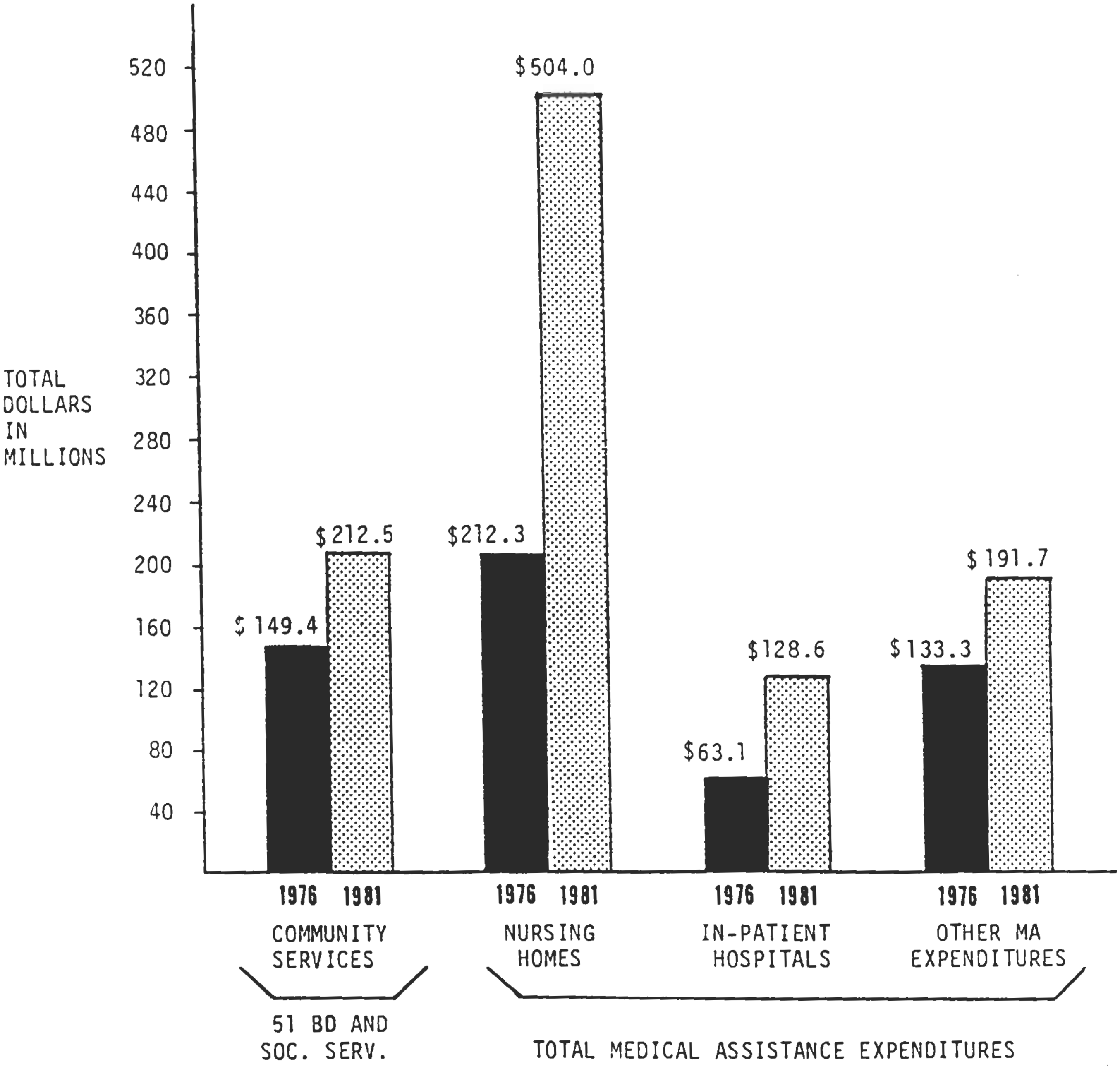


Exhibit 2 compares the funding available in community and institutional settings for 1976 and 1981. The amount for community services in this graph includes *all funds* (for all services) allocated to 51 boards and departments of social services, except funds for a few categorical children's programs (Day Care Expansion funds, uniform foster care supplemental funds, Child Welfare Services funds, state direct services phase-down monies, and Youth Aids funds) and the Work Incentive Program (WIN). Thus, the amounts for community services include much more than long term support funds. The figures for nursing homes, on the other hand, reflect monies devoted exclusively to long term support services. They do not include expenditures for services to nursing home residents by other providers (e.g, physician's visits, therapies, etc.), which are estimated at about $35 million per year. The nursing home figures also do not include the cost of day services or sheltered employment provided by counties for certain nursing home residents, estimated at $6–8 million annually, nor do they include the expenditures of local property tax revenues for county nursing homes, estimated at $12–15 million annually.

Data provided by the State Department of Health and Social Services, Office of Program Initiatives, February 1983.

Exhibit 3. Community and Institutional Long Term Support Expenditures in 1981.

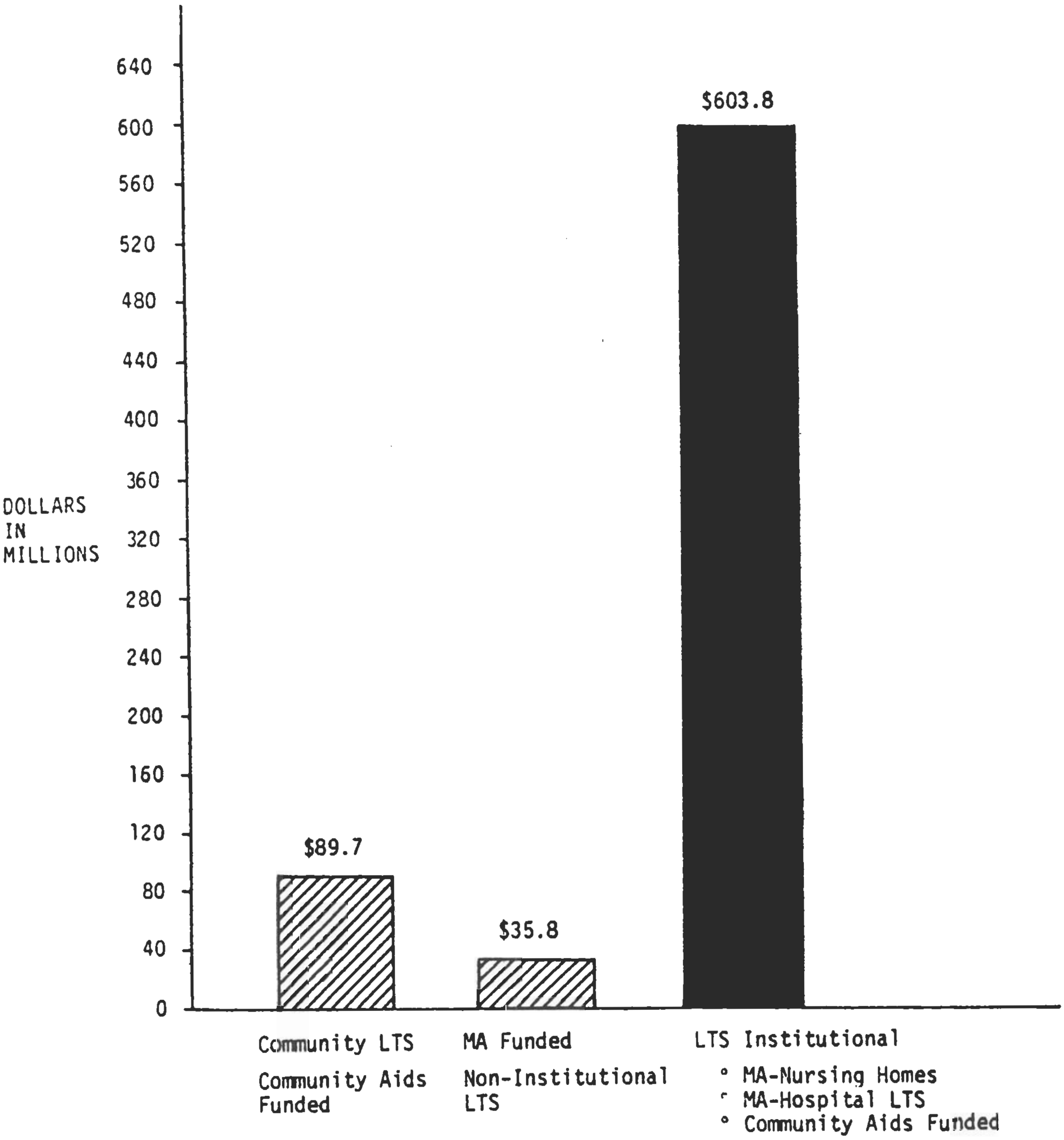


Exhibit 3 distills the 1981 information from Exhibit 2 (State and Federal Funding for Community and Institutional Services) into three categories. Some of the $212.5 million in community aids pays for services to children and to non-chronically disabled adults. We estimate that $89.7 million of the $212.5 million in community aids and $35.8 million in MA dollars pays for non-institutional long term support. MA inpatient costs for the AFDC population have been removed from the third column of Exhibit 3 above. Finally, the $603.8 million is our estimate of the amount that Medicaid pays for long term support in institutions. Keep in mind that this is only Medicaid, and therefore does not include other things, such as Medicare. The picture that emerges in Exhibit 3 puts into even bolder relief the structural imbalance between community and institutional long term support.

Data provided by the State Department of Health and Social Services, Office of Program Initiatives, February 1983.

the imbalance was growing worse. Exhibit 4 illustrates this trend by comparing relative increases in community versus institutional funding between 1976 and 1981. There was no denying that the state and federal governments had joined hands in supporting a long term support system that was massively biased toward institutional care, in direct opposition to explicit written aims.

In addition to these worrisome fiscal and policy realizations, there were some decidedly hopeful examples of what progress was possible in Wisconsin communities given government support. The most directly relevant of these encouraging experiences was the Community Care Organization (CCO), a research and demonstration project largely conceived and administered by the Office of Lieutenant Governor Martin Schreiber. Funded by a grant from the W.K. Kellogg Foundation and a medical assistance waiver obtained from the U.S. Department of Health, Education and Welfare, the CCO operated in La Crosse, Barron and Milwaukee Counties between 1975 and 1980. The program grew out of mounting concerns about inappropriate nursing home placements; it aimed, therefore, to demonstrate that "a substantial proportion of indigent [elderly and] functionally disabled persons could be maintained in the community through the services arranged for or provided by the CCO at a cost no greater than the cost of institutional care which might otherwise be required."[22]

The program established an umbrella organization or agency (the "CCO") in each pilot locale that served as the single point of contact for clients seeking alternatives to institutional care. The CCO helped assess community support needs as well as create and monitor case plans to enable elderly and functionally disabled persons to remain in their homes or in homelike settings in the community. CCO's also stimulated the development of a host of services that assisted clients with the tasks of daily living (housekeeping, shopping, meal preparation, transportation, etc.).

Experimental research results generally validated the originators' ambitious hopes. CCO clients expressed high levels of satisfaction with the program and evidenced cost-saving decreases in hospital and nursing home stays. Total public costs for experimental groups (CCO clients) were significantly less than those for control groups (non-CCO indigent elderly and disabled). State costs were about the same for both groups. Project results further suggested that inter-agency and interdisciplinary service management for different functional disabilities could be accomplished within a single program.

By the time the CCO had become a reality, the state of Wisconsin had fully implemented legislation (State Statute 51.42 and 51.437) that made counties responsible for providing treatment and rehabilitation services to persons suffering from severe mental illness, developmental disabilities and acute alcohol and drug addiction. While the State acted as a general supervisor, providing some centralized planning and evaluation functions and serving as a conduit for dollars, this newly established local-control model mandated local response to the needs of these target groups. (No such mandate existed for the elderly or the physically disabled.) This system offered a ready-made and quite unique framework for community-based programming.

Some of the first and most impressive innovations to grow out of this new arrangement were county-operated Community Support Programs (CSP's) for persons with mental illness. CSP's avoided traditional, facility-based treatment to the greatest extent possible, preferring instead to take assistance directly into the homes and work places of program clients and to make outpatient therapy and supportive services readily available. CSP's maintained 24-hour crisis intervention services and hotlines, sent mobile units to respond to calls for help, and emphasized the development of social and daily living skills for life in the community. In addition to gaining national recognition for their efficacy and cost-effectiveness, Wisconsin CSP's helped convince Department of Health and Social Service professionals that community-based treatment was appropriate for persons with severe, chronic mental illness.

Not all the useful early experiments in nursing home diversion and deinstitutionalization were products of public sector planning; some were born of crisis. When, for example, a spokesperson for the Unicare Corporation announced a precipitous closing of one section of the Riverview Nursing Home (Waupaca County, 1980), a State Department of Health and Social Services relocation team was forced to intervene on behalf of the affected residents. Within a very short time, the team was able to find successful residential placements for a third of these residents in spite of limited community resources.[23] The Riverview closing was the most dramatic of several such nursing-home crises of the period, occurring in the midst of departmental discussions that led to the COP concept. Insiders drew confidence from the intervention's positive outcome, judging that both the State and individual counties had the ability to create much broader alternatives to the existing long term support system.

Growing dissatisfaction with institutional care, the awesome fiscal bias in favor of such care, as well as heartening success stories like the CCO, the CSP's and Riverview made a strong case for major policy and program change. Chapter III sets forth the response of the Department of Health and Social Ser-

Exhibit 4. Increases in Institutional and Non-Institutional Long Term Support Expenditures, 1981 over 1976.

