

NAVIGATING
THE LONG-TERM CARE MAZE:
NEW APPROACHES TO
INFORMATION AND ASSISTANCE
IN THREE STATES



Navigating the Long-Term Care Maze: New Approaches to Information and Assistance in Three States

by

Susan C. Reinhard, RN, PhD
Marisa A. Scala, MGS

Institute for the Future of Aging Services
2519 Connecticut Avenue, NW
Washington, DC 20008-1520

The Public Policy Institute, formed in 1985, is part of the Public Affairs Group of the AARP. One of the missions of the Institute is to foster research and analysis on public policy issues of interest to older Americans. This paper represents part of that effort.

The views expressed herein are for information, debate, and discussion, and do not necessarily represent formal policies of the Association.

© 2001, AARP.

Reprinting with permission only.

AARP, 601 E Street, N.W., Washington, DC 20049

ACKNOWLEDGEMENTS

The authors are grateful to the state and local administrators whom we interviewed in Indiana, New Jersey, and Wisconsin for their willingness to share their time and their expertise. In addition, Barbara Coleman of AARP, Jane Karnes Straker of the Scripps Gerontology Center, Donna Folkemer of the National Conference of State Legislatures, and Greg Case of the National Association of State Units on Aging provided helpful comments during the review process. Special thanks to Vanessa A. Woodard-Kinard of AARP's Public Policy Institute for her administrative support and the cover design.

TABLE OF CONTENTS

FOREWORD	i
EXECUTIVE SUMMARY	ii
INTRODUCTION	1
METHODOLOGY	5
OVERVIEW	7
INDIANA	8
Background.....	8
System Design/Data Collection.....	9
How the System Works for Consumers.....	10
Funding and Resource Development.....	11
Personnel/Staffing Patterns.....	11
Outreach and Promotion.....	12
NEW JERSEY	13
Background.....	13
System Design/Data Collection.....	14
How the System Works for Consumers.....	15
Funding and Resource Development.....	17
Personnel/Staffing Patterns.....	17
Outreach and Promotion.....	18
WISCONSIN	19
Background.....	19
System Design/Data Collection.....	21
How the System Works for Consumers.....	22
Funding and Resource Development.....	23
Personnel/Staffing Patterns.....	23
Outreach and Promotion.....	24
FINDINGS: KEY PROGRAM AND POLICY ISSUES	25
Leadership.....	25
System Design/Coordination and Data Collection.....	26
Funding.....	29
Personnel and Staffing.....	29

Outreach and Promotion.....	30
SUMMARY.....	31
REFERENCES.....	32
LIST OF TABLES	
Table 1.....	2
Table 2.....	4
APPENDIX A.....	34
APPENDIX B.....	35
APPENDIX C.....	37

FOREWORD

When older persons and their families seek long-term care services — in their homes, in residential settings, or in institutions such as nursing homes — their search for information about their options is often frustrating and confusing. Most states have an array of public and private long-term care programs and services delivered by a variety of state and local agencies, private nonprofit organizations and private-sector providers. Trying to navigate such systems without assistance often means that many people cannot find quality providers, spend too money on the wrong services, or end up in a nursing home when their needs could possibly have been met with community services.

A number of states have been developing information and assistance (I & A) systems that try to address these problems. States differ considerably in their approaches to developing such systems. They provide toll-free statewide telephone numbers for people to begin their search for assistance, and they offer information about publicly funded long-term care services on state websites. They develop single-point-of-entry systems at the local level that serve as the gateway to services for persons eligible for state- or Medicaid-funded programs.

States face an even more daunting challenge when they try to build comprehensive long-term care information and assistance systems to serve all persons who are looking for help, regardless of income. The issues states must address include system design, funding, staffing, training, and outreach.

This report details how three states — Indiana, New Jersey, and Wisconsin — have tackled these tasks. These states offer varying models of I & A systems in different geographic settings with diverse populations. While these states have not conducted formal evaluations of their I & A programs, the issues they faced and the steps they have taken can be instructive for other states. There is no one best I & A model appropriate for every state, but AARP offers this report to help promote an exchange of ideas among states of ways to make long-term care services more accessible to Americans with disabilities of all ages and all incomes who need assistance.

Barbara Coleman
Senior Policy Advisor
Public Policy Institute

EXECUTIVE SUMMARY

Background. For persons of any age with disabilities and for their families, finding appropriate long-term care services to meet their needs can be a confusing and frustrating experience. While many low-income persons qualify for publicly funded long-term care services, they may be unaware of a state's programs, the programs' eligibility requirements, or the application process. Persons whose higher incomes disqualify them for these public services may have little idea about how to locate high quality, affordable private-sector long-term care services appropriate to their needs. Knowing where to turn for information and help with long-term care needs has become a major concern for millions of Americans regardless of income.

A number of states have been trying to address this concern by developing single point of entry systems, which provide long-term care information and assistance (I & A) for persons of all incomes. These entry points, which can be area agencies on aging or county offices throughout a state that maintain extensive telephone services (1-800 numbers, for example), can be a gateway to information that ranges from explanations of eligibility for public services to data on private service providers and transportation and housing options in the community. The "assistance" component of an I & A system can vary from simple follow-up calls to consumers to find out if a referral to a service was satisfactory to helping individuals complete applications for publicly funded services to comprehensive care planning and care management for an individual.

The task of building such comprehensive I & A systems can be a daunting challenge for states. The steps include designing the systems, budgeting funds, training staff, assembling and keeping current a database of providers and services, developing outreach programs, and evaluating the impact on consumers.

Purpose. This report describes the efforts of three states — Indiana, New Jersey, and Wisconsin — to develop comprehensive I & A programs for older persons and their families. The purpose of the report is to 1) describe key features that are fundamental to the success of any state long-term care I & A system, and 2) detail how these three states tackled the problems they encountered in developing comprehensive I & A programs. Although formal evaluations of these programs are not yet available, the lessons the three states have already learned can be instructive for other state policymakers and advocates as they try to make long-term care services more accessible to consumers.

Methodology. The study researchers conducted a literature review and interviewed experts on state long-term care systems who described a number of information and assistance initiatives in different states. From this review, the researchers selected Indiana, New Jersey, and Wisconsin for in-depth review and analysis as representative of the growing number of states that are developing extensive I & A programs to help people navigate through their state's network of public and private long-term care services. The three states offer differing models of I & A systems.

To provide more information on how the program works at the local level, the researchers selected one county or metropolitan area in each state based on its level of experience with its

system and on its population diversity. During the summer of 2000, the researchers made site visits to each state and local site, and interviewed state officials and county administrators who run the I & A programs at the local level. The researchers supplemented these interviews with data on each state's long-term care system and each local site's I & A operations.

Principal Findings. A growing number of states are broadening and strengthening their long-term care information and assistance services. In a few states, these efforts extend to all persons with disabilities regardless of income. For persons who are ineligible for publicly funded services, the states may impose sliding fees for certain services.

The three states in this study provide a single point of entry system for persons eligible for publicly funded long-term care services that identifies their long-term care needs, provides care planning, and assists them in applying for and receiving services. For persons with incomes too high to qualify for publicly funded services, these states provide basic information on long-term care services and providers, make care planning services available to help these clients assess their needs and learn about affordable community resources, and offer several services on a fee-for-service or sliding-fee schedule.

Findings from the three study states include the following:

- *Leadership.* State and local officials articulate a clear and consistent mission. Indiana has enabling legislation, a uniform structure built on the existing area agency on aging structure, consistent consumer involvement, and strong leadership from the state director of aging. New Jersey's efforts have been driven by state leaders and strongly endorsed by the governor. Wisconsin has strong consumer involvement, enabling legislation, and external evaluation requirements.
- *System Design.* The three states are trying to establish statewide uniformity and consistency of information for consumers, while maintaining the individuality of local culture/organizations. Indiana offers the most advanced technology with its computerized consumer satisfaction survey system, but all three states are employing user-friendly forms, software that integrates existing computer databases, and locally sensitive protocols for helping staff guide persons with disabilities through the long-term care system. Staff at the area agency on aging or county level in the three states rely on call-backs to consumers who have used the system to determine the quality of the I & A services. But since the states have not conducted formal evaluations of their I & A systems, state officials are still struggling to figure out how well their programs are meeting consumer need for information about and help with accessing long-term care services.
- *Funding.* The three states have been increasing public dollars for long-term care services in the home. Reducing waiting lists and expanding services to accommodate more people may, however, involve cost-sharing for persons whose incomes exceed the limits for publicly funded services. An important policy question for state leaders is how to structure cost sharing methods so that persons with low incomes that exceed Medicaid levels can afford to partially pay for some of their services.

- *Personnel and staffing.* None of the three states has specific statewide requirements for the credentials and experience of I & A specialists and care managers. Certification is not required, and all three states have to deal with local government rules that govern the hiring process.
- *Outreach and promotion.* Indiana has begun marketing long-term care information to businesses in an effort to reach their employees who may be caregivers for their parents or other relatives. New Jersey has begun to aggressively advertise its toll-free telephone number. Indiana and Wisconsin have been trying television, magazines, supermarket bags, state fairs, and other social marketing/outreach strategies. The three states are also using the Internet to promote their programs.

Summary and Conclusions. Developing a comprehensive I & A system for people of all income levels requires a clearly stated plan, persistent leadership, adequate funding, and considerable promotional efforts. The challenge to states is significant. However, comprehensive I & A systems with “one-stop shopping” can be a valuable way that consumers can access information about long-term care services that minimizes the amount of searching they must do and enables them to find the services they need.

Navigating the Long-Term Care Maze: New Approaches to Information and Assistance in Three States

INTRODUCTION

The U.S. long-term care (LTC) system is actually less a “system” than a patchwork of federal and state programs with differing eligibility requirements and benefits in each state as well as a proliferation of private agencies and services. There is a bewildering array of choices, and persons of all ages with disabilities¹ and their families find it difficult to navigate through this maze of providers and services to arrange long-term care appropriate to their needs, preferences, and resources.

The current reality is that most people are already in crisis when they seek help, do not know where to turn for aid, are not prepared to navigate the non-system of long-term care choices, and hear mostly about nursing homes when they talk to a doctor or hospital discharge planner. A typical case could be an 85-year-old woman who lives alone and breaks her hip. Her daughter, who lives 500 miles away, comes to help her mother leave the hospital after recovery. Neither is certain that the mother can continue to manage alone, what kinds of services might be available to help her remain at home, how much such services will cost, and what financial assistance—if any—she might receive to help pay for those services. Similar situations occur every day to thousands of families in every community in America.

