

# Appendix

## Appendix A

# Method of the Study

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Following the release of OTA's report, *Losing a Million Minds: Confronting the Tragedy of Alzheimer's Disease and Other Dementias*, in April 1987, OTA received a number of requests for a follow-on study of methods of locating and arranging services for people with dementia. The follow-on study was requested by the Senate Committee on Labor and Human Resources, Senator Charles E. Grassley, the House Committee on Energy and Commerce, and the House Select Committee on Aging. OTA received letters of support for the study from the Senate Special Committee on Aging, Senator Frank H. Murkowski, ranking minority member of the Senate Committee on Veterans' Affairs, the House Committee on Veterans' Affairs, and Congresswoman Olympia J. Snowe. In response to these congressional requests, OTA staff developed a proposal for the study, and the Technology Assessment Board approved the proposed study in June 1987.

In conducting a study, OTA generally relies on the advice and assistance of an advisory panel. The advisory panel suggests source materials, subject areas, and perspectives to consider; reviews drafts prepared by staff and contractors; helps interpret information, suggests conclusions based on the information prepared by staff; and offers advice in the development of policy options. The advisory panel for this OTA study was selected in October 1987. The 21 members of the panel were chosen to represent the professions and types of agencies and organizations involved in caring for people with dementia and locating and arranging services for them. The panelists included some individuals whose work focuses specifically on people with dementia and some individuals whose work focuses on elderly and/or disabled people in general and includes people with dementia in those categories. David F. Chavkin, of the American University Practicing Law Center, served as the panel chair. The members of the panel are listed at the beginning of this report. Between January and November 1988, three panel meetings were held. The panel meetings were open to the public, and some observers attended each meeting.

The first advisory panel meeting was held January 7, 1988. Panel members discussed the overall direction and plan for the study and examined some of the relevant definitional issues, particularly the definition of case management. The panel also helped OTA staff identify the types of agencies and providers that should be analyzed in the report with regard to their capacity to link people with dementia to services.

The second panel meeting was held on June 23, 1988. At that meeting, partial drafts of several chapters of the report were reviewed, and it was decided that a separate chapter on making decisions about services for people

with dementia would be needed. In addition, after much debate, the panel concluded that an effective system to link people with dementia to services must include four components, i.e., public education, information and referral, case management, and outreach.

The third and final panel meeting was held on Nov. 3-4, 1988. The primary focus of that meeting was the draft of the final report prepared by OTA staff. The panel discussed its strengths and weaknesses and made recommendations for changes and improvements. The panel also discussed the policy options for congressional consideration, particularly whether a system to link people with dementia to services should serve people with dementia exclusively or people with other diseases and conditions as well.

Following the third panel meeting, the report was revised by OTA staff to reflect the comments and suggestions of the advisory panel and then sent to about 60 outside reviewers, including individuals from Federal, State, and local government agencies that have programs that link people with dementia to services, private agencies and organizations, health care and social service professionals, service providers, Alzheimer's advocates, and others. The report was again revised to reflect the comments and suggestions of these outside reviewers. It was submitted to the Technology Assessment Board in July, 1989.

Early in the assessment, because of the lack of available information about several important aspects of the process by which people with dementia are--or are not--connected to appropriate services, OTA contracted for four small, exploratory studies, the findings of which are discussed in the report. The four studies are described briefly below. Due to the small size of the samples and other characteristics of the four studies, their findings cannot be generalized with certainty, but they do provide insight into the problems families and others experience in locating and arranging services for a person with dementia and the possible solutions for those problems.

A full report on each of the studies is available from the National Technical Information Service, U.S. Department of Commerce, 5285 Port Royal Rd., Springfield, VA 22161, phone (703) 487-4650. The publication number for each of the contract reports is noted below.

1. In 1987-88, a multifaceted exploratory study was conducted for OTA in Cuyahoga County, Ohio, to learn about the sources of information and referrals and other aspects of the process by which families and others locate services for a person with dementia. The study was directed by Sharen K. Eckert of the Cleveland Chapter of the Alzheimer's Association and Kathleen Smyth of

University Hospitals of Cleveland. It had five components:

- The contractors identified all the public and private agencies in Cuyahoga County that they thought might provide information, referrals, or services of any kind for people with dementia the contractors developed and mailed a questionnaire to each of the 324 agencies they identified; 97 questionnaires were completed and returned, and their results were analyzed.
- In-depth interviews were conducted with representatives of 24 of the 75 agencies that indicated on their questionnaire that they provide information and referrals for people with dementia.
- OTA's contractors analyzed information about the people who called the telephone information and referral helpline of the Cleveland Alzheimer's Association Chapter between April and June 1988.
- In-depth interviews were conducted with 26 caregivers who contacted the helpline in that time period and received a referral to a specific service provider.
- Information about people who called the telephone helpline of the Benjamin Rose Institute in Cleveland was analyzed to compare the information and referral needs and experiences of people who called the helpline for someone with a physical impairment v. people who called the helpline for someone with a mental impairment.

The findings of the study conducted for OTA in Cuyahoga County, Ohio, are discussed primarily in chapter 2 but also in chapters 1, 3, 5, and 8. A full report on the study, "A Case Study of Methods of Locating and Arranging Health and Long-Term Care Services for Persons With Dementia," is available from the National Technical Information Service, #PB 90-186933.

Following the completion of the study in Cuyahoga County, OTA staff met with the contractors and several other individuals who are familiar with the service environment for people with dementia in the county to discuss the study's findings and their implications for an effective system to link people with dementia to services. Involved in that meeting were Sharen K. Eckert and Peg Kuechle of the Cleveland Chapter of the Alzheimer's Association, David Bass and Linda Noelker of the Benjamin Rose Institute, and Kathleen Smyth and Peter Whitehouse of University Hospitals of Cleveland.