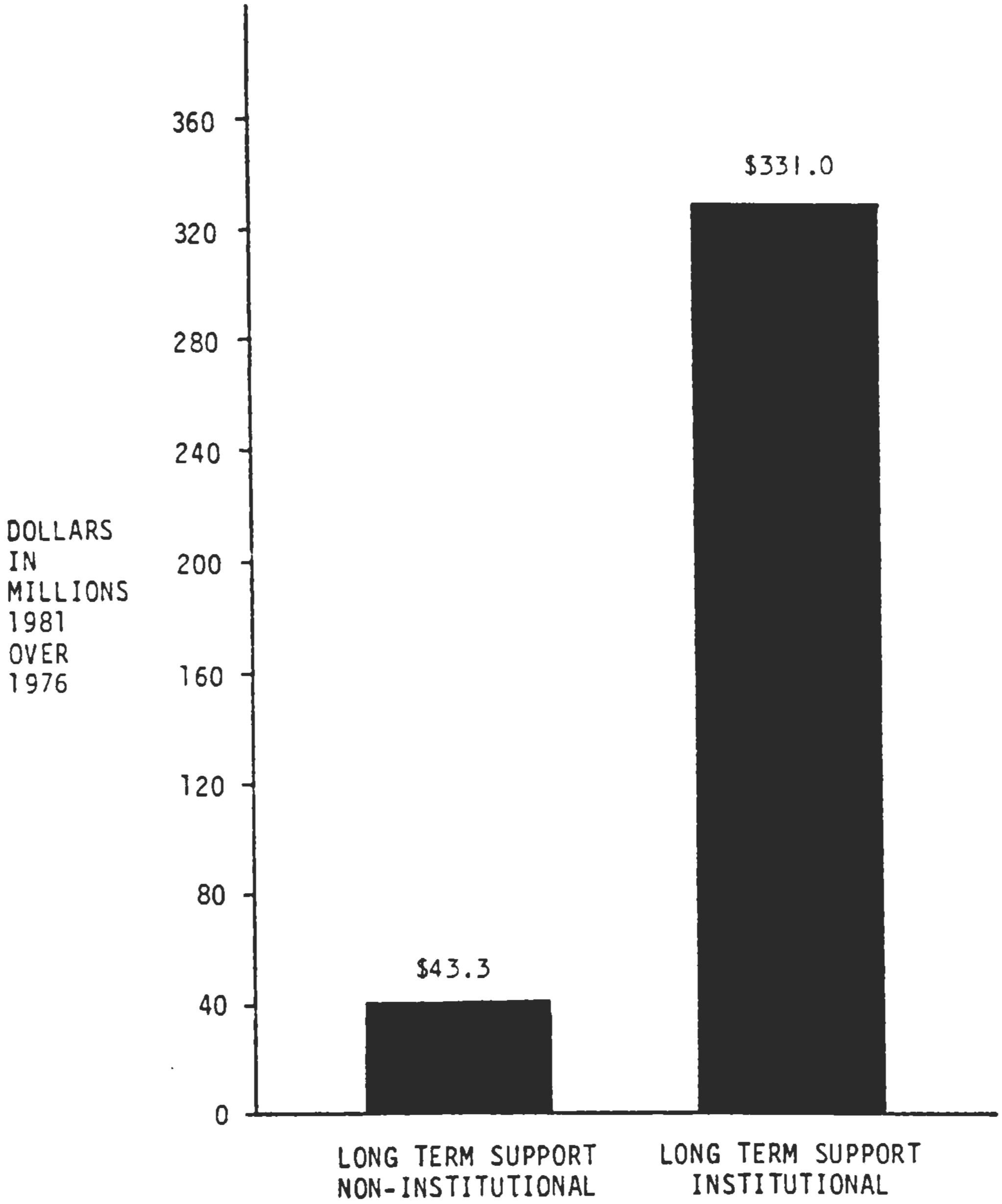


Exhibit 4 indicates the total increase from 1976 to 1981 for institutional long term care—$331.0 million—was almost 8 times the $43.3 million in community long term support.

Data provided by the State Department of Health and Social Services, Office of Program Initiatives, February 1983.

vices to these compelling forces and describes the dimensions of an idea whose time had clearly come.

III. The Birth of COP at the Department of Health and Social Services

A. COP's Authors

In the summer of 1977, Governor Martin Schreiber replaced Department of Health and Social Services Secretary Manuel Carballo with Donald E. Percy. The change was to prove much more than just another bureaucratic shuffle. The agency had recently undergone its second major reorganization in a decade, and the new governor and the out-going secretary had clashed frequently and openly over departmental issues, not the least of which were nursing home regulation and other initiatives directly affecting the elderly. These changes in leadership and organizational structure were seen by many as both a real opportunity and a mandate for charting a new course for the Department.

A planner by background, and a gifted writer and speaker with a fabled capacity for work, Don Percy quickly distinguished himself as a man with a mission who intended to leave a definable legacy of specific policies and programs that would reach far into the agency's future. He neither underestimated the difficulties of his new role nor doubted his capacities to manage Health and Social Services. His assessment of the agency's condition at the time of his arrival is reflected in a memorandum addressed to newly inaugurated Governor Lee Sherman Dreyfus, dated June 16, 1980.

> I found this agency with no sense of mission or direction, an uneven sense and record of professional performance and a myriad of detractors including: the Legislature (whose initial complaint was the Department of Health and Social Services never answered their correspondence nor made responsive presentations to its committees); the Medicaid provider groups (19, count'em) whose claims payments were months and years behind and whose reimbursement was never adequate; the categorical group advocates who would rather risk internecine warfare than settle for an integrated service effort; the counties who felt no one cared and no one listened stateside; the regulators and the regulated both sure they were right no matter what; a relatively efficient welfare system with broad benefits and persons wanting to believe the worst about recipients—yet a system in need of further reform constrained by a federal government unwilling to allow it to occur; a department which had been reorganized twice in ten years, but never organized; and, yes, the day-to-day set of crises well beyond anything we had seen in our university experience.[24]

In the same communication, he offered a fascinating glimpse of his view of both followers and leaders. He regarded respectable bureaucrats as those who were "willing to overcome or ignore stereotypes and take risks creatively."[25] He believed his proper role to be that of " 'an environmental engineer' " seeking to allow creative bureaucrats to become what their potential promised in the first place.[26] The COP story clearly suggests a successful effort to create an internal administrative framework and an organizational climate that freed and focused the talents and professional passions of "creative bureaucrats," and which widened the agency's channels of communication, providing a more effective link with advocates and consumers of department services. Subsection A sketches the broad outlines of Percy's efforts to construct a productive managerial environment and provides thumbnail portraits of several "creative bureaucrats" who exemplify one or more of three critical roles with respect to COP's development process: (1) the managerial enablers (2) the program translators and (3) the "missionaries."

The reorganization provided Percy with tools never before available to a Health and Social Service agency secretary: centralized policy analysis, and planning and budget capabilities, which had the potential to help him draw together for the first time the far-flung "principalities" that made up Health and Social Services. He moved immediately to strengthen these central services and to establish department-wide planning and evaluation functions that would become the structuring administrative processes of his tenure.

Barely a year later he had enlisted these new resources in a search for five or six over-arching goals that would serve as agency priorities for the foreseeable future. He insisted on the widest possible range of inputs into this search. Hundreds of letters requesting ideas for agency goals were sent to Health and Social Services employees at all levels, external advocacy groups, advisory committees, county officials and workers, agency clients and virtually anyone else who was likely to have an opinion on the matter. His planning staff conducted informational interviews with "key informants," including advocates, county staffers and state employees at all levels. Open-ended responses were encouraged and welcomed. After planners had pored over the results of their data-gathering efforts, they presented the Secretary with a list of common themes. From this list Percy identified five goals that would shape the agency's future initiatives: Long Term Support, Welfare Reform, Children's Services, Health Promotion and Protection and Improving Local Human Service Delivery Systems. Each initiative was to be elaborately conceptualized in a planning guideline "developed with broad citizen and local official input" and designed to embody the values and directions associated with each initiative.[27]

Percy selected Long Term Support as the agency's first central planning effort. This choice was both pragmatic and value-oriented. It was believed that the Long Term Support Initiative would be easier to conceptualize than welfare reform because it did not necessarily contain mutually exclusive goals, and because the notion of community-based long term support had a kind of conceptual coherency that was not necessarily true of the other goal areas. Furthermore, Percy's principal advisers were "on fire" and pressing for a strengthened community-based policy and there was spirited external advocacy feeding this internal zeal. The Department of Health and Social Services was determined to make the most of a great opportunity to effect a major redirection in agency policy.

To begin the development of the planning guideline that would serve as the conceptual map for the Long Term Support Initiative, Percy once again reached out in all directions for ideas. In doing so he typically nodded respectfully at agency hierarchy by stressing both vertical and horizontal communication. He also emphasized what he called "diagonal communication," which allowed employees with a special talent and passion for a given issue to have major developmental roles, irrespective of their relative ranks in the organization. Employees were thus regarded as "citizens of the Department," rather than as functionaries in isolated work units.

He took pains to cultivate the expression of conflicting opinions but insulated creative thinkers from obstructionist elements in the bureaucracy, so that "radical" ideas could surface and evolve without being obscured by artificial issues or squabbles over turf. Fortunately, this inclination was mirrored by many key managers at the division level and below, partly because of Percy's personnel decisions, partly because his subordinates chose to "copy" his management style, and partly because of fortuitous peer placement. This widespread practice permitted an internal value consensus to develop before a policy was officially formulated and announced. Once issues had been substantially fleshed-out through discussion and debate, Percy himself would review areas of agreement and contention and make the final decisions about agency direction.

Policy formulation at the Department of Health and Social Services was not, however, merely an internal affair. Percy had great respect for the function of advocacy, and he demonstrated it routinely by hiring vocal advocates and giving them space to work inside, and by making certain that all relevant advocacy interests were represented in policy choices and program decisions. He also gave outside advocates direct access to his office. Institutional representatives of major advocacy groups sought audiences with him two or three times per year with structured agendas and official roles to play; both these representatives and more grass-roots types understood that informal input would also be listened to, subjected to tough examination and respected as part of the policy formulation process. The efforts of advocates representing all of COP's client groups strongly influenced the shape of the program and its subsequent political destiny.

In May of 1980, Percy published *Planning Guideline #1 Long Term Support*, announcing that it prescribed "a process for interdivisional efforts to resolve longstanding issues within a departmental context" and "would become a model for future initiatives."[28]

> Long Term Support Services have developed rapidly in recent years and undergone major changes in guiding philosophy, program emphasis, and in the delivery system itself. There continue to be dislocations and inappropriate services within this system, however. The concerns identified include lack of responsiveness to the needs of severely or multiply handicapped persons; the continuation of incentives for institutionalization; and a need for improved evaluation, program integration and control mechanisms. A process of policy review, planning and reallocation of resources is needed to make available a *comprehensive* and *balanced* system of *appropriate* supportive services for *persons with chronic needs*.
>
> Long Term Support Services should be developed and delivered in a manner consistent with the Department's mission to ". . . enable people to sustain wellness and independence in the physical, mental and social dimensions of their lives . . ." Goals are established for both individuals and the delivery system which are consistent with the mission. Goals for individuals include normalization and least restrictive setting, self-sufficiency and independence, and participation. These require programs focused on individual dignity and rights, seeking the realization of maximum potential and including clients and their families in program planning and development; such programs should emphasize skills, behaviors, and service settings which foster maximum feasible participation in community life.
>
> Goals for the service delivery system include comprehensiveness; availability/accessibility; cost/effectiveness; integration; balance; coordination; and state/local partnership. These goals emphasize the importance of flexibility, responsiveness and sequencing of service which respond to the changing needs of individuals and communities. They assume that systemic problems must be resolved through effective focusing of policy, staff and fiscal resources with reallocation where necessary. There is no expec-

> tation of substantial additional resources to meet the identified problem areas.
>
> An Action Plan to resolve Long Term Support issues will involve a DPB [Division of Policy and Budget] analytical team and staff from program divisions on specific task assignments. Divisions expected to have substantial interest and continuing involvement in policy development are DOH [Division of Health], DCS [Division of Community Services], and DVR [Division of Vocational Rehabilitation]. All divisions are asked to identify issues which must be resolved to meet these goals and staff responsible for any effort currently underway. Program division staff will be heavily involved in task assignments resolving specific issues. Opportunities for program division staff to participate in broader conceptual design will be offered to divisions wishing to participate at that level. Commitment to state/local partnership will be honored throughout the policy development process. Questions of involvement of county, 51 program, and other local or advocate representatives will be resolved on an issue by issue basis.[29]

Elsewhere, the *Guidelines* asserted that the resulting long term support system "must contain a bias toward community services while continuing to provide out-of-home care of adequate quality for those persons who genuinely require it."[30] The choice of an alternative system was to become the client's prerogative.

Only a month or so later, Percy sent out a series of memoranda outlining ten separate task assignments and establishing task forces charged with resolving policy questions and strategy issues in ten different long term support areas. Although the Secretary's input processes leading to the development of the *Guidelines* and its resulting task forces were wide-open and unstructured, the assignments themselves were highly structured, as well as demanding and ambitious. *Task Assignment #1.9: Nursing Home Preadmission Screening and Community Service Integration* is a representative example of the ten assignments because it contributed most directly to COP's ultimate program design, and because it is an excellent demonstration of Percy's managerial concerns for depth of research, coordination of effort, and comprehensiveness, as well as planning structure and closure (see Exhibit 5.).

The memorandum and the initiatives it fostered are also noteworthy in a number of other respects. As usual, Percy's staffing requirements ensured interdivisional cooperation and communication between the Division of Community Services, Department of Health, Division of Planning and Budget and the Division of Vocational Rehabilitation. They also respected divisional hierarchy at the same time that they mandated and opened further possibilities for active participation from persons outside the normal chain of command. Broad-based participation by the very county agencies most likely to be involved in program implementation was emphasized as well (local social service agencies, boards for the developmentally disabled and mentally impaired and area agencies on aging).

Less obvious are the assignment's strategic treatment of leadership roles vis-à-vis different advocacy group interests. Major client groups were represented by at least one insider well-known and highly respected by each group. Leadership on the task groups, as well as subsequent nuts-and-bolts committees was shared by these representative insiders, so that no one group would appear to have a special mandate. This strategy helped to create a "coalition of categories" that would prove to be essential to COP's success in winning both broad advocacy support and legislative approval. It was not unusual for county representatives and advocates on nuts-and-bolts committees to outnumber state staffers by a fair margin.

Finally, the assignments built in deadlines, as well as both short and long term reporting requirements that were adhered to rigorously, and framed to enable the inclusion of meaningful policy and program recommendations in the upcoming biennial budget process. Divisions also had six-month work plans covering the major initiatives, as well as other operational priorities. Percy and his planning shop reviewed these plans regularly. Top administrators met with the Secretary bi-weekly and always discovered that their boss had been fully updated in advance by his planners on the progress of each task in the six-month plan. Managers who moved forward on the major initiatives could expect to be rewarded in the agency's budget, through necessary new personnel allocations and the like.

While Percy's own style and administrative mechanism provided a managerial framework that enabled creativity, the hard work of COP's conception and delivery was left to others. It would be a mistake to assume that their work on the task assignments and on COP's other arduous intellectual and political chores proceeded in a strictly formal, cerebral or mechanical fashion. What is perhaps most distinctive about the atmosphere in which COP was born was the remarkable degree of enthusiasm emanating from the program's principal authors and the high degree of cooperation between program-level "zealots" and their respectful but more management- and process-oriented colleagues in the centralized Division of Policy and Budget. While many new program ideas suffocate in the bad air generated by warring advocacy-oriented professionals and budget-shop skeptics, COP flourished in the fertile chemistry that developed between these two essential groups.

This constructive relationship was less a matter of

Exhibit 5.

State of Wisconsin \ DEPARTMENT OF HEALTH & SOCIAL SERVICES

OFFICE OF THE SECRETARY
1 WEST WILSON STREET
MADISON, WISCONSIN 53702

April 18, 1980

TASK ASSIGNMENT #1.9
DHSS PLANNING GUIDELINE #1
Long Term Support
1979-83 Initiatives Series

TO: ROBERT DURKIN, DIVISION OF HEALTH
PETER TROPMAN, DIVISION OF POLICY AND BUDGET
BURTON WAGNER, DIVISION OF COMMUNITY SERVICES

FROM: Donald E. Percy, Secretary D.E.

SUBJECT: Nursing Home Preadmission Screening and Community Service Integration

A. Issue Summary

In Wisconsin, Title XIX residential care has grown to become the dominant element in what should be a continuum of services and care for disabled adults. Recent state laws remind us of individuals' right to treatment and care which is provided under the least restrictive possible conditions. Placement reviews indicate that our present continuum of support is incongruent with this goal.