To help consumers with these problems, many states are making access to services easier through single-point-of-entry systems at the local level. These single-entry points are most often county government agencies or area agencies on aging (AAAs) located throughout a state, where persons with disabilities can find information about services and benefits, be assessed for publicly funded programs, work with care managers to develop a care plan, and arrange for services (Fox-Grage, 1997; Ladd, 1997; Coleman, 1996; Pan, 1995). Single-point-of-entry systems aim to provide “one-stop shopping” for persons seeking a range of services.²

Still, many older adults of all incomes levels may be confused about their options or unaware of the choices available to them. Knowing where to turn for information and help before or after a crisis occurs has become a major concern for millions of Americans.

A strong and comprehensive information and assistance (I & A) program can be the major foundation of a state’s network of private and publicly funded long-term care services.

¹ Although Information and Assistance (I & A) programs serve persons with disabilities of all ages, most clients are older persons and their families. Therefore, this report hereafter will generally use the terms “older persons” or “older adults” when referring to I & A clients.

²The Indiana system described in this report provides comprehensive I & A services to *all* persons with disabilities through its network of area agencies on aging. Wisconsin has a single point of entry system for across ages, but at the local level, the state may contract with different agencies to work with one or both populations. The local New Jersey program in this report serves older persons; the state has other I & A systems for non-elderly persons with disabilities.

Operated through single points of entry throughout a state, I & A programs could be the first point of contact for consumers to long-term care services in the community, whether a consumer is financially eligible for publicly funded services, must arrange for private sector services, or coordinate some combination of both. Individuals can access I & A services by visiting an office at various locations around a state or within a county, or get information by telephone. Such information can range from explanations of eligibility for publicly funded services to lists of private service providers and transportation and housing options in the community. The “assistance” component of an I & A system can run the gamut from I & A staff calling a consumer back to see if she needs any further information or whether the information she got from her initial call was satisfactory to helping individuals complete applications for services, or providing an assessment of their needs and developing a care plan.

Developing an I & A program is no simple task for a state. The steps involved include designing the system, budgeting funds, hiring and training staff, assembling a LTC services database and keeping the information current, developing an outreach program, and monitoring how well the program is meeting its goals. This report provides case studies of I & A systems in three states – states that have shaped their systems in different ways to address their unique political and governmental structures, demographics, and publicly funded LTC programs.

The three states featured in this report — Indiana, New Jersey, and Wisconsin — were chosen for some specific features (see methodology), but are by no means alone in their efforts to improve I & A services (see Table 1 for other examples). Indeed, as a condition for receiving funds under the Older Americans Act (OAA), states must operate I & A systems. As a result, nearly 3,500 OAA-funded I & A programs have been created across the country (NASUA, 1997; Jacobsen, 1993; GAO, 1991).

Table 1.
State Information and Assistance Efforts

State	What they are doing
Alabama	Aging network developed statewide resource database and adopted common I & A software.
California	Ensured I & A and Health Insurance Counseling and Advocacy Program sites have hardware/software for Internet access and expanded user-friendly resources on State Unit on Aging (SUA) Web site.
Connecticut	Integrated all existing information systems into one program to support information and assistance.
Florida, Montana	Developed rural I & A model.
Georgia	Designed software package to help aging network improve I & A services.
Illinois	Established LTC information and assistance kiosks in local pharmacies.

State	What they are doing
Kentucky	Implemented computerized data collection for I & A and State Health Insurance Assistance Program (SHIP); launched user friendly Web site of I & A/SHIP resources.
Louisiana	Aging network adopted I & A software package statewide and developed interactive Web site for network and consumers.
Massachusetts	Implemented statewide aging network resource database and on-line interagency communications network.
Minnesota	Established single 800# statewide with point of access routing. Implemented extranet network for enhanced client tracking, shared resource database, and reporting between SUA and all AAAs.
Mississippi, Utah	Conducted statewide assessment of information and assistance program to assist in restructuring and reform efforts.
New Hampshire	Developed ServiceLink New Hampshire enhancing 800 telephone access and Web access to I&R.
New York, Nevada	Developed web-based access for consumers to find information.
North Carolina	Developed comprehensive standards and protocols for I & A to ensure more uniform statewide system.
North Dakota	Developed own I & A software package to meet their specific needs for client tracking and resource database development.
Oregon	Maintained single-point-of-entry system for information and case management that was implemented in the 1980s.
South Carolina	Developed Senior Access Initiative as single-point-of-entry system for information on services and benefits, enhanced access to LTC services for at-risk persons, and computerized information sharing between agencies.
Tennessee	Standardized I & A statewide, including common software package and increased access to LTC services.
Washington	Developed detailed standards and protocols for information and assistance.

(Case, 2000)

As summarized in Table 2, national efforts have also been launched through the toll-free Eldercare Locator system and through efforts to establish a 211 directory assistance number for community services. However, the Eldercare Locator has yet to become a resource familiar to many Americans, and the 211 system is still in very early stages of development.

Table 2.

National Information and Assistance Efforts

The Eldercare Locator

Since 1991, the Administration on Aging has funded the Eldercare Locator, “a nationwide, directory assistance service designed to help older persons and caregivers locate local support resources” (AoA Web site, 2000). This service, which is administered by the National Association of Area Agencies on Aging and the National Association of State Units on Aging, offers a national toll-free number (1-800-677-1116) and operates Monday through Friday, 9 am to 8 pm EST. By providing their zip code and a brief description of their needs, older persons and their families get referrals to service providers in their local area. It is expected that the Eldercare Locator will soon be available on-line.

The 211 Movement

The Alliance for Information and Referral Systems (AIRS) and the United Way are spearheading a movement to establish a 211 directory assistance number for community services for persons of all ages. In 1998, the National 211 Partnership filed a petition with the Federal Communications Commission to designate 211 as the community information and referral number; in July 2000, they received this designation. 211 is designed to be a national symbol that is easy for consumers to remember and to identify with human services information. Through 211, consumers can access information, referral, and crisis intervention services. First started in Atlanta, Georgia, now more than fifteen states are active in this movement. 211 lines are staffed by professionals with extensive training who can “bring people and services together”; this line is open 24 hours a day, 7 days a week (Aberg, 2000).

Despite these national efforts to improve I & A services, great disparity exists among the states in terms of how effectively OAA-funded I & A programs are reaching older adults with the information and assistance they need to make decisions about their long-term care alternatives (NASUA, 1997). State officials continually grapple with this problem of reaching people with long-term care needs and providing them with the most useful information possible. This report describes that effort in three states—Indiana with more than nine years of experience developing its program, and New Jersey and Wisconsin, states that are in the process of building and refining I & A programs as part of redesigned and expanded home and community-based service programs at the local level.

The work of these three states can help suggest the program and policy issues and decisions that all states face as they try to develop comprehensive I & A systems. Although no formal evaluations are available, one state, Wisconsin, has plans for a systematic study of its I & A efforts. Wisconsin has commissioned studies of its Family Care program, of which the I & A program is a part. The first of five reports on the status of the Family Care implementation was released in November 2000 (Alecxi et al., 2000; Chang, 2000).

METHODOLOGY

This study centers on an examination of the long-term care information and assistance systems in three states: Indiana, New Jersey, and Wisconsin. These states were chosen because:

- They have gone slowly, phasing in programs at the local level over periods of months and years to see what is working and what is not;
- They have encouraged diverse approaches by local governments while aiming for consistency across the state on assessment tools and reporting requirements; and
- They have targeted their efforts to people of all income levels.

Among these three states, Indiana has had legislative authority to develop an enhanced I & A system to inform older adults and people with disabilities about their long-term care options since 1992 (Styring & Dueterberg, 1997). New Jersey has been phasing in its single-point-of-entry system of information for older adults of all incomes since 1996 (Ladd, 1997), and Wisconsin has only recently begun its ambitious Family Care program with aging and disability resource centers providing information and assistance (Alecxi et al., 2000).

The selection process was informed by a literature review (Feder, Komisar, & Niefeld, 2000; Kane, Kane, & Ladd, 1998; Weiner & Stevenson, 1998; Alecxi, Hercik, 1997; Ladd, 1997; Lutzky, & Corea, 1996) and interviews with key federal stakeholders from the Administration on Aging, the National Association of State Units on Aging, the National Association of Area Agencies on Aging, and the National Council on Aging (see list in Appendix B).

The case studies that follow are drawn from on-site interviews conducted in each state with state officials (from the state unit on aging, state Medicaid agency, and other relevant state offices as needed) and county administrators who run the information and assistance program at the local level, as well as from data collected by these organizations (see Appendix A and Appendix B). In each state, a county or metropolitan area was selected based on its level of experience and population diversity. For example, CICOA The Access Network (formerly known as the Central Indiana Council on Aging) serves the largest metropolitan area in Indiana. In New Jersey, Union County was one of the first four counties to implement the state's new vision for enhanced I & A/single point of entry; it is also one of the most diverse counties in New Jersey both in terms of ethnic/cultural and economic diversity (it includes the cities of Elizabeth, Union, and Westfield). Finally, in Wisconsin, Milwaukee was selected because it developed the I & A model that the state is trying to implement statewide.

It is important to note that in all three states, there is an acknowledged variance in implementation by county. The counties selected for this study are not necessarily representative of the state. Rather, they offer a good mix of implementation and policy lessons and questions.

In the case studies, we emphasize key features that are fundamental to the success of any system that attempts to provide information and assistance to older adults across all income levels (NASUA, 1999). They are:

- **Background of the I & A State/Local System/Leadership**

The history behind each state's effort affects the nature of the core services offered and the population(s) targeted. Similarly, the source for the impetus for change—state leadership, legislation, and/or strong consumer involvement—can affect program development.

- **System Design/Data Collection**

System design involves assembling a database of information for consumers on home and community-based services and providers in the community, and keeping that information current. Data collection involves developing systems that enable a state to track information requests and the characteristics and needs of the callers so that the state can continue to perfect its information systems and provide follow-up help when appropriate. Technical issues include the selection of data collection instruments and the development of procedures and reporting standards to document information requests and service provision, follow-up, and quality monitoring.