2. To explore the question of what is different or special about case management for people with dementia, OTA contracted for an exploratory study of case managers' views regarding the unique aspects and difficulties of working with people with dementia and their families and family caregivers' views regarding the process by which case managers arrange services for their relative with dementia. The study was conducted for OTA by Steven H.

Zarit, Eileen MaloneBeach, and Diana L. Spore of Penn State University.

The study was carried out in 4 counties in central Pennsylvania and involved in-depth interviews with 15 staff members from 5 area agencies on aging (AAAs) and 46 family caregivers of people with dementia. The 15 AAA staff members who were interviewed for the study included the case management supervisor and two other staff members selected by the supervisor at each AAA; the staff members selected by the supervisors included eight case managers and two case aides. The 46 family caregivers who were interviewed included some caregivers who were identified by the AAA case managers and some who were recruited independently. The primary sources of the independent sample were support groups, a day care program, and other subjects. The interviews with the AAA staff members and the family caregivers were based on interview schedules developed by OTA's contractors.

The findings of the study are discussed primarily in chapter 3. A full report on the study, "Case Management as an Approach to Dementia: An Exploratory Study," is available from the National Technical Information Service, #PB 90-123191.

3. To learn about how ethnic minority people with dementia are linked to services and to identify any special problems that may arise in the linking process for them, OTA contracted for an exploratory study that was carried out in Los Angeles and San Diego Counties, California. The study involved interviews with the families and other informal caregivers of black, Hispanic, Japanese, and American Indian people with dementia and with staff members of agencies that provide services for people in the four groups. The study was directed by Ramon Vane of San Diego State University, Lourdis Birba of American Health Geriatric Systems in Los Angeles, Josephine Yelder of Pepperdine University, Yasako Sakamoto-Kowalchuk of Little Tokyo Service Center, Ralph Forquera of the American Indian Health Center, Rose Cosgrove of the Indian Health Council, Inc., Rincon Reservation, and Denise Nelsen of San Diego State University.

In all, 88 ethnic minority caregivers were interviewed, including 35 blacks, 25 Hispanics, 18 Japanese, and 10 American Indians. Forty-eight staff members of agencies that provide services for the four ethnic minority groups were interviewed. The interviews were based on interview schedules developed by OTA's contractors. The interview schedule for the caregivers was translated into Spanish and Japanese, and the interviewers for the Hispanic and Japanese caregivers were bilingual.

The findings of the study are discussed primarily in chapters 1 and 2. A full report on the study, "Linking of Ethnic Minority Elderly With Dementia to Long-Term

Care Services” is available from the National Technical Information Service, #PB 90-186446.

After OTA’s contractors compiled the results of the interviews, the contractors and OTA staff met with some of the interviewers and local service providers for three of the four groups--blacks, Hispanics, and Japanese--to discuss the study findings and their policy implications. It was not possible to arrange a meeting with the American Indian service providers in the time available for the study. Participants in the meetings, held in Los Angeles in December 1988, were: Yasako Sakamoto-Kowalchuk and Yosh Bill Watenabe of the Little Tolgo Service Center in Los Angeles; Margaret Endo and Sharon Kato Palmer of Keiro Services in Los Angeles; Josephine E. Yelder of Pepperdine University; Camella J. Barnes of the Watts Health Foundation, Inc. in Lynwood, California; Jean Daniels of California State University, Northridge; Monica Hampton of People Coordinated Services of Southern California in Los Angeles; Marguerite V. Hedge of the American Lung Association in Los Angeles; Maria P. Cordero-Aranda of Calmecac Educational Services in Los Angeles; Lourdis Birba of American Health Geriatric Systems in Los Angeles, Maria Elena Gomez and I. Maribel Taussig of the University of Southern California in Los Angeles.

4. To learn about the information and referral procedures of Alzheimer’s Association chapters and the capacity of Alzheimer’s Association chapters to function as the basis of a national linking system for people with dementia, OTA contracted for a survey of 10 chapters. Nancy L. Mace conducted the survey. A questionnaire was developed and mailed to 10 chapters. The chapters were selected to reflect diversity in size, in services provided, in composition of staff (i.e., urban, suburban, or rural), and in other characteristics. The 10 chapters surveyed by OTA’s contractor were:

- . the Palm Beach County Chapter,
- . the Detroit Area Chapter,
- . the New York City Chapter,
- . the Honolulu Chapter,
- . the Albuquerque Chapter,
- the Central Virginia-Lynchburg Chapter,
- . the Eastern Massachusetts Chapter,
- . the Western North Carolina Chapter,
- the North Central Montana Chapter, and
- the Greater Kansas City Chapter.

OTA’s contractor interviewed each chapter’s president or executive director by telephone to obtain answers to the questions.

The findings of the survey are discussed primarily in the section on Alzheimer’s Association chapters in chapter 8. A full report on the study, “The Role of ADRDA Chapters in Providing Information and Referral Services for Persons With Dementia” is available from the National Technical Information Service, #PB 90-123209.

In addition to these four small, exploratory studies, OTA contracted with Lisa P. Gwyther of Duke University for an analysis of factors that interfere with the use of services by people with dementia and their caregivers. The contract report, “Barriers to the Appropriate Use of Community-based Services by Families of Persons with Dementia,” draws on the findings of several Duke University studies of people with dementia and their families but particularly the Duke University Respite Care Demonstration Project conducted from 1985-1987 in four counties in North Carolina. The conclusions of the contract report are discussed primarily in chapter 3. The full report is available from the National Technical Information Service, #PB 89-225205.