The Long Term Support Initiative is an effort to remedy this situation by developing a coherent and progressive state policy for meeting the treatment/support needs of individuals with chronic problems in the least restrictive, most normalizing settings possible. One critical component of this Initiative is the review of access to nursing home care. This is necessary in order to develop mechanisms to ensure that clients receive the most appropriate form of care, mechanisms which now exist in only a few Wisconsin counties. Preadmission screening offers a significant point of client contact as well as an opportunity for greater usage of community care. While the state cannot and will not deny nursing home services to those who definitely want them, experience with nursing home preadmission screening processes in other states indicates that most individuals requiring long-term support prefer alternatives to nursing home care.

About 65% of nursing home admissions are from general hospitals and 16.5% are from private residences. Of discharges from nursing homes, about 40% return to general hospitals, 26% die, 17.5% go to private homes and only .5% are discharged to alternate care. Yet there are current estimates that at least 17% of geriatric residents, 11% of the chronically mentally ill, and 7% of the mentally retarded in nursing homes could readily function in an environment providing less medical care. This is in addition to people who, with appropriate medical and non-medical support services, could function in a less restrictive, normalized environment more like that of the general population.

We know as well that private pay patients, who often later become publicly supported, find their way into health care facilities without any governmental review, and that reviews of Medicaid patients in nursing homes are after the fact. Once a person is in a nursing home, discharge to alternate care is often impossible because a dependency has developed and transfer trauma could occur.

Over the years, Wisconsin and other states have developed preadmission screening proposals and programs. The New York preadmission screening long term care program reports promising results. For example, in 1978 there was a 28% decline in nursing home admissions of Medicaid patients, and the cost of home care for Medicaid clients was less than half the comparable institutional cost. Virginia, Washington, and Georgia have also developed successful nursing home preadmission screening programs.

More generally, there is a need for coordinated review of residential placements not only where community-based systems interface with the state-administered Title XIX system, but also within local systems where Chapter 51 and social service domains meet. Improved linkages should encompass pre-admission screening, periodic review of placements in effect, discharge planning, and service coordination related to both Title XIX and non-Title XIX residential programs.

Improving the above linkage areas will constitute a formidable endeavor. It may therefore be appropriate to begin the effort by focusing initially on nursing home preadmission screening, placement review, and discharge planning within the overall context of strengthening service coordination in the community-based system. This means, among other things, that community agencies must be accorded sufficient responsibility and authority in Title XIX residential placements to allow for true service coordination and integration.

Finally, it is inadequate to improve screening or local service integration without also ensuring that the resources for services are both available and sufficiently flexible to allow use in those services determined appropriate by any review process. For this reason, efforts under this assignment must be coordinated with Task Assignments 1.7 and 1.8.

B. Task Committee

To address the above issues, I am creating a work group to which the following individuals from your Divisions should be appointed:

From DCS: Gerald Born (as committee chair)
Donna McDowell (as committee vice-chair)
Cathy Swanson
Beverly Scholtes
Jeanette Nelson
Angie Dombrowicki

From DOH: Peg Smelser (or designee)
Jan Rabidou
Ed Minihan

From DPB: John Goergen
Marilyn Slautterback
Robert Griss
Sherwood Seigel

From DVR: Richard Kosmo

If there are additional or alternate personnel you feel should be members of this group, please submit their names to me and I anticipate your request will generally be approved, contingent on committee size and required expertise.

In addition, one representative from Social Service Departments, one from the 51 boards, one from the Area Agencies on Aging and one from the DHSS regional offices should be added to the committee.

C. Committee Responsibilities

The Committee should:

1. Become familiar with the Nursing Homes without Walls Program in New York, Virginia's preauthorization of nursing home admissions system, Monroe County's (New York) Access Project, the CCO Project, the Triage Project in Connecticut, the nursing home preadmission screening programs in Washington and Georgia, and other relevant models.

2. Determine those key agencies at the local level from the health, social service, and 51 board systems which should be involved in and responsible for the screening and review process, and how coordination between involved agencies might be effected.

3. Determine other administrative arrangements necessary at the local level to ensure effective screening and coordination. The screening and review administrative arrangement should actively involve local agencies such as the 51 board and social service department while at the same time allowing sufficient independence to ensure as much objectivity as possible. The arrangement should also lend authority to the review process results, and should be compatible with the Functional Assessment Process for personal care and supportive home care developed under Long Term Support Task Assignment #1.1.

4. Determine how a nursing home preadmission screening process can be integrated with the work of task committees under 1.7 and 1.8.

5. Determine how a close working relationship might be established with hospital and IMR/IPR discharge planning, and how the local service coordinator role identified in the IMR/IPR discharge planning policy might be integrated with the processes developed under this Task Assignment.

6. Review available products of the case management project to determine ways in which case management can be coordinated or integrated with the processes developed under this Task Assignment.

7. Determine methods of funding the screening, review and coordination processes.

8. Determine administrative arrangements necessary at the state level.

9. Develop methods of ensuring coordination and service integration related to services for individuals residing in Title XIX facilities, including consideration of the following possibilities:

   (a) Requiring local agency (51 board/social service department) approval of service plans for some or all MA residents.

   (b) Requiring nursing homes and community agencies to sign agreements on roles and responsibilities for MA residents.

(c) Requiring or allowing community agency participation or attendance in IMR/IPR reviews.

(d) Requiring or allowing community agency staff to replace state developmental disability teams for nursing home reviews.

(e) Developing effective means of communication to inform community agencies of the status of MA residents and progress in service plans.

10. Determine how effective case management and service coordination might be ensured.

11. Determine how alternate resources will be identified and arranged.

12. Determine what assessment tools will be used, any mechanics of the process not identified previously, and the manner in which appropriateness of placement will be ascertained.

13. Determine how the process might be implemented, including the possibility of phasing, and/or voluntary piloting, and any incentives or sanctions which might be desirable.

14. Determine how to ensure participation of private pay patients in any nursing home preadmission screening process or local service integration effort being considered or recommended.

15. Determine how data on the number of persons diverted from nursing homes should be collected and reported.

D. Timeline

The committee should proceed in two phases. The first phase should cover those items necessary for consideration by other long term support committees and/or related to the biennial budget. The primary such item is identification of the composition, funding and administrative arrangements for a screening, progress review and service coordination process. The second phase should involve development of the full specifications for this process.

In particular:

1. Within six weeks from the date of this memorandum the committee is to complete Task #1 and draft tentative responses or options to #2.

2. Within 8 weeks, draft responses or options for Tasks 3 through 8, 13 and 14.

3. Within 10 weeks, draft a response to Task #9.

4. Within 12 weeks, complete responses to Tasks 2 through 8 and 13.

5. By October 15, 1980, complete all other Tasks (9, 10, 11, 12, 14, 15) and add any details I find are necessary after I complete my review of the work done on Tasks 2 through 8 and 13.

chance than one of conscious intention and will. Next to Percy himself, the chief management enabler of this cooperation was Peter Tropman, head of Policy and Budget during COP's development and statewide implementation processes. Charged with coordinating the overall policy development process, Tropman cultivated spirited debate and constructive participation by all relevant parties. He also exhibited consistent support for the community-based long term support idea that had so engaged program-level professionals. His particular blend of fiscal realism and philosophical backing lent internal and external credibility to the evolving COP concept. Later, his experience as a former state legislator would prove invaluable when the program moved into the political arena.

COP's principal hands-on authors numbered only a dozen or so. They personified the value system inherent in the COP idea, and they exuded a kind of "religious" faith in the program's values and prospects. Through their commitment, conviction and productivity, they collectively created a kind of in-house social movement. While zeal characterized all of their contributions, the major members of this in-house social movement wore two different hats: some operated as program translators integrating and communicating management and advocacy concerns; others operated as pure "missionaries," aggressively defining and asserting the needs and interests of individual client groups.

The special inspiration that characterized both of these groups is perhaps best exemplified in a speech by one of COP's most articulate translators, Douglas Nelson, then Assistant Administrator of the Division of Community Services. In a speech delivered before the Community Living Ways and Means Conference in Wausau, Wisconsin in 1980, shortly after the publication of *Planning Guideline #1—Long Term Support*, Nelson elaborated his vision of the movement's philosophy.

> I've chosen to dwell on what I consider the horror and strength of the systems that we're up against [medically intensive institutional care] to establish what is almost the inexpressible importance of making community care succeed. In every meaningful sense of the word, peoples' lives are at stake in this business. . . . First, those of us who are committed to the concept of community care must not be casual or resigned about that commitment. This is not, let me emphasize, a job or a profession, this is a movement. We cannot afford to dwell on the difficulties, the limitations or the risks of offering community care under existing circumstances. . . .
>
> We are involved in nothing less than changing a major economic and political system in this state and in this country. We are at a very early stage of that effort. The task, in my judgment, is enormously difficult, the odds are not particularly good, but the stakes in this effort are so incalculably high that all of us who really care are obliged to make a passionate and even desperate effort to change that system. For reasons that I don't fully understand and I don't think that I can articulate, I somehow remain confident that we will prevail.[31]

An aging advocate and a disciple of the "normalization" principles that grew out of Wolfensberger's work on developmental disabilities, Nelson was widely regarded to be "the conscience of Health Social Services" on the COP issue. His gifts as a conceptualizer, writer and teacher allowed him to communicate the philosophy and values of COP to a broad range of insiders and outsiders and to help translate conscience into program design.

He was often joined in these efforts by Donna McDowell, Director of the Bureau on Aging. Her credentials in aging-program advocacy and management, as well as earlier training in journalism served her well in her important role as one of COP's foremost translators. As the program structure evolved, key committee decisions would be routinely presented to her to be transformed into official descriptive language reflecting the agency's vision. Her compelling speeches and communiqués humanized bureaucratic language, thereby influencing the attitudes and perceptions of both insiders and outsiders. Her professional advocacy gave COP preeminence on the political agenda of the powerful network of advocates for the elderly. The efforts of "creative bureaucrats" like Nelson and McDowell helped ensure that COP not only retained its identity as a program for real people, but that it also became marketable to categorical interests in spite of its multi-disability ("generic") approach.

Clearly other groups needed to hear this message, as well. Advocates for persons with developmental disabilities saw a trustworthy agency leader in the person of Gerry Born, Director of the Bureau on Developmental Disabilities. Born was an ardent believer in the principles of "normalization" and a long-time supporter of state deinstitutionalization initiatives. He saw COP as a systematic way of achieving what the Bureau had tried to bring about through a series of different and somewhat fragmented experiments. His leadership on the COP issue helped turn good intentions into program structure that appealed to developmental disability advocates, inside and outside of the agency.

Less visible perhaps was Tom Hamilton, Assistant Director of the Bureau of Alternative Care. Regarded by many as the unsung father of COP, Hamilton came to the development process with a planner's background, and a strong social conscience but no specific background with any of COP's major constituency groups. It fell to him to convert broad policy and agreed-upon general program characteristics into an operational plan that could be implemented in 72 different counties. Reputed to have worked 80-hour weeks in 1979 and 1980, Hamilton welded together values, program elements and hard data to form an evolving series of operational plan options. Further, COP's fiscal formula had to be designed and placed into a context that made sense in terms of the monetary language of medicaid-supported institutional care. He also supervised a small staff of "missionaries" in the Division of Community Services. They mapped out budget strategy, coordinated the activities of the bureaus and divisions affected, and forged coalitions among outside advocacy groups. Later, they prepared data for the legislature and trained county staffers engaged in the implementation of the program.

Translators and managers depend to a large extent on the perceptions and hard labor of the "missionaries," the often single-minded and uncompromising program-level advocates for the basic needs and rights of individual disadvantaged groups. "Missionaries" are the closest to the street and to the pain of individuals and are therefore best able to define the specific dimensions of a special need and the specific barriers to its fulfillment. Without them, programs lack heart and concreteness and are vulnerable to failure in either the political arena or the operational context. Dennis Harkins, at that time a planner in the Developmental Disabilities Office, is a representative example of the many internal "missionaries" who gave COP much of its vitality. He was, for example, the chief architect of the Riverview relocation initiative that vividly demonstrated how large numbers of very disabled persons could effectively be relocated from nursing homes to the community. Harkins reflected an intense and unshakable commitment to the principles of normalization and to the form those principles took in the broader program design of COP.

Surely part of the special zeal and competence of COP's cadre of authors was due to specific individual temperaments and to the fact that more than a few of these principals had come to maturity in the 1960s when ideas of social change were cultural staples. But there were also strong institutional supports that unleashed their talents. To a large extent this appeared to be the work of Percy himself. He provided them with a mission and a suitable administrative structure. He also persuaded them that excellent performance would receive his support and that their initiatives would ultimately result in real change. Once he had set the planning and development process in motion, he stood to the side, synthesizing and monitoring the evolving program research and debate. When these endeavors were concluded and committed to paper, he wove together core areas of consensus and he resolved conflict through managerial decision-making. Within two years, COP was transformed from a concern about existing long term support policy into a full-blown program proposal in Governor Dreyfus's Executive Budget.

B. COP's Program Structure

COP's program structure grew quite logically out of its major goals: to preserve client choice in the determination of long term support needs and in the election of relevant services to fulfill those needs. Thus, client-centered needs assessment and case-planning processes were at the heart of COP's program design, as were incentives for the development of coordinated health and social services in the local community. While COP represented a striking departure from earlier long term support policy, it was, at a conceptual level, quite simple, taking its basic program elements largely from what already existed but had not been brought together: client preferences for the maintenance of self-directed life at home, the expertise and processes of various county social service agencies, and existing state and federal funds,as well as budding support services and programs at the community level. At the center of COP's basic structure was the functional relationship that existed between the State Department of Health and Social Services and Wisconsin's 72 counties (see Exhibit 6).

By the time COP had become a budget proposal in 1980, State legislation establishing county responsibility for treatment and rehabilitation services for the mentally and developmentally disabled, as well as for chronic alcoholics and drug abusers, had been in force for six years. Substantial experience with local response offered a foundation for a community-based long term support structure. County social service departments and statutory 51.42 and 51.437 boards were the functional agencies in this unique local response system. They were joined in 1979 by county-based area agencies on aging that provided programs and services for the elderly and would play major roles in the selling of COP. This unique state-county relationship became the structuring principle of COP. It must be acknowledged that the relationship also gave rise to tensions caused by a partnership in which one party (the state) had the money and authority, while the other (the counties) had the responsibility of dealing with complex mandates and administrative challenges.

Although COP was to be funded by the State, the statute authorizing COP left virtually all significant program administrative decisions to the counties through the county board, which remained the ulti-

Exhibit 6. The COP Administrative Structure.