- **How the System Works for Consumers**

The most fundamental aspect of each I & A system is what happens when an older adult or family member calls for help. Staff efforts to coordinate state assistance with the private sector, employers, and other public programs, such as Medicaid, are important in developing a “seamless system” so that consumers do not need to contact multiple agencies to get answers to their questions. This report examines how three states are attempting to provide “one-stop shopping” for I & A for older adults across all income levels.

- **Funding and Resource Development**

Improving an I & A system requires a financial as well as a political commitment. The report explores the level of funding that these states provide to their I & A systems, the sources of these funds, and the extent to which states are willing to supplement OAA funding for I & A.

- **Personnel/Staffing Patterns**

The effectiveness of an I & A system depends upon the staff capacity to respond to requests for information and help. The case studies examine how states are preparing I & A staff and volunteers to help older adults and their families understand and act upon their long-term care choices, through requirements for staff training, credentials and experience.

- **Outreach and Promotion**

Enhancing an I & A program is ineffective if the public is unaware of the program. Marketing to reach people of all income levels, including adult children of older persons and long-distance caregivers, is essential if families are to learn about this resource.

OVERVIEW

This report offers a case study of each state in its handling of these critical components, although some areas receive more attention than others depending on the lessons that state can provide. Also, each state program has unique features at both the state and local level. This report intentionally provides the kind of program details that might stimulate state administrators to consider potential technical challenges. While not providing full details about all program aspects in each state, this report highlights different efforts and achievements in the case studies and the concluding key findings. The summary also raises key questions that states need to consider as they pursue the systematic design of consumer-friendly I & A systems.

INDIANA

Background

Indiana has a population of nearly 6 million people, with 12.5 percent above the age of 65, just slightly below the national average of 12.7 percent.³ The 92 counties in this state vary in size, population density, and political strength.

Indiana's Bureau of Aging and IN-Home Services (BAIHS) is the state agency charged with providing a broad range of in-home and community-based services to persons of all ages with disabilities. Housed within the Family and Social Services Administration, BAIHS administers both the Medicaid and state-funded home care programs. In addition to its oversight role and responsibility for monitoring the quality of the in-home services system, BAIHS provides technical assistance, funding, and support to the 16 area agencies on aging (AAAs) that serve as the single points of entry for home and community-based services, including information and assistance.

The administrator who has headed the Bureau of Aging and IN-Home Services for over 12 years helped direct the effort, beginning in 1992, to coordinate state and federally funded long-term care services through the IN-Home Services Program. This consistent leadership has been bolstered by the support of both Democratic and Republican governors for the development and expansion of the IN-Home Services Program, and by the lobbying of a citizen coalition, the Indiana Home Care Task Force. The citizen coalition has knitted together a diverse group of nonprofit and business organizations that has successfully campaigned for increased funding for home care services each biennial budget.

The IN-Home Services Program began in 1987 on a pilot basis, and was enacted into law as a statewide program in 1992. The program brought together five Medicaid home and community-based "waiver"⁴ programs, Older Americans Act and Social Services Block Grant services, and a new state-funded program known as the Community and Home Options to Institutional Care for the Elderly and Disabled (CHOICE).

CHOICE is designed to provide services to persons whose incomes, while low, are still too high for them to qualify financially for Medicaid services. The program uses a cost-sharing mechanism, a sliding fee scale for people whose incomes exceed 150 percent of the poverty level.

The law that created the CHOICE program created a single-point-of-entry care management system to administer all the programs under IN-Home Services for all persons with disabilities, including children. At the local level, the AAAs serve as the single entry point in

³ (<http://quickfacts.census.gov/qfd/states/18000.html>,2000).

⁴ Under "waiver" programs, a state can waive certain Medicaid requirements and provide services for specific groups, such as persons with developmental disabilities or traumatic brain injuries, rather than for all Medicaid beneficiaries, and can include a wider range of benefits than offered under a standard Medicaid program.

administering the IN-Home Services Program, an enhanced information and assistance effort, and the care management system.

Through the AAAs, consumers can access:

- Information and assistance
- Pre-admission screening for nursing home placement
- Comprehensive assessment
- Care planning
- Care management
- In-home services (including home health, respite, homemakers services and more)
- Education (including health fairs and workshops)
- Employment services (limited to 2 AAAs including CICOA).
- Community services

(Information, assessment, and care management are free for all persons, but in-home services through the CHOICE program are delivered on a sliding fee scale. Only persons eligible for Medicaid may receive Medicaid-funded in-home services.)

In this case study, we focus on CICOA The Access Network, which serves eight counties (Boone, Hamilton, Hancock, Hendricks, Marion, Johnson, Morgan, and Shelby) including urban (the city of Indianapolis), suburban, and rural areas. According to CICOA, in the 8-county region they serve, nearly 12 percent of the population is age 65 or older (166,980 people).

System Design/Data Collection

Indiana has made a considerable investment in computerized assessment, care management, and quality assurance methods for its home and community-based care long-term care system. This computerized system goes beyond the development of a database of information that can be provided to consumers. It assures consumers that once they enter the system, they have access to assessment and screening, if they wish, to see if they are eligible for Medicaid- or state-funded services.

Indiana attempts to offer consumers throughout the state similar experiences in seeking and receiving help. To facilitate this consistency, the state has streamlined its paperwork and processing by creating one assessment instrument, one eligibility screen, one reporting system, and one quality assurance system. The eligibility screen is used for in-home services and for nursing home placement, and the assessment instrument is used for care management of both CHOICE and Medicaid waiver clients. State officials have focused on training the AAAs to use the statewide assessment and eligibility tools as a means of consulting with consumers and making them more aware of their choices.

The state has developed a statewide database and reporting system called INsite, which is one of its chief strategies to facilitate a uniform statewide system so that consumers can receive competent assistance wherever they try to get information and services. INsite tracks clients who receive care management, pre-admission screening, and nutrition services. All data from

the assessment tool and care plan, which are utilized for consumers who receive home visits or care management services, are entered into a standardized computerized record for each consumer in the system. The state is in the process of phasing in a new INsite I & A module that will include a resource database and directories, referral and reporting systems, and other features. At the present time, the agency is working to standardize data collection about consumers' requests for information and assistance and their use of the toll-free number.

In addition, through a Robert Wood Johnson Foundation funded grant project, BAIHS and Indiana University worked in partnership with consumers and with AAA staff to develop the "Quality Improvement Process," which includes an automated consumer satisfaction measurement system. AAAs sample at least 10 percent of consumers statewide to get their opinions about the quality of the services that they are receiving; care managers perform the survey in consumers' homes using laptop computers. AAAs use this information to give performance feedback to service providers.

How the System Works for Consumers

Both state and local staff at CICOA are proud of their efforts to provide information and assistance to people across all income levels, and help them avoid the need to contact many different agencies to get the help they need. They describe their I & A system as beginning with a call from a consumer. The consumer can call either a local number or the toll-free number 1-800-986-3505 (that long-distance caregivers can dial from anywhere in the nation), which bounces the call to the local AAA's Call Center. Indiana was one of the first states to spearhead this consumer-friendly toll-free telephone access. This number is administered by the Indiana Association of Area Agencies on Aging (IAA) and funded by the AAAs. CICOA also has its own local and toll-free information and assistance numbers, and its toll-free number can also be accessed from out-of-state. Calls that come in after hours automatically go to voice mail and are answered immediately the next morning. While there is not a high volume of calls from non-English speaking clients in its area, CICOA arranges for translations (which are handled by staff from outside agencies) whenever necessary.

For about 18,000 callers per year (of all ages, incomes, and disability levels), I & A staff at CICOA do a brief telephone assessment, discussing the problem presented and probing for underlying issues, personal resources, and potential eligibility for publicly funded services. I & A specialists discuss possible options and determine the next step with the consumer. About two-thirds of the calls CICOA receives are from consumers requesting basic information about a service (such as transportation or housing) or referrals to local agencies. Staff refer to both proprietary and nonprofit agencies as part of their information and assistance service. They also mail out supporting brochures and paperwork as needed. (More than 2400 information packets are mailed each year.) About one-third of their calls are referred in-house for employment assistance (CICOA is also a licensed employment agency), help with nutrition (home delivered meals), or potential in-home services and care management. CICOA care managers make home visits to about 2,900 consumers a year to complete a client assessment and care plan. All data are entered into the standardized computerized record for each consumer.

To determine the payment source for care, the care manager facilitates one of several processes—with a strong focus on coordination with multiple agencies. If the person may be eligible for Medicaid services or a Medicaid waiver program, the care manager determines functional eligibility (the physical or mental impairments that would qualify a person for home care services) through the assessment, and directs the consumer to staff in one of the appropriate county offices of the Division of Family and Children for a financial eligibility determination. The care manager can help the consumer navigate the Medicaid determination process, but it can take up to several months, depending on how soon the county Medicaid office completes the necessary paperwork.

For services under the CHOICE program, the care manager helps the consumer complete the cost share worksheet. Staff report that older adults often resist providing personal financial information, and may refuse services rather than pay any cost share. Since the waiting list for CHOICE services is approximately 7,000 statewide, it appears that many consumers do provide that information (although the total cost share collected is only about \$200,000 per year, or less than one-half of one percent of total CHOICE funding). The care manager may also include “free” services funded by OAA or local funding and volunteer sources, such as friendly visitors or chore services. Or the care manager may recommend a private fee-for-service if the consumer can afford that service. The goal is to “avoid compartmentalizing people and hook them up to what they need with whatever combination of funding it takes to get there; the funding sources should be invisible to the person, except for what they are paying for” (Spilly, 2000).

However, waiting lists throughout the state for in-home services are long and growing, with about 6,500 people waiting for Medicaid waiver services, and approximately 7,000 for the CHOICE program statewide. These waiting lists are managed at the county level, and are a cause of frustration for I & A and care management staff who are the people delivering the bad news about waiting lists to consumers.

Funding and Resource Development

The Bureau of Aging and In-home Services has approximately \$1.4 million a year budgeted for information and assistance; the overwhelming majority of this money (\$1.2 million) is dispersed to the AAAs, with much of the rest (\$170,000) going to the Indiana Association of Area Agencies on Aging to fund I & A training. In its-eight county area, CICOA will spend \$296,000 on I & A expenses during fiscal year 2000, of which \$180,000 is for salaries.