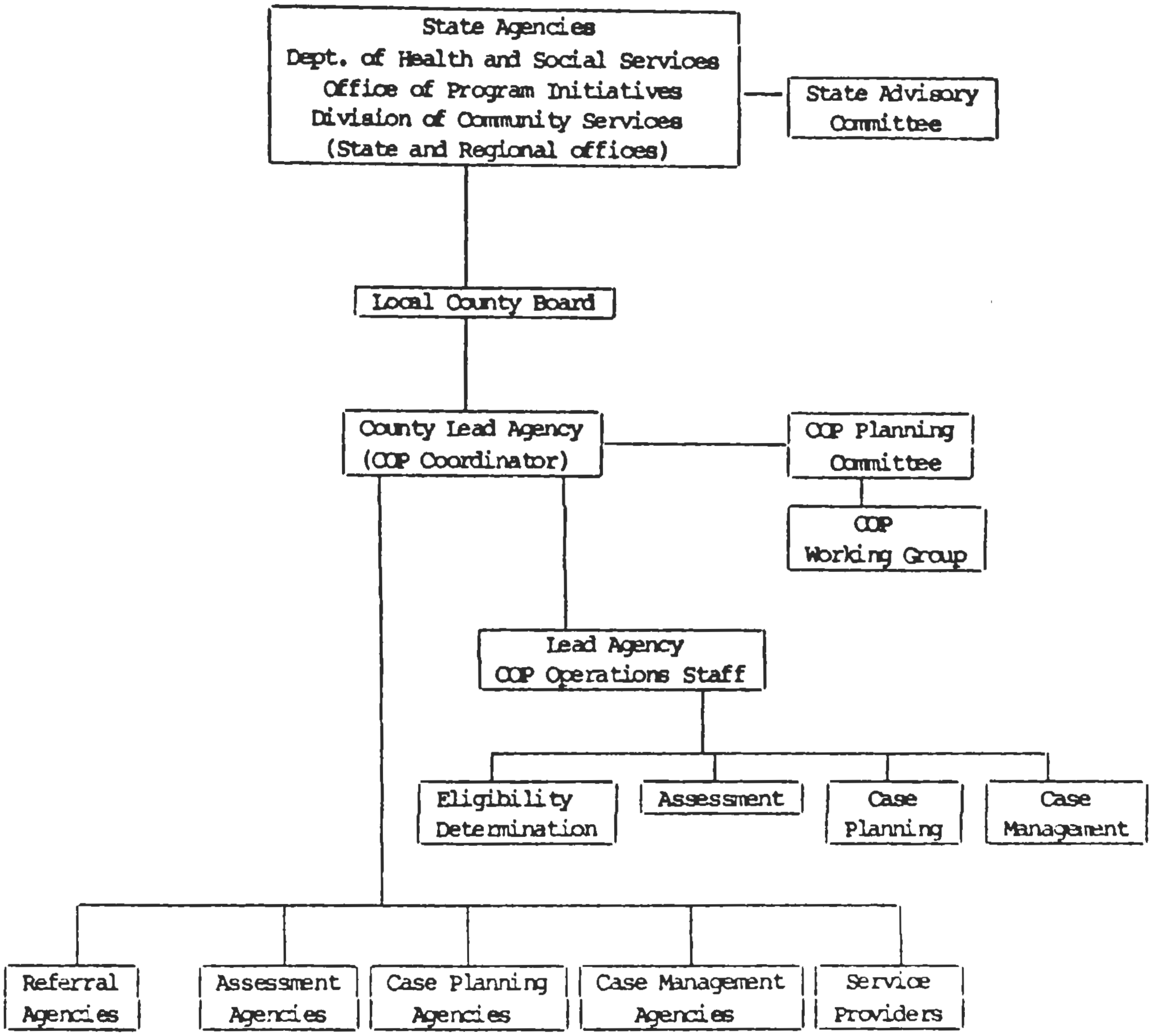


Chart provided in ***Final Report / A Study of the Early Implementation Experience of the Wisconsin Community Options Program*** (Madison, Wis.: Mathematica Policy Research, 1984), p. 17.

mate authority at the local level. Even the choice of when to begin COP program participation remained largely a county decision. While all 72 counties would ultimately participate, only those who volunteered to participate would be part of the initial and intermediate phase of the implementation (see Appendix A for county phase-in schedule). The State reserved the right to mandate participation if an appropriate blend of counties did not materialize on a volunteer basis, but this right did not need to be exercised.

Participating counties were also allowed to phase-in their own program implementation, using a high degree of discretion in determining the best methods for gradually achieving full implementation. State planners reasoned that the highest possible degree of flexibility in all program dimensions was desirable to achieve the best results and to limit conflict in what had always been a delicate and difficult relationship. The gradual implementation concept also acknowledged limited start-up funds, the need for time to debug as county capabilities evolved, and the limited nature of existing community-based services.

At an operational level, the program was to be run by a county-based planning committee to be determined by the local county board. The committee's overriding tasks were to take care of COP's basic planning activities, coordinate the often fragmented and sometimes contentious sub-agencies within individual county systems and produce a COP plan that detailed the local program. Designed specifically to foster a coordinated and comprehensive program outlook, the Planning Committee was to contain, according to statute, an elected county official, as well as representatives from county health and social service functions, commissions on aging and 51 board structures. COP's concern for client empowerment was reflected statutorily in its mandate to have at least two clients on the central planning committee. Day-to-day operational decisions were made by a lead agency, often the social service department, sometimes both the social service department and the 51 board structure.

At the center of the program's value base was the notion that money, program decisions and services should "follow" the client and be sufficiently flexible to allow for maximum client choice. This concept necessitated a strong assessment process and empowered case planning. The statute honored these aims by allocating funds for precisely these purposes. Counties were to be reimbursed an average of $60.00 per client assessment for medicaid-eligible persons. Separate allocations were earmarked for detailed case plans to be developed for COP-eligible persons whose assessment indicated that nursing home or state center diversion was both desirable and feasible. Each case plan was to be reimbursed at an average rate of $200.00. Any monies not used for assessments and case plans could be transferred for use in actual diversion services, such as personal care attendants, chore assistance, home modifications, occupational therapy, and the like.

It is worth noting here that while non-medicaid-eligible persons must pay for their own COP services, they are not barred from the program, and, in fact, receive state-funded assessment and case-planning services. The decision to broaden the program's client base in this way proved extremely wise, since it went a long way toward distancing COP from the stigma of "a welfare program," at the same time adding greatly to its advocacy and political appeal.

Funds for community-based diversion services were designed to be highly flexible and gap-filling in nature, augmenting existing state and federal monies through such sources as community aids, meals-on-wheels, home health care, supplementary security income (federal SSI), HUD and Section 8 Housing Subsidies. To enable persons to remain at home or in another non-institutional setting, the COP statute allowed counties to spend an average of $400.00 per month per client, an amount estimated to be the average state share of nursing-home reimbursement per person in 1980. So long as counties did not attempt to use COP funds to cover pre-existing obligations, they were free to purchase virtually anything or any service that would help the client stay out of an institutional setting. In addition to flexibility, the state statute attempted to ensure funding stability, stating unequivocally that counties would not become liable for services beyond those funded out of state and federal funds. Counties, of course, had legitimate historical reasons to fear that such legislative promises could be confounded by rising local demand for services and changing legislative funding priorities. These fears would later lead to spirited jousting as COP was debated in the political arena.

The program design mandated outreach of a new kind. Unlike many earlier programs, COP avoided a categorical approach, asking counties to merge their separate treatment modalities for different disabilities, to form a common program based on individual need. Money was therefore allotted to service processes (assessment and case planning), rather than to individual disability groups. There was a method to this new madness. In addition to mobilizing the several client groups in support of COP, the State wanted to encourage counties to learn how to serve a broader range of disabilities and to offer an incentive for sometimes disjointed staff functions to work together.

It should be noted here that the enabling statute built a high degree of discretion and flexibility into the timeframe for achieving this new generic outlook.

Counties could prioritize disability groups in the start-up phase based on existing service capabilities, although all groups had to be served by a time certain in the future. Flexibility was also allowed to counties in determining the goal number of assessments per year, although it was understood that local programs would ultimately make an assessment available to everyone about to enter a nursing home or to those currently placed in nursing homes. Since COP planners believed that roughly 10–20% of current institutional placements were inappropriate, they reasoned that COP might serve a like percentage of persons once it was fully implemented. Early descriptive estimates were often somewhat more conservative, in the range of 10–12%.

Planners were equally cautious in predicting the program's ultimate fiscal impact. Many of the original cadre of COP authors in fact shied away from selling COP on any fiscal grounds. To them, its primary goal was to assist elderly and disabled persons to lead lives in the community with as much dignity, value and independence as possible. Early descriptive literature does, however, include rather guarded optimism in terms of cost-containment. Predictions of this kind suggested that COP would on average be no more expensive than institutional care and might be less expensive. Such expressions were typically linked to a faith that the moratorium, too, would help at least slow Wisconsin's escalating medicaid expenditures.

No such restraint was evident in planners' faith in COP capacity to effect major changes in local systems of long term support. In their view, COP was bound to increase counties' capacities to coordinate their often fragmented service capabilities, to create new linkages between systems of social services and health care, and to help counties better mobilize and package diverse community services. Some goal statements even predicted that COP would begin to create a new interface between community-based services and institutions, to better meet client needs.

C. COP's Clients

Perhaps the most illuminating examples of COP's purpose and program design are to be found in the real life stories of its clients. The eight vignettes that follow illustrate the range of problems and disabilities that bring people to COP, the many services it provides, as well as the costs involved in addressing vastly different life circumstances. All of the COP stories were researched and written by the State Department of Health and Social Services, Office of Program Initiatives.[32] The vignettes document client arrangements made during the first year or so of the program's operation. Names have been changed to guard client confidentiality. In all other respects they are factual. (See appendix B and C for news articles featuring still other COP clients.)

1. An older woman disabled by a stroke spent an unusually long time in the hospital while many professionals and family members tried to convince her that she needed to go to a nursing home. She refused to enter a nursing home but there were not enough funds or services available for the support she needed at home. Supportive home-care funds and meal providers were available during the day, but she would not have been able to stay alone at night. COP paid for someone to stay with her at night and thus allowed her to return home. Since this woman is grateful to be home and determined to stay there, she is working extremely hard and improving rapidly. She will probably not need a person with her all night for very much longer. Her family and the professionals involved are in agreement that had she gone to a nursing home against her will she would have been permanently disabled and her condition would immediately have deteriorated rather than improved.

2. Jean Meyer, a 30-year-old developmentally disabled woman with profound mental retardation is being served in her community through the assistance of the COP. Jean was removed from her family at age 6 and lived in a state institution for 18 years. At the age of 24, she was moved to a nursing home, despite the fact that she is in good physical health, has many skills in communicating and can take care of herself without much help.

   The local 51 board was paying for a work program outside the nursing home, but they did not have sufficient resources to help her move to her own home in the community until COP. About $648 of COP money is now being spent to help Jean and two other women to set up their own apartment with one live-in staff and part-time staff. The COP money filled a gap between the $381 paid monthly by Supplementary Security Income (SSI) for personal expenses, public transportation, recreation, etc., and the $292 per month paid by the board for the cost of Jean's work program.

3. Bob Nelson, 74, went into a nursing home eight years ago following an accident. He was very unhappy and claimed that he could never even get a good night's sleep because of people who moaned all night. Although his veteran's benefits were enough to pay his nursing home bill and would have paid for whatever he needed in the community, there was no person or agency to help Bob make the arrangements to move back out.

   Bob uses a wheelchair and needed a live-in attendant and an accessible place to live. He also needed everything with which to furnish an apartment. In its capacity as a coordinating mechanism, the COP made all the contacts to obtain the apartment, furniture, supports, and services, referred a live-in attendant (recruited and trained by the nearby independent living center) and helped Bob move. Although he pays all his own bills, COP will continue to coordinate and manage the supports and services that Bob needs.

4. Before age 1, Karen Wright was in an auto accident that caused severe brain damage as well as other lasting injuries. After her hospital recovery, the local human services staff tried to secure a foster home for her until her mother was able to handle her at home. This became impossible and as a result she was institutionalized until the age of 3, when she returned to her community in a foster arrangement provided with the assistance of the COP.

   Karen requires total assistance in all self-care areas including feeding, dressing, bathing, toileting and positioning. She has little control over her body movements and spends most of her time in a wheel-chair. Because she has seizures, she needs to have four different medications administered. She has few verbal responses, except whines or coos when she becomes uncomfortable in her chair.

   COP money pays for her to live with a foster family who love her and consider her part of their family. The family is also provided with in-home services for a home training specialist and some respite. Without COP, she would be living in a large institution, isolated from the rest of the world at a cost of more than $30,000 per year. Instead, about $6,500 per year of COP money maintains her as part of a family and a community. It is hoped that this arrangement will allow Karen's birth mother to once again become involved in her life.

5. Sometimes, more than one family member is able to benefit from the Community Options Program. One example is an 86-year-old woman who has cared for her 60-year-old retarded son throughout his life. Recently, this became increasingly difficult, to the point that a nursing home for the mother, a group home for the son, and separation after a lifetime together, seemed inevitable. Funding and services come from two different agencies because of her age and his disability. Neither agency would assume responsibility for both individuals. A referral to COP and a complete assessment for both mother and son got the agencies working together and clarified what was needed.

   Since these two people need assistance both in the morning and the afternoon of every day, the existing funding sources did not have adequate money and the help was difficult to find. Finally, an arrangement was made with a granddaughter to help at times when agency supportive home-care providers do not work. She is paid with COP funds, and the mother and son appreciate having a familiar family member coming in regularly.

6. Florence Jones, a 99-year-old woman in an isolated rural area of a new COP county has been dependent on her 74-year-old daughter Emma for some time. Florence has lost her speech and requires total care including turning, lifting, feeding, suctioning, and changing. Although the daughter was extremely reluctant to put her mother into a nursing home, she was becoming exhausted by the strain. The county has no respite program, and it was becoming almost impossible for Emma to get out of the house at all or have any time for herself.

   Florence's situation was recently assessed by the county Community Options Program. One new service has been arranged so far and that is one-half day a week of care in the home by a respite worker. The COP coordinator has regular contact with Florence and Emma and monitors the need for additional services or supports to both women. The daughter says that she has peace of mind and is reassured by COP. She can get out of the house to shop and relax, and she is being recognized and supported in what she is doing. Meanwhile her mother can remain secure in her familiar home environment.

7. Jason Thomas, 22, was paralyzed in a diving accident when he was 18. He had been forced to move to a neighboring state to get the $1,000 a month worth of attendant services he needed to avoid going into an institution. Although his sister and her family were willing to have Jason live with them and his preference was to return to his home town, no funding was available to pay the sister the little she needed to offset her expenses. Almost a year ago, Jason's home county was one of the first to volunteer for the COP. Jason was one of the first people referred. He now lives with his sister, who is paid only $200 a month, and he is glad to be back in his home town.

8. The last COP vignette involves a family of five. The mother who is 34 became disabled by what is known as Lou Gehrig's disease during the summer; she worked full-time until July and by August she was in a wheelchair. Her children are 3, 5 and 12. The father has a full time job.

   This family's crisis includes different kinds of needs of all of the family members, including the long term support needs of the disabled mother. It was an appropriate referral to the Community

Options Program, which serves as a coordinating mechanism across age groups, disability categories, and funding sources. In this case, the decision had to be made whether the father would quit his job to take care of his wife, small children, and home. In that case they would have to be supported by AFDC, food stamps, and other welfare payments. The family decided that it would be less disruptive for the father to continue to work outside of the home and to obtain the supports and services necessary to enable the mother to continue to make decisions and manage her household and family as much as possible.

The Community Options Program has coordinated and/or paid for a number of different services that the woman and her family need. These include: home modifications, such as grab bars and ramps; the lifeline services, which come from another county; the therapy ordered by the woman's physician and occupational therapists, who are located in a third county; and the nurses, supportive home-care workers and backup support providers who go into the home.

Someone is in the home from 8 A.M. until 5 P.M. every day, at a cost of $700 a month in COP dollars, to do the home management, cooking, cleaning and to provide emotional support to the disabled mother as well as the rest of the family. The Community Options Program maintains involvement to ensure that services are adequate but are not more than the woman needs to remain as much in control as possible for as long as possible, and that they are flexible enough to change as the needs of this woman and her family change.

IV. Selling COP: The Agency, the Legislature, Interest Groups and Counties

While developing COP's innovative goals and program design were significant achievements, they represented only the first leg of long and arduous journey. Ahead lay the 1981–83 biennial budget process, shadowed by the constraints of a "new federalism"; beyond that a complex and increasingly expensive statewide expansion effort that would eventually (1986) involve all 72 counties and require a budget appropriation sure to dwarf the initial request of $3.6 million. COP's first challenge in the legislative arena was to gain the status of a mandate. In subsequent years, it would have to achieve its growth milestones, successfully undergo modification and stand up to the scrutiny of program evaluators and watchful legislators. Part A of Chapter IV tells the story of COP's struggle to gain a legislative beachhead in 1981. Part B highlights subsequent program developments that occurred between 1983 and 1987.

A. The 1981–83 Biennium

In many ways, COP's authors and principal advocates were in an enviable position as they prepared to take their program to the legislature in the winter of 1981. Among opinion leaders and in the general public there was a growing consensus that community-based long term support was an idea whose time had come. Governor Dreyfus was supporting COP in his Executive Budget, and gubernatorial hopefuls Earl and Kohler were giving the program nods from the hustings. Since the sitting governor was Republican and the legislature was controlled by Democrats, it even appeared that bipartisan support might emerge. Owing largely to Percy's leadership and the political savvy of top aides, the Department of Health and Social Services was then enjoying excellent relations with key legislative committees.

No one interested in COP's success was resting on predictions of easy victory, however. There were some serious early rumblings of disfavor from lobbyists both for the nursing home industry and for the County Boards' Associations. Beyond that, the Joint Finance Committee, sure to be the biggest legislative hurdle, would have tough questions about fiscal impact. Even if COP passed the legislature with flying colors, there were larger challenges ahead: agency representatives and advocates had to get the counties, the legislature and the interest groups on board for what was going to be a very long fiscal and program development process; this process would necessitate at least two additional return visits to the legislature requesting increasingly larger amounts of money. Immediately after initial adoption, futhermore, 8 counties would have to be recruited as early volunteers for the phase-in. After them, 64 counties would have to be coaxed to join the COP expansion effort over a 5-year period. None of this was going to be easy. The COP team had to get the go-ahead, start out very well indeed and then keeping the momentum going over what could be regarded politically as an eternity. All this, of course, would have to proceed in the face of opposition.

One might have expected COP's strongest opposition to come from the nursing-home industry's powerful, well-funded and superbly organized lobbyists. After all, COP was, in effect, a critique of the industry and its services. COP was also beginning to steal the limelight and might, in future budgets at least, begin to cut into the institutional care purse. Nursing-home lobbyists did in fact mount an early onslaught, asking questions about the potential quality of care in the community and the possibility of wasteful duplication of services. At least publicly, they opposed the cap on new nursing home construction, as well (see Appendix D).

Circumstances, however, conspired to weaken their positions before they could have an appreciable effect. First, the elderly had a strong and very effective lobby of its own that made clear that any group that stood against community-based services would do so at great political peril. As the primary client population of the nursing homes, they could hardly be ignored by industry lobbyists. Secondly, the atmosphere of anxiety that surrounded an out-of-control medicaid budget compromised their influence over a legislature, which had repeatedly been called into special sessions to enact budget cuts over the previous three years. Finally, lobbyists understood that the moratorium, though troublesome in some respects, would serve to decrease future competition to existing homes. In the face of all this, the nursing-home lobbyists contented themselves with licking some severe public relations wounds, keeping a polite silence on COP and turning their political attention toward securing a favorable state reimbursement rate.

The several interest groups representing potential COP clients were naturally disposed to campaign for the program but had a number of private questions and anxieties. The chief source of such questions was COP's program design feature of generic funding and service delivery. If individual disability groups were not to be singled out for categorical treatment as they always had been in the past, wouldn't the strongest lobbies walk off with the prize benefits, leaving newer, less glamorous causes in the lurch? And if county level staff had expertise in serving only a few of the target groups, who could guarantee that the others would receive competent attention? It was clear that the agency needed a way of ensuring a coalition of categories at the political level.

As it turned out, however, the major opposition to COP was to come from the Wisconsin County Boards' Association (See Appendices D and E for news coverage.). The cry of the association was rather familiar to state administrators and legislators: "Here's another fancy state program that will create an irresistible local constituency; the state will say a lot of nice words and then renege on the funding commitment, leaving us holding the fiscal bag." Here, in short, was a mandate without certain money. To some county legislative and managerial types, COP also held out the unhappy prospect of onerous, "mickey-mouse" paperwork and implementation headaches initially obscured by the emotional rhetoric of advocates and glossed over in the State's descriptive literature. More general opposition coalesced around a fear that the State would strangle the counties with administrative controls, depriving them of needed flexibility in when and how to do program implementation. Some counties with substantial vacancies in their expensive hospitals-turned-nursing-homes feared direct competition from COP.

For its part, the legislature began deliberations in a disposition quite favorable to COP. In spite of information to the contrary, however, many lawmakers' vision of the program was rather parochial and time-limited. A significant number, for example, viewed COP as "the old folks' program" or a kind of political litmus test vis-à-vis the elderly, although the State's literature stressed the generic focus of the program over and over again. Many legislators failed to understand the extent of COP's fiscal expansion plans. Some, like Paul Offner and John Maurer, however, worried seriously about money early on: "Was the initial request of $3.6 million simply a camel's nose in the tent?" Still others worried that COP was really just another welfare hand-out. Others voiced fears that COP would merely add to the long term support caseload and, by increasing absolute demand, fail to make any real difference in containing costs.

The Department of Health and Social Services had an extremely thoughtful and aggressive strategy to win both initial adoption and the critical continuing support of advocates and the county boards. Soon after adoption, the agency undertook additional measures aimed at garnering the cooperation of county line workers and advocates who would be most responsible for COP's success or failure at the local level, once implementation had begun. In a very real sense, the selling of COP began with program and statutory design. To forestall overwhelming county opposition at the legislative level, a number of strategic choices had been made in the shaping of COP.

Percy had asked his staff to develop several possible models. From these he picked the version that was least punitive and controlling from a county perspective. To create an attractive fiscal package to appeal to legislators in general and conservatives in particular, Percy and his staff had elected to go with a slow fiscal build-up model and decided against adding extra capacity-building funds. These decisions allowed him to stay within his budget constraints. At a more basic level, the idea of the moratorium on new nursing-home construction and the possibility of further cost-containment through less expensive or budget-neutral community services were practically irresistible. When these ideas were linked to the popular "new" values of client-choice, self-determination and dignity, broad-based appeal became a virtual certainty.

In a more subtle way the generic focus of the program added to its legislative appeal. Although advocates continued to have their anxieties about equal treatment, they nonetheless presented a united front that added to their political strength and relieved the legislature of the need to deal with many different advocacy groups each clamoring for its share of the pie. Those few "fiscal minimizers" who could hold out against all these blandishments were quickly visited by well-prepared managers from the agency's Division of Policy and Budget, and/or treated to heart-rending testimony from people who were destined to be COP's first clients.

When lobbyists for the County Boards' Association persisted in pounding the local-control drum at legislative hearings, Representative Mary Lou Munts—the major Assembly "broker" for COP—facilitated a series of meetings attended by advocates, agency professionals, lobbyists and skeptical legislators. Some 17 issues were put on the table for debate and resolution. In the end, the State yielded on a majority of them, regarding many as matters of language and administrative detail. Some, in fact, had been included initially as possible bargaining chips.

The issue of who would determine when and if a given county participated in COP was, however, clearly a matter of great importance. Initially, counties wanted participation to be completely voluntary. The State wanted to be assured of having a statewide program and an appropriate blend of counties for each step of the expansion process. Movement on the issue was finally achieved when the legislature allowed counties to "volunteer," with the proviso that the State could exercise a pre-selection option if an insufficient number and/or mix of counties resulted at any phase of the implementation scenario. As it turned out, the State's reserve option was never exercised and the apparent compromise cleared the air by removing the onus of a fiat.

The Department's strategy for selling COP and maintaining its growth momentum reached far beyond features of program design and the formal settings of legislative debate. While large new programs often use a mass media blitz to drum up public support, agency professionals judged that the receptive political and social climate obviated the need for such an approach. Although early informational discussions were held with *Milwaukee Journal* editorial writers and social service reporters, strategists' energies were for the most part directed elsewhere: to grassroots advocates and county decision-makers and future program implementors.

The agency used a wide array of client-oriented advocacy groups as a major source of political muscle. These groups were cultivated in a conscious and thoughtful way before, during and after the 1981–83 biennial budget deliberations. The first step in winning advocacy support occurred inside the department, as planners tried assiduously to shape a non-bureaucratic language that would both match and convey COP's nontraditional value base, its home and hearth orientation and its people-centered program elements.

The descriptive literature, manuals, and external correspondence that emerged were pitched toward the consumer, remarkably free of bureaucratic jargon, and often quite personal in tone. An open letter to advocates and county health and social service professionals that appears as an introduction to COP's first (1981) guidelines and procedures manual (see Exhibit 7) is a good example of this approach. Addressing its audience as respected colleagues and partners in a noble and difficult venture which was going to change society, the letter defines the goals of COP in surprisingly ordinary and emotional terms. Its four closing paragraphs create appeal by capturing the special power of COP to preserve independent life for its clients. This life is described in terms of the sights, sounds and familiar presences of an ordinary day at home.

Language like this was directly lifted by advocates for immediate use in newsletters, articles, flyers, alerts and other informational pieces. Once the COP story began filtering into this large advocacy network, organizations began mobilizing politically and approaching the local press in their communities. Human interest stories began popping up in newspapers around the state.

Advocates also went to see their senators and assembly representatives. Groups like the highly visible Wisconsin Coalition on Aging swarmed the legislature. They were joined by other advocacy organizations like the Wisconsin Coalition for Advocacy, the Survival Group, and the Wisconsin Difference. All of them buttonholed key legislators, identified riveting client testifiers and kept the legislative hot-line ringing off the hook. The campaign was so successful in 1981 that some legislators demanded that agency staffers cool down the super-heated grass-roots troops.

Once COP had been resoundingly voted in, the agency continued to disseminate information and work up support. After a year of operations, for example, the Division of Community Services hired a highly specialized media consultant who put together a slide tape of six successful and very touching COP client stories. Soon after, the Division of Community Services and the Council on Developmental Disabilities jointly purchased an extensive media library that it made available free of charge to county political leaders and program implementors, as well as advocacy groups. There consumers could find and use any number of audio-visual aids on community-based service provision for a variety of different disability groups.

Between 1979 and 1984, the State sponsored or participated in at least 200 major conferences and presentations related to COP. Managers prepared speeches for many of these events, which were charismatic evocations of basic COP values and compelling solicitations for advocacy support. (See Chapter 3, p. 22 for an excerpt from one such speech). During the same period, State and county administrators and direct service workers were urged to attend COP-

Exhibit 7.

State of Wisconsin \ DEPARTMENT OF HEALTH AND SOCIAL SERVICES

DIVISION OF COMMUNITY SERVICES

1 WEST WILSON STREET
P.O. BOX 7851
MADISON WISCONSIN 53707

December 8, 1981

Dear Colleagues,

For a number of years, we have all pursued agency and program goals which have been framed in the rhetoric of "independence ... dignity ... self-determination ... least restrictive." But we have pursued our goals, as indeed we still do, in a policy environment which encourages institutional care, and which places the needs of buildings and bureaucracies above the needs of persons.

The development of the Community Options Program has fostered a new optimism that we have the means and the will to provide for disabled persons in caring communities. Our optimism comes from the new coalitions forged among representatives of the disabled, from the public affirmation of a common sense approach to long-term care, and from the wit and skill of professionals who have volunteered to develop and implement this initiative.

The Community Options Program will ultimately demand that we pool our collective knowledge and resources and apply our imaginations to support in our communities larger numbers of more severely disabled people than our history of pilots and demonstrations has prepared us for.

We are bridging a formidable gap between medical and social care. We are venturing into non-categorical, multi-disciplinary territory with its risks of turf battles and over-professionalization. We are testing the reliability of our assessment, case planning and case management technology. We are, even more, testing the social fabric of our communities: our collective capacity to value differences as well as similarities; to acknowledge and empathize with the struggles of individuals to overcome personal adversity; to accept responsibility for the protection and at the same time encourage the independence of vulnerable individuals.

The success of this venture depends on our ability to articulate and achieve goals which are meaningful to the citizens we will serve. When we speak of options and alternatives to institutions, we are generalizing from some much more personal particulars about <u>quality of life</u>:

We are offering more than access to services. Hopefully, we are seeking for disabled citizens access to public transportation, libraries, theatres, grocery stores, churches and softball fields.

Exhibit 7, continued

2-12/8/81

We are offering a home with a kitchen table and a dresser cluttered with souveniers and a fridge stocked with snacks to a retarded adult who chooses and maintains his own personal possessions and associations.

We are seeking with disabled citizens the secure neighborhood sounds of roller skates on pavement, basketballs thudding on garage doors, mothers shouting to their children, screen doors slamming and the greetings of neighbors carrying out the trash.

Even for the old person who will not leave her room again, we are offering the faces and voices of family and friends in order to preserve the familiar, to evoke the past and offer the reassuring continuity of the presence of future generations.

These may be sentimental, but they are not trivial sentiments. We believe them to be the goals of the Community Options Program - that we can assist disabled people to create or preserve environments and experiences which make lives whole and meaningful.

Gerry Born

Gerry Born, Director
Bureau of Developmental Disabilities

Donna McDowell

Donna McDowell, Director
Bureau of Aging

Wm M. Buzogany, MD

Bill Buzogany, Director
Bureau of Mental Health

Larry Monson

Larry Monson, Director
Bureau of Alcohol and Other Drug Abuse

Dan C Johnson

Dan Johnson
Physical Disabilities Coordinator

Bill Griffin

Bill Griffin, Director
Office of Coordinated Community Services

Douglas W. Nelson

Douglas W. Nelson
Assistant Administrator of Program

focused training and "Pass" workshops that taught program and service evaluation techniques based on the Wolfensberger principles of normalization. In all this, the State was selling an instrument designed to help implement a social movement.

B. COP Developments 1983–87

> In general, the program has been successful in accomplishing its goals of supporting individuals in the community at somewhat less cost than would be incurred if they entered nursing homes, though this savings may be offset by growth in the number of persons served.[33]
>
> Dale Cattanach, State Auditor
> February 20, 1987

If the 1981–83 biennium saw COP achieve the status of a legislative mandate, the next four years saw its expansion into all of Wisconsin's 72 counties. During this period COP underwent no less than three full-scale evaluations at the State level, as well as a host of smaller studies undertaken by individual counties. Legislative scrutiny has increased markedly as appropriations have grown. This scrutiny, the lessons of implementation experience and evaluation findings, have led to several significant program modifications. The balance of Chapter IV offers a brief status report on COP's current scope and effectiveness, points to the major findings of the Legislative Audit Bureau (LAB) 1987 evaluation of COP, and highlights program changes and unresolved issues.