Personnel/Staffing Patterns

CICOA has four full-time I & A specialists, two volunteers (who do some phone work and run the resource center library), and a director. The five full-time professional staff have a combined experience in the human services field of 55 years. There are no requirements for education or certification credentials, but most of the I & A and care management workers have a Bachelors degree in social work, psychology, or a related field. One is a masters-prepared gerontologist. In the other CICOA divisions, there are 49 care managers (42 full-time and 7 part-time) and additional staff conducting pre-admission nursing home screening (7 full-time equivalents or FTEs), training, and clerical duties.

The state has given considerable attention to the training of I & A specialists and care managers, and implements standardized training through a contract with the Indiana Association of AAAs. In 1999, the Association sponsored more than twenty training events in which over 1,700 people participated. Examples of training include basic orientation to the in-home services system and Medicaid waivers; customer service skills such as dealing with difficult clients; techniques for asking questions; use of the Internet as a tool; and time management. In addition, the Association will also provide training on the standardized computer system and the new I & A software as it rolls out.

It should be noted that although Indiana provides computerization and uniformity of forms and extensive training, data collection requirements take considerable staff time. Local staff told researchers that they listen to the caller and then have to go back and fill in the form they need to complete for that caller, when they would often prefer to “just answer the next call.”

Outreach and Promotion

Indiana state officials describe their information and assistance outreach as broad, social marketing outreach efforts to reach different markets in a variety of ways. The statewide toll-free number has been in operation since 1997. In addition, information on services is provided through the state Web site, where citizens wishing services, their relatives and friends, and long-distance caregivers can find a way to begin their search. The widely attended annual state fair (more than 20,000 people attend each year) and the Indiana Governor’s Conference on Aging and In-Home Services that attracts 1,000 older adults and professionals are two additional promotion vehicles. Finally, the state disseminates information about long-term care services through news releases, public service announcements, presentations for consumers and providers, radio shows on choices in long-term care and how to find resources, brochures, and an annual report.

There appears to be an increasing awareness on the part of the AAAs of the need to identify market segments and develop improved outreach and assistance tailored to these different markets. Some AAAs have a marketing plan to reach out to older people who are not eligible for publicly funded programs. They also would like to do more to inform baby boomers about care options for their older family members. For example, CICOA now offers a new program called “Elder Solutions” that is considered “enhanced I & A sold to businesses” (Spilly, 2000). Local businesses purchase the “Elder Solutions” service for their employees as a benefit. They expect that advertisements for Elder Solutions will get the word out to more middle-income older adults and their families about the services that CICOA offers.

CICOA also publicizes its service through television ads, as well as articles and ads in the free press, such as the *Indianapolis Woman*, a free paper targeted to middle income women. It also gives community presentations, participates in health fairs, and uses radio spots to advertise its services.

NEW JERSEY

Background

With 1.1 million people age 65 and older, New Jersey has a slightly higher than average proportion of older adults to total population (13.6 percent, in contrast to the national average of 12.7 percent).⁵ The state has 21 counties with strong local control.

New Jersey's I & A program is part of NJEASE (Easy Access Single Entry), which began with the help of a three-year grant from the Robert Wood Johnson Foundation in 1995. At that time, state officials and consumers alike viewed the state's long-term care "system" as being complex and fragmented, with the search for assistance requiring multiple calls and visits to different agencies as well as repetitive paperwork to determine and establish program eligibility.

The impetus for a new long-term system came in 1994. Key state officials joined the new administration of then-Governor Christine Todd Whitman with a high priority goal to redesign home and community-based services for older persons. They crafted a plan for changes at the local and state level that included NJEASE, a single-point of entry system at the county level. The changes also included consolidating into one department the senior services divisions and programs in four departments — Health, Human Services, Community Affairs, and Insurance. The new Department of Health and Senior Services (DHSS) is now responsible for all programs and funding streams for older adults, including Medicaid-funded nursing home care, assisted living services, and the home and community-based waiver program serving older persons.

NJEASE was a key component of this proposal to Whitman who made services for older people a focus of her administration. She not only adopted the NJEASE plan, but strongly backed its implementation throughout her administration, and attended a number of county NJEASE kickoffs ceremonies to show her support. She also provided increased funding for community long-term care services throughout the late 1990s.

NJEASE was designed to offer older adults of all income levels and their families "one-stop shopping" for their health and social service needs. (Younger people with disabilities receive information about long-term care services through the County Offices on the Disabled.)

The state initially decided to work with 13 counties on NJEASE, phasing in a few counties at a time. (As of 2000 all 21 counties have agreed to participate, although they are at varying states of implementation.) There was no guiding state legislation, which state officials say helped them maintain flexibility in collaborating with each of the counties as partners. During the planning phase, the state also established an advisory committee of providers and consumer advocates to guide the development of NJEASE. However, there was no strong consumer-led movement to reform the I & A program.

⁵ <http://quickfacts.census.gov/qfd/states/34000.html>, 2000

Counties adopted different models, but in each case, they designated the county office on aging (which also serves as the area agency on aging) as the lead agency. This lead agency may choose to partner with and subcontract out some services to partner agencies (which may be public or private, for profit or nonprofit entities); this is the case in Union County, the county featured in this report. The lead agency in Union County is the Union County Department of Human Services Division on Aging. The I & A component of the NJEASE program provides the following core services, which are available without cost to all persons regardless of income:

- Information and assistance
- Benefits screening and outreach (through home visits)
- Comprehensive assessment
- Care planning
- Care management
- Reassessment of service needs.

The state role in the NJEASE system is providing training and technical assistance to the counties. In addition, the state is taking the lead on the computerization of the NJEASE system (i.e., assessment tools and resource linkages). In the coming year, DHSS will also increase its role in publicity and marketing of NJEASE, with a new promotional campaign that was launched in the fall of 2000.

Systems Design/Data Collection

State and county officials view the consistency of NJEASE for consumers throughout the state a critical issue. During the planning process, the state (and the working groups it organized) spent a great deal of time developing a standardized assessment instrument known as the Comprehensive Assessment Tool (CAT), which was designed to ensure uniform evaluation of consumer needs and resources. New Jersey is also striving to achieve consistency for consumers through protocols for dealing with consumer calls, training for I & A staff, and the creation of performance standards for care managers and I & A specialists.

At the state level, New Jersey is also working toward the computerization of its information and assistance system. The CAT is not yet computerized, except for the portion that represents the pre-admission screen for admission to a nursing facility. Once computerization is complete, the state hopes to use CAT data for local and statewide community needs assessments to assist the counties and state in trending consumer needs and service gaps. Like most states, New Jersey presently relies on the collection of county-level data for the Administration on Aging (as a condition of receiving Older Americans Act funding). To date, there are no additional standardized data collection, reporting, or analysis requirements.

The Departments of Labor, Human Services, and Health and Senior Services also are in the process of establishing One-EASE-E-Link, a statewide network that will link NJEASE provider agencies. Part of this network will include Helpworks, Web-based software that will computerize the benefits screening process, and Factors, care management tracking software for care managers. County-level staff will be trained on these systems in the coming months. In the

meantime, the state reports that some counties already use the Internet as a vehicle for getting information about services to older people and their families.

How the System Works for Consumers

Modeled after Indiana, consumers can enter the system through a nationwide toll-free number. They are then automatically connected to the lead division or agency in their home county; consumers may also be transferred toll-free to the lead agency in a different county, if they so desire. (Many counties also have instituted their own toll-free numbers for consumer access.) State and county staff are available during regular business hours to handle calls. After hours, calls are picked up by an answering machine, and consumers are given instructions as to what to do in case of emergency. In 1999, the Division on Aging in Union County (and their subcontracted partners) fielded nearly 27,000 calls from consumers.

Union County is located in central New Jersey, and contains the urban areas of Elizabeth, Union, and Plainfield. Nearly 15 percent of the county's population is age 65 or older, approximately 73,800 people.⁶

Population diversity in Union County presents challenges with regard to language and translation. Presently, the county serves consumers who speak 48 different languages and dialects. While the agency has access to the AT&T toll-free language line as well as some staff who speak Spanish and other languages, translations can still be difficult. Their future plans include the establishment of a volunteer language bank, which should help alleviate this problem.

Through NJEASE, consumers in Union County can access:

- community programs (such as care management, transportation, pharmaceutical assistance, and health insurance counseling),
- in-home services (such as home health services, home delivered meals, and chore services), and
- housing and long-term care options (such as adult day care services, respite care, assisted living, and alternate (adult) family care).

Once consumer calls reach the appropriate county, they are fielded by information and assistance/outreach specialists. These specialists provide general information (i.e., referrals to different public and private agencies or long-term care facilities) and assess consumers' needs and resources using portions of the CAT. To assist in this process, the state has developed consumer call protocols for I & A workers, which are designed to be teaching tools for answering calls, for guiding consumers through the service system, and for eliciting more specifics from consumers about their situations and their needs. These protocols are designed to ensure that calls are handled in a consistent manner by the specialists. Consumers who require a home visit or more intense assistance are then referred to care managers.

⁶<http://quickfacts.census.gov/cgi-bin/country?cnty=34039>

Regardless of income, consumers can get information about both publicly and privately funded long-term care resources in the community, including such public programs as Pharmaceutical Assistance to the Aged, Food Stamps, or Medicaid. For no charge, they can also receive referrals to other public and private agencies and help in contacting them, an in-home comprehensive assessment to determine their need for services, and development of a care plan to identify and arrange for services.

Consumers who are not financially eligible for Medicaid nonetheless have access to information and assistance and care management through NJEASE. I & A workers refer these consumers to private agencies (both proprietary and nonprofit) and individuals (i.e., private geriatric care managers). People who can afford to pay for services and require more intensive care management are typically referred to private care managers.

Middle- and upper-income consumers may also be eligible to receive some services through the Older Americans Act and other programs, but these services are limited, particularly with the shortage of home care workers in the state (and the country). To alleviate this problem, the state began phasing in Jersey Assistance for Community Caregiving (JACC), a flexible state-funded, sliding-scale home care program targeted toward middle-income older persons. Implemented in 2000, this program will not only help to provide options for older people who do not qualify financially for Medicaid, but also to fill in the gaps left by Medicaid waiting lists. All of the home and community-based programs for lower- and middle-income older adults will allow them to hire family members and friends in a consumer-directed model of home care.

People who are eligible for publicly funded long-term care services often have to contact several different agencies for those services. While state and local staff have been working to make it easier for these consumers to get the help they need without having to contact multiple agencies, coordination remains a challenge. For example, NJEASE staff do not establish financial or functional eligibility for Medicaid programs, although several counties are beginning to establish a functional eligibility process for the state-funded home care programs.