COP has managed to expand more or less on schedule, surviving a change of administrations and maintaining its integrity as it spread throughout the state. The program has consistently enjoyed very high client satisfaction ratings. Surveys in a broad range of counties suggest that recipients of COP services believe that COP is giving them what they need and is doing it in a satisfactory manner. The new LAB evaluation also found ". . . that most Community Options clients are well served."[34] Departmental sources estimate that over 10,000 persons have undergone COP assessments, and the LAB study reports that 6,400 actually received services in 1986.[35]

Despite an increasingly hostile funding environment, the program has grown steadily by large increments, as Exhibit 8 indicates. To a great extent, this growth was anticipated in COP's original program design; fiscal evolution has not, however, proceeded without setbacks. Program requests were cut by $3.5 million in the 1985–87 biennial budget process and by another $3.5 million in the 1986 Fiscal Management Bill.

Although some growth seems assured for the near term, the rate of this growth is likely to decrease. Department support for very substantial expansion remains strong, but the new governor (and perhaps the legislature) seems likely to take a more conservative approach, as this statement in the LAB evaluation indicates:

> The Department's 1987–89 biennial budget request includes a 45 percent increase in GPR over the previous biennium in Community Options funding to serve up to 10,200 individuals per year by 1988–89. The Governor's budget recommendation includes a 15 percent increase in funding over the previous year.[36]

The fiscal picture is not without its bright spots. The moratorium has remained in place, and the LAB evaluation (as well as earlier studies) has indicated that COP services on a per client basis are cheaper than those provided in institutional settings:

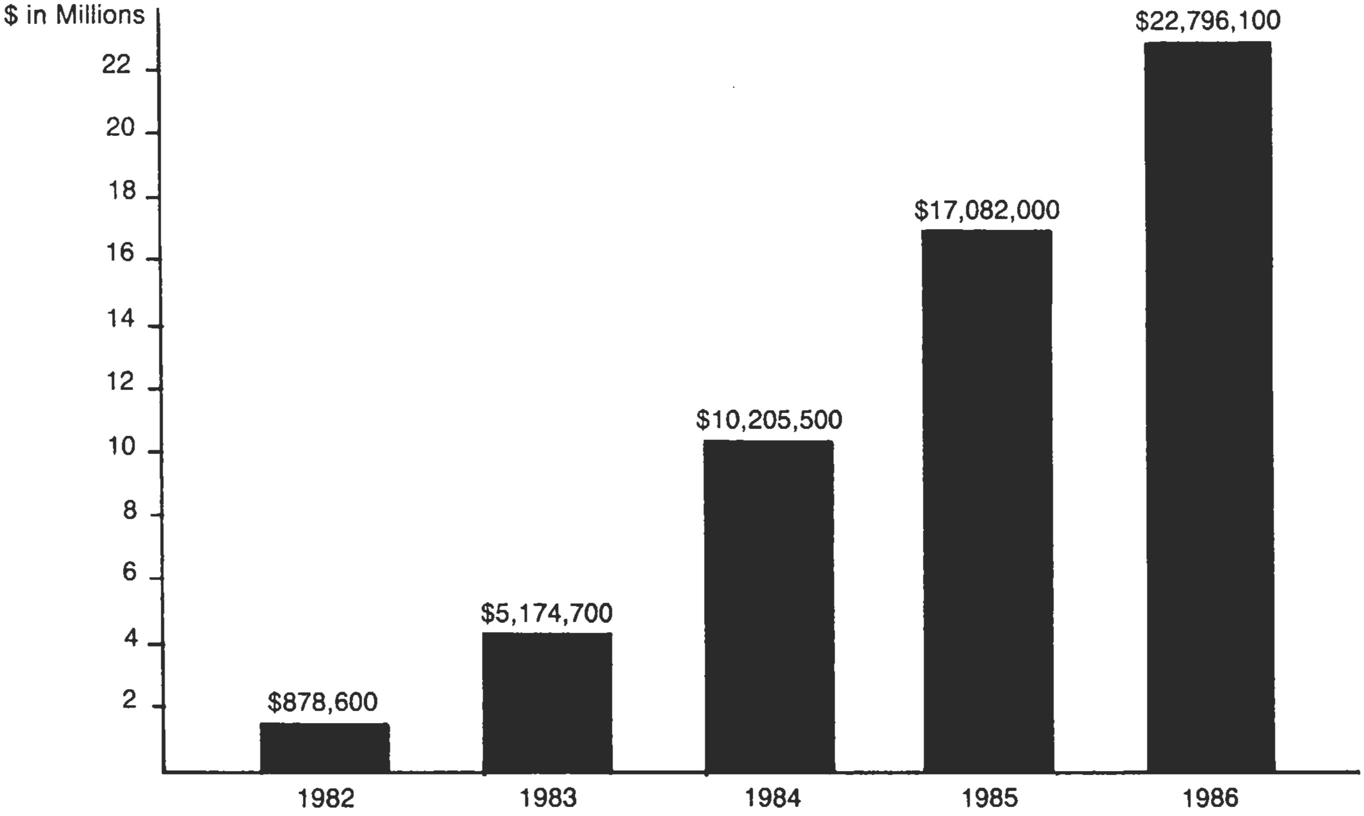
> ". . . the total public cost of the Community Options [Program] clients is approximately one-half the cost of nursing home care [$752.00 as opposed to $1,478.00]; and, the state portion of the cost is somewhat less than the state portion of nursing home costs [$558.00 as opposed to $625.00].[37]

Precise cost comparisons are difficult to achieve, however, and advocates as well as skeptics worry that in the long run, savings may be offset by growing demand and by rising prices in the community-based service sector. COP's values, appealing as they are, have always gained a measure of protection from the program's cost containment potential. Advocates in particular fear that these values may lose ground or be seriously compromised should current fiscal anxieties find objective validation in the future.

Two major client targeting issues have received continuing scrutiny over the last four years. The legislature has repeatedly pressed the Department and the LAB to investigate whether COP is serving only those persons who would, in fact, otherwise be in nursing homes or in one of the State centers, a question that obviously reaches to the concern about limiting consumer demand. Early evaluation findings (1983) indicated that approximately 80% of those served were COP-eligible, strictly speaking. The recent LAB evaluation suggests that such targeting has improved markedly and is now in the range of 90%.[38]

A second targeting issue relates to the relative proportions of different disability groups served by the program. Evaluation data from the first year of operation indicated that elderly clients were being referred to the program in disproportionately high numbers. Non-elderly disability groups—persons with mental illness and the chemically-dependent, in particular—did not appear to be faring as well in terms of either numbers of persons served or appropriateness of service. To correct such problems, the legislature instituted so-called "significant proportions" or goal percentages for each disability group. In implementing

Exhibit 8. COP's Fiscal Development in Terms of General Purpose Revenue, by Calendar Year.



Data provided by the Division of Policy and Budget, State Department of Health and Social Services.

the program, counties are required to meet these goals in terms of allocating services per disability group. The LAB evaluation suggests that ". . . the program was reasonably successful statewide in 1985 in serving the proportion of clients from each group. . . ."[39]

In spite of the significant proportions and the generally good statewide performance, equity problems remain to some extent, and some disability groups are convinced that COP does not serve all groups equally well in terms of sheer numbers and in terms of program effectiveness. Recent legislative testimony, for example, shows that 33 of 59 counties studied have offered no services to the chemically-dependent. A State point-in-time survey conducted to monitor county achievement of significant proportions for persons with severe mental illness showed that 36 of 72 counties had failed to meet the 7–11% significant proportion established for this group as of June 1986.[40] Beyond numbers, advocates for this disability group worry that COP treatment modalities may be more effective in serving the elderly than in serving persons with mental illness. While the political and fiscal advantages of the generic approach currently prevail, the "coalition of categories" is tenuous in some respects.

Counties, too, have their concerns. The State's original diversion rate estimate of 10–12% has proven to be too conservative for some counties that may experience diversion demand as high as 30–40%. This disparity has resulted in funding short-falls and in long waiting lists in a few counties, a circumstance that creates difficult problems for local implementors to address. County officials and workers also complain about planning requirements of dubious value, onerous paperwork requirements and burdensome complexity in fiscal tracking imposed by COP's program design. There seems to be no doubt that COP's fiscal concept of letting the money follow the client presented a new and cumbersome monitoring challenge to counties accustomed to block-grant funding and auditing mechanisms. Legislative concern for program evaluation led to additional documentation demands, as well.

County personnel and some legislators are also uneasy about COP's legislative status as "the" community long term support program, suggesting that it has the effect of starving out other necessary and extremely valuable programs (e.g., CSP, youth aids, child welfare, to name only three). These contentions are disputed by agency professionals who maintain that other programs have continued to grow and that their primary vulnerability from a legislative point of view lies in their block-grant fiscal format. The thrust of all these complaints seems to point toward improving COP, rather than to any radical change. Direct service workers, in particular, want to see more COP money and legislative recognition that there are needs that must be addressed through other programs and funding mechanisms.

All this is easier said than done. Most COP watchers acknowledge that, from a political perspective, money is the biggest problem facing COP and other social programs. Legislative scrutiny of COP has increased steadily as the program has evolved. COP, like all rising stars, has lost a bit its of luster as other priorities have moved onto center stage and as the fiscal pie has shrunk. Since the economy may remain shaky for the foreseeable future, and since there is a growing resistance to raising taxes, no program, however popular, can be sure of its future, particularly if that future involves expansion.

A second overriding concern expressed from all quarters is the issue of quality assurance. To date there have been no scandals in the COP program, no lurid stories of patient abuse or fraudulent billings. Nonetheless, a reform system that grew out of a critique of the heavily monitored nursing-home industry can hardly afford to operate with its fingers crossed. Professionals at the Department of Health and Social Services, social workers and advocacy-oriented friends of COP all identify effective quality assurance as a challenge only slightly less compelling than the need to insure COP's continued fiscal health. Developing a monitoring system that truly measures such intangibles as personal autonomy, community participation, social interaction and other normalization values will not be easy. Equally difficult is the challenge of ensuring compliance with basic fair employment laws and principles. Should quality client services be had at the expense of COP's "employees," some of whom have no union representation, earn little more than minimum wage and may not have basic benefits? Planners are now directing their attention to these qualitative priorities.

A final concern raised repeatedly in the LAB evaluation is the need for improved fiscal management practices. Investigators found uneven performance in their sample of counties and recommend better, more uniform controls at the local level. The report also found that "the Department does little monitoring of the effectiveness of county operations" and urges more oversight by the Department of Health and Social Services.[41] Clearly the State's reluctance to impose additional requirements on counties already complaining about "onerous" demands, will have to be balanced off against legislative interest in achieving improved program management.

V. Conclusions and Considerations for the Future

Many fortuitous circumstances converged to facilitate the birth of COP. A call for national and local social change and compelling fiscal pressures offered decisionmakers unique problems and opportunities. Aggressive, talented leadership capitalized on these difficulties by crafting a program that made its case on both deeply felt values and fiscal prudence. While COP's client numbers and funding levels remain limited by comparison with institutional standards, there is already a consensus regarding its major contributions to date. Near-term challenges and unresolved issues are also relatively clear.

COP has without question created the possibility of real choice for elderly and disabled persons who less than a decade ago would have no alternatives. Attitudes about what constitutes effective long term support have been altered among policy-makers and practitioners as well as among clients. It can also be argued that the consumer is in the driver's seat to a much greater extent than at any time in recent memory, in terms of defining the locus of long term supportive care.

COP seems to have been a catalyst for major system change, as well. It has helped foster the development of a newly strengthened array of community services; it has empowered case management that focuses on client needs, strengths and prospects, rather than on limitations and institutional convenience. While the relationship between the State and the counties remains complex, COP seems to have introduced a degree of funding and program flexibility that is unique, if not totally to counties' liking. Some counties have reported that COP guidelines have played a positive role in unifying and coordinating county long term support agencies and services. While performance and support levels vary widely among counties, COP seems to have brought to many a coherent long term care philosophy, linked to flexible money and useful system improvement requirements.

Certainly difficulties and uncertainties lie ahead. If COP is to grow as an alternative to its still mighty institutional counterpart, it will need to secure substantial new funds on a continuing basis. Some of these monies can be realized through economies achieved by improved program and fiscal management, but additional State and federal funds are obviously needed. While the current atmosphere of fiscal restraint persists, new appropriations at the State level will be harder to win, and the trade-off between values and dollars is likely to become both more painful and more painfully evident.

COP's "coalition of categories" remains somewhat uncertain and may yet come unraveled. Planners and advocates may succeed in modifying the existing program to address disparities felt by individual disability groups; if this is not possible, a well managed "divorce" may be the next best option. Hopefully, should the latter materialize, the circumstance can be handled so that program values and existing services are not compromised.

Planners and implementers busy with installing and expanding COP between 1982 and 1986 must now turn their attention to issues of quality assurance. Standards, monitoring mechanisms and resources relevant to the program's goals must be created to ensure that appropriate services are being provided and to guard against damaging scandals. The State and the counties must cooperate to improve fiscal controls and operations management without further complicating state-county relations.

Sheer demographic pressures will make long term support a major national policy issue for years to come, as a Mathematica Policy Research study has recently shown:

> Changing demographic patterns have been a major factor contributing to the growth in the need for long term care. Nationally, the proportion of the U.S. population over age 65 has risen from 3.1 percent in 1900 to 10.9 percent in 1980; Wisconsin's share is even higher, at 11.9 percent. The old/old group—those over age 75—is growing at an even faster rate (Glick 1979). This over-75 group, which has a much greater likelihood of institutionalization, represents 41.5 percent of Wisconsin's elderly; only six states have a higher proportion (GAO 1983). In addition to the elderly, national data estimate the number of handicapped adults at 9.6 million individuals, with an additional 11 million individuals experiencing developmental disabilities (NASW Committee on Long Term Care 1981).[42] In Wisconsin, there are 5,000 developmentally disabled individuals in nursing homes, and an additional 2,785 individuals in state centers for the developmentally disabled (DHHS 1981). (See Appendix F for more detailed, local demographic analysis).

At aging conferences around the country, planners and practitioners are beginning to debate such concepts as trust funds for long term care based on 1% payroll taxes, special HMO coverage, as well as innovative private/public asset mixes. It seems clear that no one is sure yet how to manage the long term care question in a comprehensive way.

Many observers, advocates and others are daring to imagine several different futures for COP; several of these possible futures are considered in the following outline.

1. The most pessimistic prospect sees COP as destined to be starved for additional funds. Should the cost-containment-through-diversion idea lose its legislative appeal, COP could be maintained as a separate program for 3–4 years and then lose its separate identity and gradually be folded into general categorical community aids programs for elderly and disabled persons.
2. More hopeful is the notion that COP will retain its separate identity and be funded in a reduced

growth mode for the indefinite future. This would allow it to function and gain strength in the newer counties, but still fail to solve the problem of waiting lists.

3. A variant of this conservative but somewhat hopeful notion sees COP being broken out by disability group, with each group forming its own "COPlet" and fighting on its own terms for funding.
4. Optimists hypothesize that COP will continue to grow, but that its chief source of new monies will be federal in nature. These theorists believe that the federal waiver will become the key to COP's future growth and health. The state is now pursuing three different federal waivers, each of which would have the effect of channeling new federal monies into the community-based side of the long term care equation, thereby reducing reliance on State general purpose revenue (GPR) to fund COP's continuing growth.
5. Still more ambitious is the COP that becomes "indexed" to some objective measure of client demand growth, such as the demographics discussed above. This is a COP still largely dependent on State GPR, a foundation which, of course, leaves it open to frequent political tinkering.

Whatever view is advanced, there is a general consensus that community-based support is destined to be a permanent fixture in our society, as the Cabinet Secretary of Department of Health and Social Services, Linda Reivitz, noted in her recent remarks to a Winnebago gathering, celebrating the county's fifth anniversary as a COP "pioneer" county.

> There is nothing so powerful as an idea whose time has come, and I would suggest to you that the ideas of community integration, and normalization, and least restrictive care, are ideas whose time has come. We may lose a little ground here and there. There may be a budget which is disappointing, or a court case that we wish had gone the other way, or changes in personnel that make us concerned about the future.
>
> There is surely hard work that needs to be done. But the genie is out of the bottle and he will not go back. Long term care, in communities, is here to stay and I think we can all be proud that we played a role in this quiet revolution.[43]

Notes

1. Samuel Gridley Howe is quoted by David Braddock in *Challenges in Financing Community Integration in Wisconsin and the United States* (paper delivered before the Wisconsin Council on Developmental Disabilities, Living Strategy Forum II), June 20, 1986, pp. 35–36.
2. Ann V. Rugg. *Children of Misfortune/One Hundred Years of Public Care for People with Mental Retardation in Wisconsin, 1871–1971 (Madison, Wis.: Wisconsin Council on Developmental Disabilities, 1984), p. 35.*
3. *Ibid.*, p. 3.
4. "The Medicaid Morass," The *Blue Print* (Winter, 1985), p. 1. (Newsletter published by the Wisconsin Council on Developmental Disabilities.)
5. Rugg, p. 41.
6. "The Medicaid Morass," p. 2.
7. *Ibid*, p. 3.
8. *Final Report/A Study of The Early Implementation Experience of the Wisconsin Community Options Program*, (Madison, Wis.: Mathematica Policy Research, 1984), p. 2.
9. William T. Gormley, Jr. *Muscles and Prayers: Bureau-bashing and Its Alternatives* (Madison, Wis.: unpublished manuscript, 1987), p. 18.
10. *Ibid.*, p. 19.
11. Rugg, p. 48.
12. *Ibid.*, p. 41.
13. *Final Report/ Wisconsin's Task Force on Problems of People with Physical Handicaps* (Madison, Wis., 1974), pp. 119–120.
14. *Ibid.*, p. 5.
15. *Ibid.*, p. 8.
16. Judy Zitske and Betty Hallgren. *Life in Limbo/A Report on People with Disabilities in Nursing Homes* (Madison, Wis.: Wisconsin Coalition for Advocacy, 1980), pp. 62–63.
17. *Ibid.*, p. 71.
18. Douglas Nelson. Transcript of speech delivered at the Community Living Ways and Means Conference, Wausau, Wis., 1980, p. 18.
19. *Life in Limbo*, p. 90.
20. *Ibid.*, p. 91.
21. *Ibid.*, p. 19.
22. *Wisconsin Community Care Organization*, original grant proposal submitted to the U.S. Department of Health, Education and Welfare, September 19, 1974, p. 6.
23. *Discussion of the Community Options Program*, prepared by the Wisconsin Department of Health and Social Services, March 1981, pp. 39–40.
24. Donald Percy. Memorandum to Governor Lee Sherman Dreyfus, June 16, 1980, p. 1.
25. *Ibid.*, p. 3.
26. *Ibid.*
27. *Ibid.*
28. *Wisconsin Long Term Support Planning and the Community Options Program*, prepared by the

Office of Program Initiatives, (Madison, Wis., 1983), p. 7.

29. *Ibid.*, pp. 7–8.
30. *Ibid.*, p. 15.
31. Nelson, pp. 21–22.
32. *Personal Experiences/The Community Options Program*, 1983, pp. 1–6.
33. Letter introducing *An Evaluation of the Community Options Program/Department of Health and Social Services*, prepared by the State of Wisconsin Legislative Audit Bureau (LAB), April 1987.
34. LAB evaluation, p. 26.
35. *Ibid.*, p. 3.
36. *Ibid.*
37. *Ibid.*, p. 9–11.
38. *Ibid.*, p. 12.
39. *Ibid.*, p. 14.
40. *Point-in-Time Survey Conducted on December 31, 1985 to Monitor Significant Proportions*, by the Wisconsin Department of Health and Social Services.
41. LAB evaluation, p. 27.
42. *Final Report* (see n.8 above) Mathematica Policy Research, p. 3.
43. Linda Reivitz. Transcript of speech delivered in Winnebago, Wis., November 13, 1986. Letter to author.

Case Study Resources

Resource Persons for COP Case Study

(In Alphabetical Order)

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Bibliography of Resource Materials

The following resource materials have been divided into two broad categories: Section I includes all those materials directly cited in the text of the case study; Section II includes those materials that provided useful background information, but are not cited.

I. Cited Resource Materials

A. Program Memoranda, Evaluation and Information Materials

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8. *Personal Experiences/The Community Options Program*, prepared by the Office of Program Initiatives, State Department of Health and Social Services, 1983. (Includes 14 written vignettes of early COP client experiences plus several related news articles.)
9. *Point-in-Time Survey Conducted on December 31, 1985 to Monitor Significant Proportions*, prepared by the Department of Health and Social Services.
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11. *Selected Graphs on Long Term Support*, prepared by the Wisconsin Department of Health and Social Services, Office of Program Initiatives, February 1983.
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13. *Wisconsin Long Term Support Planning and The Community Options Program*, prepared by the Office of Program Initiatives, February 1983 (Includes descriptive overview of COP development process and all major Long Term Support Initiative Task Assignments, as well as *Planning Guidelines #1—Long Term Support*).

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2. Earl, Anthony (Governor). Speech to the Statewide COP Conference, Milwaukee, December 12, 1985.
3. *Final Report/Wisconsin's Task Force on Problems of People with Physical Handicaps*, Madison, Wis., 1974.
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5. Nelson, Douglas. 1980 Keynote Speech at Community Living Ways and Means Conference, Wausau, Wisconsin.
6. ______. "A Community Care Program," in *Perspective on Aging* (July/August, 1985):pp. 12–14.
7. Reivitz, Linda. "COP Day of Sharing," speech delivered in Oshkosh, Winnebago County, to local COP program implementors and supporters, November 13, 1986.
8. Rugg, Ann V. *Children of Misfortune/One Hundred Years of Public Care for People with Mental Retardation in Wisconsin, 1871–1971*. Masters thesis published by the Wisconsin Council on Developmental Disabilities, Madison, Wisconsin, 1984.
9. *The Medicaid Morass*. Third article in a series entitled "By Reason of Condition" in *The Blueprint* (Winter, 1985).
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II. General Background Materials

A. Program Memoranda, Evaluation and Information Materials

1. Evaluation data on COP program operations for 1982 and 1983, published by the Department of Health and Social Services, Division of Policy and Budget.
2. Evaluation and survey data on COP, Portage County, 1985.
3. Information pieces describing COP, developed and published by the Department of Health and Social Services, Office of Program Initiatives, February 1983 and February 1985.
4. Memoranda on the Long Term Support Initiatives from Health and Social Services Secretary Donald Percy, 1980–82.

5. Memorandum on the Long-Term Support Initiatives by Jean Logan, Milwaukee County Health and Social Services, October 1980.
6. Memoranda on COP prepared by the Legislative Fiscal Bureau for members of the Joint Finance Committee, March 1981 to April 1985.
7. Memoranda from the Wisconsin Office on Aging to the Long Term Support Management Reference Group and others, July and August 1986.

B. Articles, Speeches and Audio-Visual Materials

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2. COP speeches by Department of Health and Social Services Secretary Linda Reivitz: October 11, 1985; September 23, 1986 and September 24, 1986.
3. COP speeches by Douglas Nelson: August 6, 1982; February 11, 1983; October, 1983; June 7, 1984 and September 7, 1984.
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5. Feature articles on institutional care published in *The Blueprint*, a newsletter of the Wisconsin Council on Developmental Disabilities: Winter 1985; Spring 1985; Summer 1985 and Fall 1985.

Appendix A. Counties Participating in the Community Options Program by Year of Entry.

1982: 8

Dane
La Crosse
Pepin
Portage
Racine
Rusk
Waupaca
Winnebago

1983: 20

Ashland
Brown
Calumet
Chippewa
Eau Claire
Jackson
Jefferson
Kenosha
Manitowoc
Marathon
Marinette
Menominee
Milwaukee
Outagamie
Rock
Sauk
Vernon
Walworth
Washington
Wood

1984: 9

Clark
Door
Dunn
Lincoln
Oconto
Ozaukee
St. Croix
Shawano
Waukesha

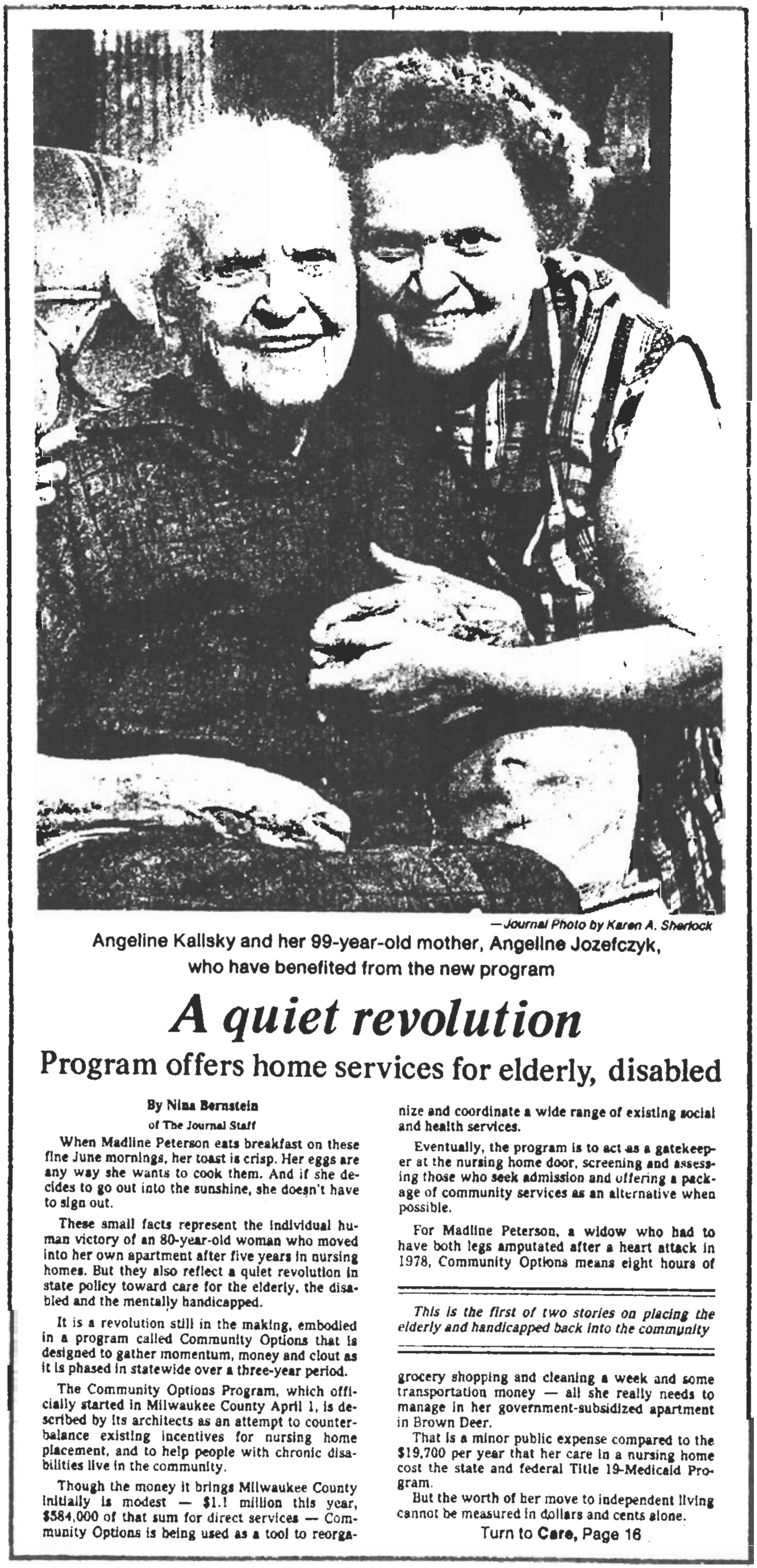
1985: 22

Adams
Barron
Bayfield
Burnett
Columbia
Douglas
Fond du Lac
Grant
Green
Iowa
Iron
Monroe
Oneida
Pierce
Polk
Price
Richland
Sheboygan
Taylor
Trempealeau
Washburn
Waushara

1986: 13

Buffalo
Crawford
Dodge
Florence
Forest
Green Lake
Juneau
Kewaunee
Lafayette
Langlade
Marquette
Sawyer
Vilas

Appendix B. "A quiet revolution," ***Milwaukee Journal***, June 26, 1983.



—Journal Photo by Karen A. Sherlock

Angeline Kalisky and her 99-year-old mother, Angeline Jozefczyk, who have benefited from the new program

A quiet revolution

Program offers home services for elderly, disabled

By Nina Bernstein
of The Journal Staff

When Madline Peterson eats breakfast on these fine June mornings, her toast is crisp. Her eggs are any way she wants to cook them. And if she decides to go out into the sunshine, she doesn't have to sign out.

These small facts represent the individual human victory of an 80-year-old woman who moved into her own apartment after five years in nursing homes. But they also reflect a quiet revolution in state policy toward care for the elderly, the disabled and the mentally handicapped.

It is a revolution still in the making, embodied in a program called Community Options that is designed to gather momentum, money and clout as it is phased in statewide over a three-year period.

The Community Options Program, which officially started in Milwaukee County April 1, is described by its architects as an attempt to counterbalance existing incentives for nursing home placement, and to help people with chronic disabilities live in the community.

Though the money it brings Milwaukee County initially is modest — $1.1 million this year, $584,000 of that sum for direct services — Community Options is being used as a tool to reorganize and coordinate a wide range of existing social and health services.

Eventually, the program is to act as a gatekeeper at the nursing home door, screening and assessing those who seek admission and offering a package of community services as an alternative when possible.

For Madline Peterson, a widow who had to have both legs amputated after a heart attack in 1978, Community Options means eight hours of grocery shopping and cleaning a week and some transportation money — all she really needs to manage in her government-subsidized apartment in Brown Deer.

This is the first of two stories on placing the elderly and handicapped back into the community

That is a minor public expense compared to the $19,700 per year that her care in a nursing home cost the state and federal Title 19-Medicaid Program.

But the worth of her move to independent living cannot be measured in dollars and cents alone.

Turn to **Care,** Page 16

New program offers care alternatives

Care, From Page 1

"It's really a joy being in the place," she told a visitor recently, beaming from the wheelchair she maneuvers expertly through the sunny one-bedroom apartment.