Functional eligibility for the Medicaid programs is determined by the state's regional Long-Term Care Field Offices under the auspices of DHSS. Income eligibility is still handled by the County Boards of Social Services (which fall under the state Department of Human Services). Some counties, however, have integrated the Medicaid financial eligibility units into the NJEASE lead agencies. It can take anywhere between 30 days and nine months for the financial eligibility determination to be made, depending on the county and the complexity of the individual's situation. NJEASE county lead offices can provide consumers with a list of the documentation that they will need at the County Board of Social Services, which can help to expedite the process; NJEASE care managers also assist consumers with completing the paperwork and tracking applications as they are processed by other agencies.

Waiting lists for public programs are also maintained at the Long-Term Care Field Offices and shared with the County Boards of Social Services so they can communicate effectively with the consumers who call them. The state hopes to move the waiting list

responsibilities to the NJEASE county lead offices in order to make it easier for consumers to receive interim services while on a waiting list. Consumers in New Jersey spend an average of nine months to a year on the waiting list for Medicaid home care services, although in July 1999 the state authorized \$60 million to expand the home and community-based programs through two Medicaid waiver programs and a state-funded home care program. Throughout 2000, this expansion was implemented in 12 counties, allowing the counties to hire more workers and give consumers the opportunity to get off the waiting lists. (Rollout in the other counties is planned for 2001.) Those currently on the waiting list may receive some interim services through the Older Americans Act and other funding streams.

Funding and Resource Development

In 1999, the overall budget for NJEASE was \$6.4 million, which covers the core services mentioned earlier. As is the case with many state information and assistance systems, funding for NJEASE comes from a variety of sources, including: the Older Americans Act, Social Services Block Grants, Medicaid, state funds (both direct funds for NJEASE and contributions from other state-funded long-term care programs such as the JACC program), allocations from the county governments, and funding from county partner agencies. New Jersey began providing state funds to participating counties in the NJEASE system in 1997 for computers and software, and increased funding for care management in 1999 as the management of the home care programs was shifted to the NJEASE offices. (Prior to 1999, some counties chose to commit the dollars out of their own budgets for enhanced I & A and care management.)

Personnel/Staffing Patterns

County level staffing varies by location. Union County has the equivalent of 3.5 full-time workers dedicated solely to providing information and assistance and doing outreach to consumers, although according to staff, “everyone in the unit does some I & A.” Most of the staff are older adults themselves and are very knowledgeable about the resources in their county. They are supported by volunteers and administrative staff. In addition, there are four NJEASE care managers in Union County, plus a program assistant who provides administrative support. Care managers have bilingual administrative support, as well. These staffing figures do not include care managers and I & A specialists at their subcontracted partner agencies in Union County.

In general, the state has taken the lead on providing training for NJEASE staff (with some subcontracts with outside organizations), although in Union County, the lead agency also provides some basic on-the-job training for I & A specialists. The state offers the following training: orientation to the aging network, information and assistance basic training, care management basic training (provided by the Pennsylvania Care Management Institute), care management advanced training, and continuing education courses on such topics as the use of information technology and communication with consumers. As part of developing information and assistance standards, DHSS also plans to explore the issue of credentialing I & A workers.

In New Jersey as in Indiana, there is some resistance from local staff to data collection since the work of filling out the comprehensive assessment tool takes “too long,” some workers say.

Outreach and Promotion

Both state and county officials believe that promotion of the NJEASE system is critical to its success; however, the state also considers it to be an area needing much improvement. Up to now, publicity has mostly been the result of grassroots efforts at the county level. For example, the Union County NJEASE office has its own toll-free number in addition to the state toll-free number. I & A/outreach staff participate in several health fairs each year and do an equal number of speaking engagements at various events around the county. The Union NJEASE office also sponsors an annual conference with the local Alzheimer's Association. The bilingual team visits different sites around the county two to three times per month to assist consumers with application for benefits. Staff also write articles and provide information through their own newsletter, a regular column in a local newspaper, and a monthly cable television show.

In late 2000, the state launched a \$500,000 promotional campaign for NJEASE, designed by a public relations firm. This campaign includes a new Web site, radio and television paid and public service announcements, billboards in prominent locations, ads on local buses, and more. They are also in the process of filming a 60-minute public television program on services for older adults, which will advertise NJEASE.

WISCONSIN

Background

Wisconsin is a state with 72 counties, 10 tribes, and a population of approximately 5.2 million people. The state has a strong county structure. The proportion of persons over the age of 65 in Wisconsin (13.2 percent)⁷ is slightly higher than the national average (12.7 percent). Wisconsin also has one of the most extensive long-term care systems in the country, spending 50 percent more than the national average for each Medicaid-eligible older person (Wisconsin Department of Health and Family Services, 1998). The Community Options Program (COP), Wisconsin's home and community-based services program, which includes a state-funded, sliding scale option and a Medicaid home and community-based services waiver option, also has a long waiting list (nearly 8,000 consumers statewide). At the state level, long-term care in Wisconsin is handled by the Department of Health and Family Services, which is the single state Medicaid agency.

In 1998, then-Governor Tommy Thompson announced a redesign of Wisconsin's long-term care services system. This redesign was the culmination of three years of planning that included the participation of steering committees comprised of service recipients (people of all ages with disabilities), family caregivers, and providers. These committees gave feedback about the system in place at that point and recommended ways the system could be improved. The new system is being phased in over a ten-year period.

The redesign includes three main elements:

- **Aging and Disability Resource Centers (ADRCs)** in each county, which are designed to market and offer “one-stop shopping” for information and assistance about public and private services, resources, and benefits for consumers and their families and generally assist consumers of all income levels with locating and obtaining services, including determining eligibility for Family Care;
- **The Family Care benefit**, which combines all of Wisconsin's long-term care funding streams for institutional, therapeutic, and in-home care (these services presently have 47 different sources of funding) into one flexible long-term care benefit through which Medicaid-eligible consumers can access services and supports that meet their needs and preferences; and
- **Care Management Organizations (CMOs)**, which manage the Family Care benefit and purchase or arrange all services identified in a comprehensive care plan. CMOs are funded on a capitated basis and are the cornerstone for this managed long-term care system.

⁷ <http://quickfacts.census.gov/qfd/states/55000.html>, 2000

Ten counties and tribes were selected as pilot sites for ADRCs and Family Care, although only nine ended up moving forward with this initiative. One of these sites is Milwaukee County, the county featured in this case study. The agency which serves as the ADRC is the Milwaukee Department on Aging (MDA). At the time it was selected, the Milwaukee Department on Aging had a well-established information and assistance program for older adults and their families called Elderlink. In fact, the Aging and Disability Resource Center concept was modeled after this program. MDA serves as an Aging, but not a Disability, Resource Center; a separate agency will provide I & A for younger people with disabilities in Milwaukee County.

Strong ADRCs are considered to be critical to the success of the Long-Term Care Redesign. By providing comprehensive information and assistance and “long-term care options counseling,” it was hoped that not only will they be able to provide consumers with the information (and services) that they need, but also enable consumers to spend their money more wisely and conserve their resources for the future (thus delaying eligibility for Medicaid).

ADRCs provide the following services to all persons regardless of income:

- Information and assistance
- Long-term care options counseling (assistance with long-term care decision-making and pre-admission counseling prior to entry to long-term care facilities)
- Benefits counseling
- Emergency response
- Prevention and early intervention (information and targeted interventions that center on decreasing the risk of disabilities in the community-dwelling population, i.e., medication review or exercise programs).
- Assessments for consumers who wish to determine if they are eligible financially and functionally for the Family Care Benefit.

Through its various divisions coordinated by the Center for Delivery System Development in the Wisconsin Department of Health and Family Services, the state has assumed the main leadership role in orchestrating the Long-Term Care Redesign, including convening focus groups and working groups to discuss redesign issues, developing the delivery system for Family Care, and selecting the pilot Aging and Disability Resource Center sites. While counties are primarily responsible for the actual establishment and implementation of the Resource Centers, the state also keeps in close contact with the counties implementing the new system through monthly work groups, frequent phone calls, and site visits with the ADRCs. Finally, the state also enforces the mandate that requires nursing homes and other community-based residential care facilities to refer all consumers seeking admission to the facilities to the ADRCs for pre-admission consultation.

A feature unique to the Wisconsin program (and not found in Indiana or New Jersey) is its evaluation component. The legislature required the Legislative Audit Bureau to contract with an organization to evaluate the cost-effectiveness, access to services, and quality of care provided by the Family Care pilot projects.

The contract was awarded to The Lewin Group, a Virginia-based research consulting firm, which is conducting the evaluation in three stages: 1) a Family Care Implementation Process Evaluation Report (which was issued in November 2000), 2) an impact evaluation (the extent to which the pilot projects meet the stated goals of Family Care, and 3) an assessment of the benefits and costs of the program. In its first report, The Lewin Group said that from March through June 2000, the four pilot county Resource Centers recorded 15,734 calls, nearly five times larger than had been projected for this time period. The majority of the contacts “were inquiries concerning disability and long term care-related services, basic needs and financial-related information, and long term care living arrangements” (Alexih et al. 2000).

System Design/Data Collection

With Family Care still in its developmental stages, Wisconsin is working to standardize protocols for providing information and assistance to consumers through the ADRCs. At the present time, the standards developed by the Alliance for Information and Referral Systems (AIRS)⁸ are the foundation of the state’s I & A system.

At the county level, MDA has developed a customized online resource database, which has lists of services (including the definitions of these services) and agencies that provide those services. I & A workers develop the service descriptions and update the provider information. They can search this database by type of service, zip code, or provider name, and they can print out this information and mail it to consumers or e-mail the information to them.

Among the three states studied, Wisconsin offers the most systematic plan to collect and report standardized data. The ADRCs collect client-level data through the Wisconsin Long-Term Care Functional Screen, which is used to determine eligibility for Family Care. The state also collects a large amount of data about the information and assistance component of the long-term care redesign. Pilot ADRC sites are required to submit a monthly information and assistance report to the Center for Delivery Systems Development (see sample in Appendix C).

In terms of quantitative data, these reports include information about: who the caller was; the age of the person for whom information was requested; the timing and urgency of the call; the time frame for the information (i.e., was the call about a present or future need); the issues or needs discussed during the call; the outcome of the contact; and time spent on various I & A components (actual consumer contacts, marketing and outreach, training, quality assurance, planning and networking, resource file development, and administrative). In addition, there is also a narrative portion in which counties describe what has worked or not worked, “success stories” about ways they have helped clients, and general comments or suggestions.

Finally, the state has developed a Web site (<http://www.dhfs.state.wi.us/LTCare/>) which has comprehensive information about the Long-Term Care Redesign, including the contract

⁸ The Alliance for Information and Referral Systems (AIRS) is “the professional association for nearly 1,000 programs throughout North America that provide information and referral on human services in their respective communities” (<http://www.airs.org/default.html#AboutAIRS>). AIRS has developed a set of standards for effective information and referral and a taxonomy of I&R terminology. They also offer an accreditation program for I&R programs and a certification program for I&R practitioners.

between the state and the ADRCs, preliminary evaluation findings, and more. MDA also has new Web site at <http://www.milwaukeeecountry.com>. Through this Web site, consumers can access information and ask questions. Staff at MDA have found that over 20 percent of their requests for information now come through their Web site. They have plans to make their resource database available on their Web site in the future.

How the System Works for Consumers

Generally consumers access the Resource Centers through one of two ways: 1) a “self-referral” in which consumers or caregivers contact the ADRC directly via phone, walk-in, or the Internet, or (2) a pre-admission consultation referral from a hospital, nursing home, or other community-based residential care facility (CBRF). If a person applies for admission to a residential care facility or nursing home, whether paying privately or through Medicaid, the facility by law must refer the applicant to an ADRC for pre-admission screening. That screening will enable the ADRC to assess the applicant’s functional and cognitive needs, and advise the person of community care options.

Facilities must tell consumers that they are making the referral, and then they must fax some basic consumer information to the ADRC. The ADRC will then contact the consumer within three days to provide options counseling, to offer a Long-Term Care Functional Screen, and to provide a Financial Declaration and/or a financial application for Family Care. Consumers are not obliged to go through this process, however. Facilities that do not refer consumers may be fined \$500 for non-compliance. As of December 2000, only CBRFs, adult family homes, residential care apartment complexes, and nursing homes had been phased in. Referrals from hospitals have been suspended at this time because too many referrals were being sent for older adults who intended only to go from the hospital to a sub-acute care unit of a nursing home. Better targeting is needed for appropriate pre-nursing home consultation.

With regard to self-referrals, the state does not intend to have a nationally accessed, statewide toll-free number that consumers and long-distance caregivers can call, but some counties have toll-free numbers. In Milwaukee County, the number is staffed from 7 am to 7 pm. After hours, calls are fielded by an answering service, and there is a social worker on call to handle any emergencies that may arise. MDA has a bilingual social worker (Spanish-speaking) and uses the AT&T language translation line service to answer calls in any other language. In 1998, they fielded more than 35,000 calls (see Table 3). In Milwaukee County 13.6 percent of the population is age 65 or older (approximately 123,250 people).⁹

The heavy volume of calls reported by Alecxi and her colleagues (2000) indicate an extensive use of the I & A Resource Centers to obtain information about LTC choices. In Milwaukee County, consumers can speak directly with trained I & A specialists, who ask brief questions to assess consumers’ needs and financial resources. If consumers need more than just simple information (e.g., referrals to providers, phone numbers, etc.), they are referred to the Access Unit where enrollment specialists will make an appointment with the consumer -- regardless of the individual’s income level -- to do long-term care options counseling and a brief

⁹ <http://quickfacts.census.gov/cgi-bin/county/cnty=55079>

assessment (called the Wisconsin Long-Term Care Functional Screen) to see if the consumer might be eligible for Family Care.

If from their preliminary questions, I & A specialists think that a consumer might be eligible for Medicaid, they will send a Service Support Worker from the ADRC out to the person's home to help her gather the necessary paperwork and complete the Medicaid application. The agency developed this service to help eliminate the barrier of consumers having to go to the county welfare office to apply. The service support worker will then take the application to the Economic Support Unit (within the county welfare office), which is co-located in the same building with the MDA. (As of the summer of 2000, one of the Economic Support Unit workers works under the direct supervision of an MDA enrollment specialist to process applications from MDA clients). Generally the Economic Support Unit has 30 days to approve the application, but it can take longer if there are problems with the paperwork.

Consumers who are not Medicaid eligible may still receive information and assistance (such as long-term care options counseling) through the ADRC. When it is fully functional in all counties, Family Care (implemented in July 2000 in Milwaukee County) will offer home and community-based services (such as personal care services for bathing, dressing, and eating) to all consumers on a sliding-scale basis to all persons who are eligible because of functional disability. However, as of December 2000, the program was focused on getting people off the waiting lists for the COP program. Everyone on a waiting list is presumably eligible for the Family Care benefit.

Funding and Resource Development

In Milwaukee County, the budget for the Resource Center is over \$3.5 million. Similar to the other states in this study, funding comes from a variety of different streams, including state funds, Older Americans Act, Community Aids dollars, and Medicaid (administrative dollars from the Community Options Program Waiver).

Personnel/Staffing Patterns

The ADRC at the Milwaukee Department on Aging is large, with 14 full-time equivalent (FTE) staff providing information and assistance. In addition, there are 48 other FTEs in other Resource Center roles, such as pre-admission consultation, intake, service support specialists, and administrative support.

In terms of credentialing and certification, the contract between the Department of Health and Family Services requires that I & A workers have a Bachelors degree in social work or a related human services field, plus one year of experience working with elders. This represents a conscious effort to define information and assistance as a professional service. As such, MDA does not use any volunteers to provide information and assistance. In addition, the state recommends, but does not require, that information and assistance specialists become certified through the Alliance for Information and Referral Systems.

The Center for Delivery System Development plays a major part in providing training and technical assistance to the pilot ADRCs, including day-long training sessions on the

mechanics of the redesigned system (e.g., access issues, enrollment/disenrollment, etc.) and the annual state long-term care conference. At the county level, MDA offers mostly operational and procedural training (e.g., how to use the resource database and other technology).

Outreach and Promotion

With the exception of the state Web site, marketing of the ADRCs essentially is left up to the counties. Since MDA views promotion as critical to the success of the Resource Center, the agency has undertaken an extensive marketing and outreach campaign. This campaign includes: a Web site, large numbers of community presentations, health fairs, consumer “favors” (i.e., magnets, pens, bulletin boards, and rolodex cards), mailings to Employee Assistance Programs to reach caregivers, media outreach (ads in newspapers and church bulletins), and various publications (such as the agency’s popular *It’s Your Choice* guide to community services and resources).

MDA co-markets with other groups, such as the Arthritis and Brain Injury Foundations who mail out Elderlink information. The agency has also sent I & A workers to hospitals and senior housing to provide on-site long-term care counseling. Also, it has an arrangement with WalMart in which the Elderlink ad appears on WalMart prescription bags. Finally, MDA also does outreach to professionals in aging through its “First Friday” program in which MDA staff do presentations or updates of different topics, such as Family Care.

FINDINGS: KEY PROGRAM AND POLICY ISSUES

Based on interviews with national leaders and in-depth case studies of these three states, several findings emerge. There is broad agreement that older adults and their families need better information about public and private long-term care services and their costs in their communities as well as assistance in locating such services. For persons who are not eligible for publicly funded services, information and assistance centers can help assess their needs and choices, and put them in touch with community resources.

Although many states are trying to strengthen information and assistance services, only a few states are making a concerted effort to integrate a basic I & A program that provides information and referrals to community providers with more extensive care management of long-term care services. And few states are overtly attempting to reach out to older people of all income levels by offering fee-for-service and sliding scale programs as well as Medicaid services.

The challenges to offering this kind of universal help are considerable. This in-depth review of three states' efforts confirms the complexity of the task. There is no magic formula to make it all come together. Each state has its own driving and restraining forces for change. But these case studies do show us that states can move forward. Most importantly, they highlight many of the program and policy issues that other states should seriously consider in developing enhanced I & A programs.

Leadership

Developing a comprehensive program of I & A as the foundation for a single point of entry system for long-term care is very complex, with multiple operational challenges and many state and local policy challenges. It is easier to do nothing than to confront the thorny political and management obstacles that can hamper effective change. Before initiating this kind of multi-year, statewide change, officials should consider the following questions:

- Which governmental, private, and consumer organizations will help push for reform to create statewide systems for long-term care information and assistance?
- Is there a clear vision and strong enough leadership to effect and sustain reform?
- Is state legislation needed or will voluntary movements by local agencies suffice?
- How much local variation can be supported?
- Will staff in county/local agencies embrace the change?

One of the most compelling findings across the three states is that both state and local officials are committed to making it easier for all older adults to find the information and assistance they need to make the best personal long-term care choices possible. They vary in how they created and sustain this goal, but they frequently bring conversations back to the reason they do what they do—often with passion.

Indiana has had the benefit of strong consistent leadership from the state unit on aging for more than a decade—a leader that is also well-networked nationally through organizations that

share ideas across states. Indiana has also had consistent consumer involvement, a history of strong support of area agencies on aging by the state department of aging, and enabling state legislation that codified a uniform I & A structure built on the existing area agency on aging structure. Reform has been planned, steady, and incremental with apparent public and legislative support through several gubernatorial administrations.

New Jersey's reform efforts have been driven by state leaders and visibly endorsed by the immediate past governor. It is too soon to say how the next governor will respond, or whether the statewide elections for the governor and all legislative seats in 2001 will have any effect on the development of NJEASE. Relying on voluntary participation by local government agencies, state officials claim that they have been able to form collaborative relationships with the county agencies and build upon the strengths of each local structure and networks. No one model is mandated and the area agencies on aging have not been formally designated as the single entry point for information, assistance and care management. County officials feel they might be better positioned to seek more resources and credibility if they had enabling legislation. Thus far, there has been no vocal consumer advocacy as the system has evolved.

Conversely, Wisconsin is notable in its assertive consumer involvement. Enabling legislation lays out the vision and implementation plan, which will take a decade to implement fully. A competitive process permits different public agencies to assume the I & A and the care management functions.¹⁰ The state also has built in external evaluation requirements to guide its evolution, an extraordinary legislative requirement that will provide important insights for other states.