She laughed about the pleasure of having a private bathroom, after sharing one with four other nursing home residents ("We practically had to take numbers!"). She talked of being able to eat the odd foods she once longed for in vain ("Creamed corn — I really missed creamed corn") and of playing her record collection of Broadway musicals for the first time in five years, on the stereo that wouldn't fit into a nursing home room.

"The little things in life that you take for granted mean a lot to a person," she said.

"I will say they were wonderful to me at the nursing home — all the nurses, the aides. But you didn't feel free. You weren't free."

Nursing home costs

During the years that Madline Peterson spent in two nursing homes, nursing home care became the largest and fastest growing service in the state's soaring Medicaid budget — reaching almost 70% of a nearly $1 billion program.

With about 52,000 beds in 490 nursing homes, Wisconsin's rate of nursing home use has been one of the highest in the nation. And despite an official philosophy favoring community services over institutions, between 1976 and 1980 state and federal spending on nursing home care continued to increase steeply — four times more than spending for programs to keep people in their own homes.

Ironically, nursing homes were once defined as community placements by the state planners who moved thousands of mentally ill and mentally retarded people from state institutions to nursing homes in the early 1970s.

Advocates for these groups, for the elderly and for the young physically disabled soon began arguing that nursing homes were institutions, too, and unsuited to the needs of many of their residents.

But nursing homes had an unbeatable drawing card: money. Put people in a nursing home, and an unlimited pool of federal and state Medicaid money could be tapped for their care. Keep them in their own houses and the supportive services they needed — delivered meals, for example, or help in bathing — came out of a strictly limited pot of community services money for which many other groups in the county were competing.

Forerunner of program

The lure of Medicaid-financed programs was so great that in the late 1970s some county and state officials tried to replace an inexpensive county program called Home Care — actually a modest forerunner of the options program — with a Medicaid service that would provide less care at much greater cost.

But as the Medicaid budget soared out of control, federal officials began to threaten to put a cap on the supply of money. And the state share of the bill — roughly 40% to the 60% federal portion — began to pinch intolerably as the economy tightened.

Suddenly the advocates had a new and attentive audience for their arguments that human value, dignity, and independence demanded community alternatives to nursing homes.

"It was a merger between philosophy and fiscal reality," said John Easterday, who helped design the options program when he worked for the state and now is one of the many county officials responsible for putting it into practice.

The fiscal imperative is both the engine and the brakes on the options program machine. Though advocates say the program would be worthwhile for humanitarian reasons even if it turned out to be no cheaper than institutional care, the legislation creating the program clearly was intended to guarantee a payoff.

A concern voiced by some legislators was that instead of diverting the elderly and disabled from expensive nursing home care, the program would simply extend services to elderly and disabled people who are managing to stay in the community anyway — managing badly, perhaps, but inexpensively.

the program to become a nursing home gatekeeper when the program is fully implemented in all counties in 1984 at a cost of about $12 million.

Buys more independence

The original bill would have denied nursing home admission to any Medicaid-eligible person judged suitable for community care. However, the enacted version allows clients and families to opt for a nursing home even when the assessment team recommends community care.

Whenever possible, clients assessed by the options program will be served through existing services and programs. When program service money is spent, the monthly cost per case will not exceed an average of $400. That's equivalent to what the state has to pay toward the $1,000 monthly Medicaid bill for care in the average nursing home.

Easterday believes that because of these cost controls the option program's integration into basic county programs, and Wisconsin's 2-year-old moratorium on nursing home construction, the program will be more successful at saving money than similar programs elsewhere have been.

"Dollar for dollar, COP money will buy more independence than any other program we have today," says William Hatcher, director of Southeastern Wisconsin Independent Living Center, one 15 community agencies linked to the program.

The difference in the option program's dollar is flexibility, said Geri Lyday, coordinator in Milwaukee County.

"It's gap-filling money, and the money follows the individual," she said.

"You can use it to build ramps, for housing, to pay a relative to help — whatever the individual needs. That's really the unique part about it."

Support for families

For a 50-year-old schizophrenic man with diabetes, for example, the program paid for a daily drug dispenser to help cure him of his habit of mixing up different medications and taking the pills haphazardly.

The man, who had spent the better part of 24 years in mental institutions, recently moved from the county nursing home to a Downtown hotel room. The program is paying about $60 a month for a case manager whose role has included helping the man open his first checking account, arranging a day treatment program for him and monitoring his medication.

"He wants to be free," said Susan Lucas, the case manager and a nurse at the Mental Health Complex. "He wants to be able to come and go. He likes the idea that he can choose where he eats breakfast."

In another case, the option program is paying for a day's respite for a South Side woman who cares for her frail and increasingly confused mother.

"As long as I can care for her I will, because she's my mother," the daughter, Angeline Kalisky, said. "But there are days when I feel it's too much.

"Sometimes at night she comes and crawls in with me, just like a little kid. I can't even go to the bathroom. If I mow the lawn, she'll be rapping on the window."

—*Journal Photo by Karen A. Sherlock*

Madline Peterson has her own apartment now, thanks to the recently developed Community Options program

Now every Friday, her 99-year-old mother, Angeline Jozefczyk, goes to a day-care program at Clement Manor nursing home and gets a whirlpool bath while her 60-year-old daughter gets a break.

Supporting families and friends, not supplanting them, is part of the program's philosophy, Lyday said. And the program is not just for persons who obviously don't need to be in a nursing home, she stressed, but for those who obviously would need to be there without special help.

In other counties, the program has served the elderly almost exclusively, she said, but in Milwaukee a special effort is being made to reach the developmentally disabled, chronically mentally ill, young physically disabled, and alcohol or drug abusers, too.

This year, Lyday said, the program has targeted cases that are especially hard to serve, or that fall into the cracks between other programs.

Michael Howden, who supervises the program's cases being handled by the Adult Services program of the Milwaukee County Department of Social Services, said:

"A big part of the problem has been all the myriad of funding and services that pass in the night. Their computers don't talk to each other, the administrators don't talk to each other. Now Community Options is making a system out of a nonsystem."

Appendix C. "COP helps disabled to live more full lives"

For Carole Ann Parsons, the choice was clear: Either leave her family and move to a state where she could get more money to hire an attendant, or spend the rest of her life in a hospital in intensive care.

Parsons, a resident of Madison's far east side, had polio during the 1950s and now breathes only with the help of a respirator 24 hours a day.

Early last summer, Parsons realized her parents "were at the point where I felt they were physically having difficulty caring for me," and she needed to make a decision soon.

"In my case, a nursing home wasn't an option," Parsons said, "because they wouldn't be able to handle my respiratory status or give me the number of hours of care I need.

"I had already explored several states, but I kept procrastinating about making any definite move. Yet if I would have to live in a hospital, my life would have absolutely no meaning. I would cease to want to exist," she said.

After six months of feeling "extremely frustrated at the prospect of having only those two options available to me," Parsons happened to read a newspaper article about the Dane County Community Options Program (COP).

The state-sponsored program, in effect in the county the past two years, has been able to help Parsons and others like her stay out of institutions and nursing homes and live in the community instead.

"The feeling of the COP Long-Term Planning Committee is that a person's self-worth and self dignity should be recognized as having a value," Tom Fisher, chairman of the committee, said. "Even if it costs just as much to keep a person in the community, the person should have the opportunity to make that decision.

"I think we're talking about quality of life versus dollars," he added, "and quality of life has to be a serious consideration."

This year, Dane County received $597,284 in COP funding from the State Department of Health and Social Services, and anticipates getting approximately $1 million in 1984.

The program, approved by the State Legislature in response to the growing cost of institutional care, provides funds for assessments, for individual case plans for clients, and for the support services a person needs to live in the community.

From January through June of this year, the Dane County COP program diverted 66 persons from institutions at an average cost of $407 per client per month. Of those persons, 32 were elderly, 17 were physically disabled, 13 were both elderly and physically disabled, and others were developmentally disabled, drug abusers or chronically mentally ill.

Carole Ann Parsons

The COP program, which uses its own funds only when services can not be purchased in any other way, works with hospitals and nursing homes throughout the county to identify potential clients.

For Parsons, who is grateful she got into the program before an Oct. 1 waiting list went into effect, COP has meant a "complete change" in her life.

"It's made things so much more comfortable in my relationship with my parents, who still assume a great deal of responsibility for my care," she said. "I have more independence, there isn't as much tension or stress, and I don't feel guilty anymore."

By having an attendant, Parsons now has someone to take her to adult education classes at Edgewood College and the University of Wisconsin (she already has a master's degree in social work), and she is able to do other things "my parents weren't able to do.

"I'm completely overwhelmed by the positive effect it has had on my life," Parsons said. "I am very seldom depressed any longer. And with a severe disability, the will to live and a positive outlook make a complete difference."

By Barbara Mulhern
Capital Times Staff Writer

"COP helps disabled to live more full lives," *Capital Times*, Madison, Wis., October 26, 1983.

Appendix D. "Details may bog down community care plan"

Details may bog down community care plan

When the debate on the Community Options Program begins in the Legislature more questions will be asked about the details of the plan than about the concept

The Wisconsin Board on Aging, the Wisconsin Council on Developmental Disabilities, the Wisconsin County Boards Association, the Wisconsin Association of Nursing Homes, and an ad hoc legislative committee on nursing home use have declared their support of community care.

However, those declarations of support have sometimes been accompanied by reservations.

Rep. Michael Kirby, D-Milwaukee, a member of the Joint Finance Committee, predicted most questions will come from the counties and the nursing home industry.

Terry Hottenroth, human services director of the county boards organization, said her group's questions concern the pre-screening process and the freedom the counties will have to develop their program.

The association will want to "substantially modify" the department's proposal in those respects before it supports the program.

In addition, counties say the pre-admission screening will create another level of regulation. It duplicates the hospital discharge planning, nursing home admission criteria, and level of care determination requirements that already exist, Ms. Hottenroth said.

She also called it "a dangerous assumption" to say that community-based care is always cheaper than institutional care.

"A number of our counties have found that is not always the case," she said.

Both Doug Nelson and Donna McDowell said the Department of Health and Social Services knows it will have to work closely with the counties. "We're going to have to provide assistance to the counties with less highly developed networks of services to help them get off the ground," McDowell said.

She said the tensions in developing the program will be those found in any new human services program — how to give the system independence and flexibility while having it be accountable and responsible.

Nelson added the department's confidence in the program "does not mean we don't anticipate any problems or confusion or tinkering with the mechanism."

Assembly Majority Leader Thomas Loftus, D-Sun Praire, along with Sen. Paul Offner, D-La Crosse, headed an ad hoc committee on nursing home use that recommended a program similar to the department's.

Loftus predicted the nursing home industry will fight the two-year moratorium on nursing home construction that is part of the Community Options Program and the proposal to limit increases in Medicaid reimbursements to 9.75 percent during the next biennium.

"If we lose on that, there won't be enough money around to pay for some of the innovative things like this," he said.

James Bullion, from the Wisconsin Association of Nursing Homes, said that attitude amounts to "stealing money from another program."

His association said there should be additional money appropriated to pay for the program.

Bullion said the state's proposal would create "a new proliferation of agencies" and suggested nursing homes could be used as a base for community services.

Bullion said meals, nurse service, medication supervision and other services could be coordinated by a nursing home on an out-patient basis.

The association opposes the moratorium because Bullion predicted it will not accomplish its purpose. He said it will mean more restrictions in the choices available to older people.

Nelson said the department anticipated industry opposition. "It's in their interest in the long run but it may take them a while to realize that," he said.

—By Mary Frances Schjonberg

"Details may bog down community care plan," *Wisconsin State Journal*, Madison, Wis., February 18, 1981.

Appendix E. "Nursing home changes backed"

Nursing-home changes backed

A committee of the Dane County Commission on Aging on Wednesday recommended that the commission support a County Board resolution calling for significant modifications in the state's proposed Community Options Program.

The program is proposed by the Department of Health and Social Services as a way to prevent inappropriate use of nursing homes. The program would use a pre-admission screening and coordination of community-based services for those who can and prefer to live outside of a nursing home.

The commission will vote on the recommendation at its March 10 meeting.

Wisconsin counties have objected to the fact that 22 counties, including Dane, will be required to participate in the second year of the program. They also said that parts of the program duplicated exisiting services.

The County Board resolution supports the intent of the program, citing the $1.2 million it budgets for similar services, but says that it will support the program only after changes have been made.

Dropping the requirement of mandatory participation and, instead, allowing counties to apply for money on a grant basis is the major change outlined in the resolution. The county also wants the project to end after 1983, requiring specific legislative action to continue.

"If it worked and the bugs were out of it, I am sure that the counties would come running to the Legislature, demanding that the program be continued," James Collier, county human services director, told the committee.

Don Horsley of the state Bureau of Alternate Care, who testified during the meeting, said afterward that it would be a mistake to make the program voluntary with a 1983 sunset provision. He said that not enough evidence of the program's results would be available by the time the Legislature had to review it. "I'm very much afraid that the program would be cut in mid-1983 and that there would be a hiatus, at which point we'd have to start over from the ground floor," he said.

Collier said that it could cost Dane County nearly $350,000 to run the Community Options Program because the state will not provide enough money.

"We want to provide quality service and the state is not coming up with the money," Clayton Dunn of the county executive's office said.

The resolution asks that the state provide 100 percent of the funding or allow the county to stop the program after the state money is gone.

It also calls for more freedom in setting up and running the program, including the right to restrict the program to a certain number of nursing homes, to make it applicable to Medical Assistance recipients only and to use existing screening systems rather than start new ones and asks that counties not be restricted to the state's $60 estimate of each screening cost.

Horsley said that the modifications have been agreed to by the Department of Health and Social Services and sent to the Joint Finance Committee

By Mary Frances Schjonberg
of The State Journal

"Nursing home changes backed," *Wisconsin State Journal*, Madison, Wis., March 5, 1981.

Appendix F. Estimated Long Term Support Population in 1985 and Projected Growth During 1985–1995 in Wisconsin.

Age/Chronic Disability or Illness	Estimated LTS Population 1985	Percent of Total Population	LTS Population Growth 1985-1995	
			#	%
Total	**463,600**	**9.52%**	**57,700**	**12.4%**
Aged 65 and older*	**238,900**	**4.90**	**41,500**	**17.4**
Functional impairment*	238,900	4.90	41,500	17.4
Developmental disability	2,950	0.06	390	13.2
Chronical mental health problems	5,500	0.11	710	12.9
Chronical alcohol and other drug abuse	1,180	0.02	150	12.7
Physical disability	92,000	1.89	11,900	12.9
Irreversible dementias	62,600	1.28	7,400	11.8
Under age 65	**224,700**	**4.61**	**16,200**	**7.2**
Developmental disability	82,600	1.70	4,700	5.7
Chronical mental heath problems	47,200	0.97	2,500	5.3
Chronic alcohol and other drug abuse	5,560	0.11	330	5.9
Physical disability	83,100	1.71	8,300	10.0
Irreversible dementias	6,200	0.13	400	6.7

* It is assumed that all older persons with long term support need have aging process associated functional impairment.

Data taken from ***A Profile of Wisconsin's Long Term Support Population****, a report prepared by the Wisconsin Department of Health and Social Services Long Term Support Management Reference Group, Demographics Workgroup, August 1986.*