System Design/Coordination and Data Collection

While these states take different approaches, they are all trying to establish statewide uniformity and consistency of information for consumers, while maintaining the individuality of the local culture/organizations. All three states -- New Jersey and Wisconsin in particular -- have a strong county-based government structure that requires negotiation and adaptation. The three states are attempting to enforce uniform standards, training, computer systems, and assessment tools. However, the local I & A specialists and care managers are rarely enthusiastic about completing these forms, complain about the paperwork (even when computerized), and struggle with their role changes. Important questions include:

- How can states ensure that older adults throughout the state obtain the information and help they need without creating burdensome paperwork and non-productive activities?
- To what extent can technology help balance the need for uniformity and accountability with the imperative that local staff work with older adults on an individual basis?

Each of these states is mindful of these classic tensions. Indiana offers the most advanced technology with its computerized consumer satisfaction survey system, but all three

¹⁰ The competitive process for the selection of aging and disability resource centers will be expanded to include private, nonprofit agencies after June 30, 2002; for the care management organization selection process, this expansion will occur after December 31, 2003.

states are attempting to implement user-friendly forms, software that integrates existing consumer databases, and locally sensitive protocols for helping staff guide older adults through the long-term system at the neighborhood level. This balancing act is a core concern for all states to consider before embarking on statewide reform.

The most crucial coordination issue is how state and local partners design a system to ensure that older adults get the information and help they need, regardless of their income level. How can the local agency that establishes Medicaid financial eligibility at the local level be better linked to the information, assistance, and care management agency? In each state, local officials discussed their frustrations in guiding older adults through the Medicaid eligibility process, particularly for home care. Wisconsin staff offer the most promising model through their use of “service support specialists” who help older adults fill out paperwork in their homes, and “economic support specialists” who work for the local Medicaid agency but are co-located in the I & A agency (resource center). This kind of coordination at the local level can make the critical difference for older adults, persons with disabilities, and their families in getting the help that they need.

Finally, Indiana and New Jersey have developed and advertised national toll-free numbers for older adults. With only a few counties in the pilot phase, Wisconsin has not yet taken this step and does not intend to do so. On the face of it, this appears to be an important feature, especially for long-distance caregivers. However, for those states considering this policy, questions include:

- Which organizations will pay for what?
- Is the National Eldercare Locator effort well integrated into this effort?
- How will the emerging 211 system affect these efforts?
- Will there be duplication of effort?

Another pressing issue in all three states is the need for standardized reporting and data analysis so that the state and local agencies can track how many consumers are seeking help, what kinds of information they request, what they receive, and follow-up. Questions for states include:

- What data are needed for tracking and monitoring purposes?
- How can the state develop a centralized system that meets these data needs without overburdening local staff?
- Do older adults and families get the information and assistance they need to make long-term care choices that suit their needs, preferences, and resources?
- How satisfied are the consumers who use the system?
- What systems can be put in place that can answer these questions in an efficient way?

At the individual level, data for tracking cases is essential for care management and quality assurance. At the aggregate level, officials need to know how well the system is working and what trends suggest the need for programmatic, policy, and funding changes. However, throughout the country, data collection at the local level is seriously deficient (Applebaum 2000), which also translates into inadequate data analysis at the state and national levels because these

analyses depend on data reporting from the local agencies. Most often only numbers of contacts are recorded, so that it is difficult to track individual cases to monitor follow-up for consumers receiving multiple services. No consistent data are collected on income unless the older adult is screened for publicly subsidized programs. Therefore, it is not possible to determine the extent to which state I & A programs are reaching older adults across all income levels -- and what happens if people do receive information. This lack of complete and standardized data collection, analysis, and reporting makes it difficult to conduct statewide trend analysis and justify funding requests to state legislatures and Congress.

Indiana has devoted considerable time and resources to address this problem. The Insite and Quality Improvement Process systems offer much promise. Since the state has been developing and refining the system for several years, local staff more readily accept the need for consistent data collection and recognize the importance of their role in collecting data.

Although Wisconsin is just beginning to pilot its Long-Term Care Redesign, the requirements for data collection and reporting at the local level are impressive. Local staff are justifiably proud of the reports they can produce and interested in using them to monitor their own progress. Wisconsin has also laid a strong foundation through its formal evaluations of portions of the Long-Term Care Redesign. This includes a preliminary evaluation of the pilot ADRC sites by the Office of Strategic Finance in the Department of Health and Family Services and the contract with The Lewin Group to do an evaluation of the overall Family Care program. The first report issued in November 2000 concluded that the “overwhelming response to the RCs (resource centers) indicates that they are meeting a large and previously unmet need for information about long-term care choices. The number of actual contacts greatly exceeded projected contact goals for both the aged and the disabled populations” (Alexih et al. 2000).

New Jersey state officials acknowledge the need to improve data collection and analysis, and they are testing software packages and systems to do it; however, local officials there are more resistant to implementing these systems due to the extra work involved in collecting such data. As of December 2000, DHSS was just beginning to develop standards to assure quality and consistency in the NJEASE I & A and care management systems, including the reporting of consumer satisfaction data.

In all three states, staff at the AAA or county level rely on call-backs to consumers who have utilized the system to determine the quality of their I&A. (Typically I&A workers will contact their own clients.) While local staff who conduct call-backs to their own clients may obtain useful personal knowledge of their own effectiveness in helping these consumers, having staff interview their own clients will not yield objective information to use in quality monitoring.

Until states can meet the data collection, analysis, and reporting challenges they face, quality monitoring will proceed slowly. The outcomes measures for information and assistance presently under development by the Administration on Aging may aid states in this process.

Funding

State and local officials in all three states discussed concerns about the level of funding they need to operate comprehensive I & A systems — and the long-run consequences in terms of being able to meet the increased demand that might result from such a system. Questions for states include:

- How should a state department go about establishing an adequate level of funding for information and assistance – particularly in the absence of data about unmet need for this service? What exactly is needed in terms of level of staffing and technology? And once state officials agree upon the necessary level of funding for I & A operation and services, how should they go about getting the political support they need to obtain that funding?
- What are the implications of developing a good I & A system that draws more people into a long-term care system that already has long waiting lists and limited funds for long-term care services?

While many consider information to be “free,” establishing and maintaining a solid information and assistance system is not. Adequate funding is necessary for staffing, assembling a database on community services and providers and keeping the database current, outreach and promotion, development of protocols and standards, technology, data collection, evaluation, and a host of other elements that are critical to the success of an I & A program.

Waiting lists for publicly funded programs are the rule rather than the exception in many states. The three states examined here all struggle with the issue of waiting lists, although they are trying to expand funding for home and community-based services. In particular, New Jersey plans to invest an additional \$60 million in state and federal funds for home care and respite services over the next three years, and Wisconsin will expand funding of home care services as the Family Care/Resource Center model is implemented over the next decade.

For all three states an important motivating factor behind the creation of their I & A systems was to help older adults -- particularly middle and upper-income older people -- make more effective long-term care choices that allow them to use their private resources wisely. If older persons can make the most economical use of their own resources for home and community-based long-term care services, they may not exhaust those resources and be forced to turn to more costly publicly funded services, such as nursing home care.

Personnel and Staffing

An I & A system is only as effective as the person who answers the call for help. Therefore, the most fundamental question is:

- Are the I & A staff properly trained and sufficient in number to meet the level of requests for assistance?

In the three states examined here, the credentials and experience of the I & A specialists and care managers vary considerably. None have specific statewide requirements, and all have to deal with local government rules that govern the hiring process. Typically, certification is not required, although New Jersey is examining options for certification and Wisconsin recommends that I & A workers obtain AIRS certification. Local officials in Wisconsin also point to their practice of placing experienced social workers and other credentialed staff on the hotlines.

New Jersey local officials are proud of their practice of staffing I & A phones with experienced older adults, culturally diverse staff, and volunteers who know their local systems well. Indiana contracts each year with its association of area agencies on aging to provide initial and ongoing training for I & A and care management staff. And Wisconsin and New Jersey state officials view their role in statewide training to be a core responsibility. The need for this kind of support is clear. But as the field of I & A continues to grow and change, the challenge is formidable.

Funding enough staff to answer calls for help is essential, and ensuring an adequate number of staff is becoming even more difficult in today's historically low unemployment environment. Many potential employees may consider dealing with people in crisis to be too difficult. Staff in states that have combined I & A for older adults and younger people with disabilities often find it difficult to stay abreast of all of the diverse resources for multiple and complex populations. This is especially true when services for children with disabilities are included. As informants in Indiana pointed out, staff who are accustomed to working with older adults often find working with parents of disabled children challenging as the parents are often very knowledgeable (and thus far more demanding) about the services and programs to which they are entitled.

Outreach and Promotion

These three states profess to reach out to all older adults, not just those who are eligible for publicly funded services. While this is an important goal, questions include:

- Have local staff embraced this mission?
- To what extent are current state and local methods to reach older adults of all incomes and cultures effective?
- To what extent do middle-income older people want to turn to government agencies for information and assistance?

While state officials uniformly articulate the mission to reach out to older adults of all income levels, local staff in most jurisdictions are accustomed to reaching out to and assisting low-income persons with publicly funded services. This history may cause some local officials to be reluctant to extend their mission to persons of all incomes, primarily because of the frequently limited resources available for actual services. However, Indiana has had some years of experience of working with a broader population, and also has begun marketing long-term care information to businesses (through CICOA's Elder Solutions program) through which the information should flow to middle-aged and middle-income people in the workforce. Thus, Indiana workers appear more comfortable in this role than New Jersey local staff who are just

beginning to implement a similar program. States that want to adopt a more universal approach to helping older adults may need several years—or strong local leaders—to expand the prevailing mission of local governmental agencies.

It is too soon to determine how effective these three states are in reaching older adults across all income levels. Indeed, few other states are collecting the data they need to see whom they are reaching, and some are just beginning outreach efforts. In regard to the three case study states, New Jersey has just started to aggressively advertise its toll-free number, and NJEASE local staff report that many older persons have usually contacted several other sources before they found the NJEASE office. Indiana and Wisconsin describe more comprehensive efforts, including television, magazines, supermarket bags, state fairs, and other social marketing and outreach strategies. However, it is not clear how much people attend to these messages when they are not in crisis. And there is little knowledge about the willingness of middle-income consumers to turn to government agencies for information and assistance.

In terms of new methods of reaching consumers, all three states also use the Internet to promote their programs with some measurable success. For example, the Milwaukee County ADRC reports that more than 20 percent of their I & A requests now come through their Web site. Even so, the development of interactive Web sites is in its infancy (Ellis, 1999), and state and local agencies are still exploring how they can best deploy these emerging outreach methods.

SUMMARY

The three states examined here are all in different stages of evolution. All face some common and some unique challenges, and the jury is still out on how well each of these systems — especially the newer initiatives in New Jersey and Wisconsin — is working.

Developing an I & A system for people of all income levels is complex and time-consuming. It requires a clearly stated plan, persistent leadership, adequate funding, and significant promotional efforts. Strong state and local leadership, consumer involvement, and improved data collection and analysis can help propel the momentum for change.

The challenge to states is significant. It is often easier to do nothing rather than withstand the inevitable criticisms that accompany any complex initiative. But few people can make informed choices about long-term care without good information and assistance. Comprehensive I & A systems with “one-stop shopping” can allow consumers to access this information in a way that minimizes the amount of searching that they must do.

REFERENCES

- Aberg, P. (2000). "Information & referral: Bringing people and services together." Paper delivered at the National Home and Community-Based Waiver Conference, Portland, OR.
- Alecxih, L., Lutzky, S., Linkins, K., Zeruld, S., & Neill, C. (2000). *Wisconsin Family Care_ implementation process evaluation report*. Madison, WI: Wisconsin Legislative Audit Bureau.
- Alecxih, L., Lutzky, S., & Corea. (1996). *Estimated cost savings from the use of community based alternatives to nursing facility care in three states*. Washington, DC: AARP.
- Applebaum, R. (2000). "Assessing outcomes of home care services." Paper delivered at the Annual Meeting of the Gerontological Society on Aging, Washington, DC.
- Case, G. (2000). "State efforts in improving I & A systems." Personal communication and summary chart. National Association of State Units on Aging. Washington, DC.
- Chang, T. (2000). "Aging and disability resource center pilot evaluation." Madison, WI: Office of Strategic Finance, Wisconsin Department of Health and Family Services.
- Coleman, B. (1996). *New directions for long-term care systems, Volume I: Overview*. Washington, DC: AARP.
- Ellis, D. (1999). Patterns of e-mail requests by users of an internet-based aging services information system. *Family Relations* 48, 15-21.
- Feder, J., Komisar, H., & Niefeld, M. (2000). Long-term care in the United States: An overview. *Health Affairs* 19(3), 40-56.
- Fox-Grage, W. (1997). *The task force report: Long-term care in the states*. Washington, DC: National Conference of State Legislatures.
- General Accounting Office. (1991). *Older Americans Act: Promising practice in information_ and referral services*. Washington, D.C: General Accounting Office.
- Hercik, J. (1997). *Transitions: States prepare for the aging of America*. Washington, DC: . National Governors Association.
- Jacobson, A. (1997). *How to link elders to services*. Washington, DC: National Association of States Units on Aging.
- Kane, R., Kane, R., & Ladd, R. (1998). *The heart of long-term care*. New York: Oxford University Press.

- Ladd, R. (1996). "Oregon's long-term care system: A case study by the National LTC Mentoring Program." Minneapolis: University of Minnesota School of Public Health.
- Ladd, R. (1997). *State strategies and methods to balance long-term care systems*. Philadelphia: Pew Charitable Trusts.
- National Association of State Units on Aging. (1999). *Vision 2010: Toward a comprehensive information resource system for the next century*. Washington, DC: National Association of State Units on Aging.
- National Association of State Units on Aging. (1997). *Enhancing today's I & R systems to meet tomorrow's challenges*. Washington, DC: National Association of State Units on Aging.
- Pan, P. G. (1995). *Long-term care: A single entry point for three populations*. Honolulu: Legislative Reference Bureau State Capital.
- Spilly S. (2000). Personal communication. CICOA, Indianapolis, Indiana.
- Steering, W. & Disturber, T. (1997). *The cost-effectiveness of home health care: A case study of Indiana's in-home CHOICE program*. Indianapolis: Hudson Institute.
- Weiner, J. & Stevenson, D. (1998). *Long-term care for the elderly: Profiles of thirteen states*. Washington, DC: The Urban Institute.
- Wisconsin Department of Health and Family Services. (1998). "Family Care: Redesigning Wisconsin's long-term care system: (Proposal)." Madison, WI: Wisconsin Department of Health and Family Services.

APPENDIX A: Table 3. State Data

	Indiana	New Jersey	Wisconsin
<i>State Information</i>			
State population	5.9 million ¹	8.1 million ²	5.2 million ³
Proportion of population over 65	12.5% ¹	13.6% ²	13.2% ³
State-funded home care program	Yes	Yes	Yes
# on waiting list for state-funded home care programs	7,000	0	8,000 *
# on waiting list for Medicaid home care programs	6,500	250	Not applicable
<i>I & A Program Information</i>			
Statute creating I & A program	Yes	No	Yes
Population served	All ages	60+	18+
Program budget			
➤ State	\$1.4 million	\$6.4 million	\$4.5 million
➤ County	\$296,000	\$216,834	\$3.5 million
Statewide toll-free I & A number	Yes	Yes	No
Staffing (County I & A, care managers, pre-admission screening)**	46	7.5	58
Approximate number of calls per year (county)	18,000	26,241	35,000
Percentage of calls requiring additional assistance (i.e. care mgt.)	33%	Not available	10%

¹ <http://quickfacts.census.gov/qfd/states/18000.html>

² <http://quickfacts.census.gov/qfd/states/34000.html>

³ <http://quickfacts.census.gov/qfd/states/55000.html>

* Waiting list figure for Wisconsin is for their Community Options Program, which is a combined Medicaid and state-funded program.

** Does not include administrative staff.

APPENDIX B. Key stakeholders interviewed/consulted

NATIONAL

Greg Case, National Association of State Units on Aging
Virginia Dize, National Association of State Units on Aging
Janice Jackson, National Association of Area Agencies on Aging
Diane Justice, Administration on Aging
Daniel Quirk, National Association of State Units on Aging
Jeanette Takamura, Administration on Aging
Nancy Whitelaw, National Council on the Aging, Inc.

STATE/COUNTY

INDIANA

Bureau of Aging and In-Home Services

Pat Casanova
Geneva Shedd
Walter Thomas

Indiana Association of Area Agencies on Aging

Melissa Durr

CICOA The Access Network

Laura Henderson
Susan Spilly

NEW JERSEY

Department of Health and Senior Services

William Conroy
Barbara Fuller
Eileen O'Connor
Marlene Verniero

Union County Department of Human Services Division on Aging

Susan Chasnoff
Fran Benson

WISCONSIN

Department of Health and Family Services

Donna McDowell (Bureau of Aging and Long Term Care Resources, Division of Supportive Living)
Mary Rowin (Center for Delivery System Development, Office of Strategic Finance)
Sharon Ryan (Center for Delivery System Development, Office of Strategic Finance)
Pris Boroniec (Division of Health Care Financing)

Milwaukee County Department on Aging

Chris Hess

Chester Kuzminski

Michelle Lameka

APPENDIX C. Monthly information and assistance report (Wisconsin)

MONTHLY RESOURCE CENTER PILOT I&A REPORT effective 7/1/99

Month/Year: _____ County/Tribe: _____
 Report Contact Person _____ Phone: _____

Urgency of Call:

- Emergency, imminent danger to self or others
 Urgent: need for assistance within approx. 48 hrs
 Neither emergency or urgent as defined above
 Unknown
 TOTAL CONTACTS

When contact occurred: (number)

- M-F day: 8 AM – 5 PM
 Weekday evening/night: 5 PM – 8 AM
 Weekend 8AM Sat.-8AM Mon.
 TOTAL (should add up to total contacts)

Time Frames

- Has a current need or concern
 Prevention or future planning
 (note: may have both in a single contact)

Who made contact: (should add up to Total contacts)

- Unknown / Anonymous
 Self
 Relative, Guardian, Friend/ neighbor, Community member
 Agency, Service Provider, Official
 TOTAL

Issues/Needs discussed during call: check all that apply; if call did not fall into any of these categories, leave blank)

#	A. Long term care related living arrangements: considering a move for health/disability/frailty reasons; housing, home modifications, special living arrangements
	B. Disability & Long term care related services: such as in home support, care mgt., respite, equipment & training, transition planning, independent living skills, death & dying
	C. Paying for disability and long term care related services
	D. Adult Protective Services, Abuse, neglect, domestic violence, safety
	E. Health: Recuperative care, diseases, conditions, dementia, health, health promotion or medical care related (<i>other than ability to pay</i> –put paying for health care under basic needs)
	F. Behavioral health: Mental health or Substance abuse
	G. Home maintenance/chores/yardwork/home safety
	H. Employment & training: vocational rehabilitation
	I. Nutrition: congregate or home-delivered meals, nutrition counseling
	J. Transportation
	K. Basic needs & financial related: Benefits, MA, health insurance, food poverty, money, shelter (non-long term care) money problems, problems paying bills, <i>paying</i> for medical care or drugs
	L. Legal, tax law, power of attorney, guardianship, consumer rights, advocacy, discrimination, complaints
	M. Life enhancement, Education, recreation, volunteerism

Outcome of Contact (*check all that apply*)

Referrals:		Information only:	
#	to Family Care Screen (including COP assessment if screen is done)	#	long term care services/resources/information
	to APS		other services/resources/information
	to emergency services		Needs a follow-up contact from RC –but not referred for screening or services
	to private long term care services		
	to services/ resources <i>other</i> than emergency, ASP, or LTC		
	Needs brief or short term services, follow-along or service coordination		

Subject of Call Primary Target Group: Primary reason for needing assistance (where known, and where contact is target group specific) <i>should add up to total contacts</i>	
#	Age 65 and older
	Age 60 to 64
	Not disabled
	Developmentally Disabled
	Physically Disabled
	Age 18 to 59
	Developmentally Disabled
	Physically Disabled
	Under 18
	Developmentally Disabled
	Physically Disabled
	Other, Missing, Information not available, Contact not person specific

Due by the 12th of the month following the monthly activity reported. Send to:

Monthly Resource Center I&A Activity Report
 C/o Sandy Wright
 P.O. Box 7851
 Madison, WI 53707-7851

Or send electronically (paper copy on file locally) to wrihax@dhfs.state.wi.us

I & A Report



601 E Street, NW
Washington, DC 20049
www.aarp.org

2001-12 (07/01) *D17462