



The Aging and Disability Resource Center (ADRC) Demonstration Grant Initiative

Interim Outcomes Report

Prepared for:

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EXECUTIVE SUMMARY

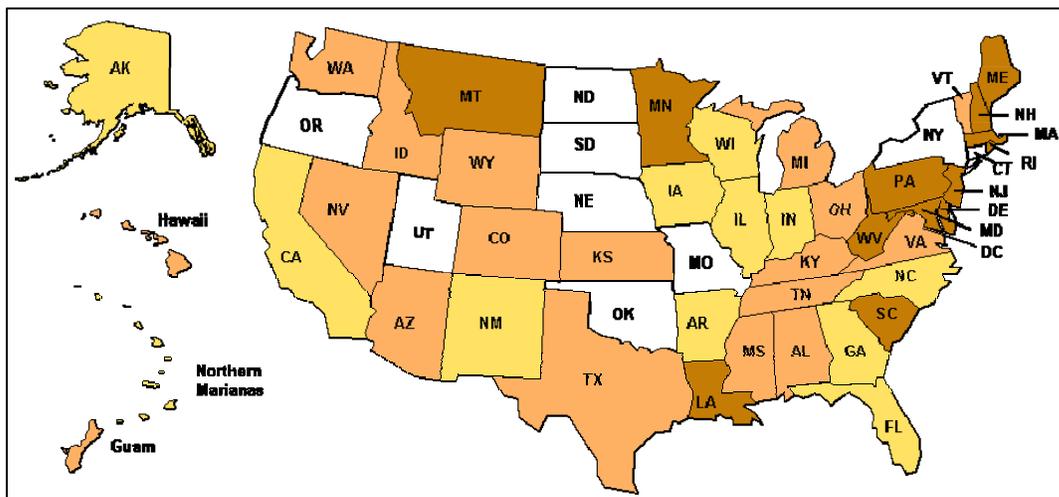
Background

The Administration on Aging (AoA) and the Centers for Medicare and Medicaid Services (CMS) launched the Aging and Disability Resource Center (ADRC) initiative in 2003. The ADRC initiative is part of a nationwide effort to restructure services and supports for older adults and younger persons with disabilities and it complements other long term care system change activities designed to enhance access to community living.

ADRCs serve as integrated points of entry into the long-term care system, commonly referred to as a “one stop shops,” and are designed to address many of the frustrations consumers and their families experience when trying to access needed information, services, and supports. Integrated points of entry strive to create community-wide service systems that reduce consumer confusion and build consumer trust and respect by enhancing individual choice and informed decision-making. This strategy can also help to break down barriers to community-based living by giving consumers information about the complete spectrum of long-term care options.

Forty-three states and territories have received three-year competitive grants since the program was launched: 12 in 2003, 12 in 2004, and 19 in 2005. ADRC grantees must meet a broad set of requirements including the provision of three main ADRC functions – information and awareness, assistance and access. Major requirements include creating visible and trusted places in the community, streamlining access to long term supports, establishing information technology systems to support the functions of the ADRC, and sustaining the program beyond the life of the grant. The federal sponsoring agencies and technical assistance team encourage grantees to design ADRC programs that build on community strengths to address their unique needs.

ADRC Grantees Across the U.S., 2006



Service Populations

As of August 2006, 63 Aging and Disability Resource Centers (ADRCs) operated in 25 states.¹ Over 38 million U.S. residents in 467 counties across the country live in an ADRC service area. Approximately 46 additional pilot sites are expected to open by the end of 2006. When all the planned pilot sites as of October 2006 open, ADRCs will serve 613 counties with a combined population of 61 million, almost 22 percent of the U.S. population.

Grantees are required to serve adults 60 years of age and older and at least one other target population of younger individuals with disabilities in at least one community of all income levels. Almost 90 percent of all sites chose to serve people with physical disabilities and nearly 40 percent serve people with all types of disabilities.

Target Populations	No. of Pilot Sites (2003, 2004 grantees)
Adults Aged 60 and Older	51 (100%) in 24 states
People with Physical Disabilities	45 (88%) in 19 states
People with MR/DD/ID	28 (55%) in 13 states
People with Mental Illness	27 (53%) in 12 states
All Disabilities	20 (39%) in 10 states

Program Budgets

...ADRC funds represent only 25% of annual pilot budgets.

The grant offers up to \$800,000 for 3 years per grantee, but grant funds represent only 25 percent of annual pilot site budgets. Most of the average annual ADRC pilot site operating budget (\$1.4 million in rural areas and \$5.5 million urban/suburban areas) come from Older Americans Act (OAA), Medicaid, state and local revenue, and other grants. Many grantees budgeted a significant portion of their grant funds, and in some cases, additional sources of funding to integrate existing services, improve service system infrastructure, such as management information systems (MIS), and to support marketing and outreach activities (\$312,000 on average, median of \$110,000). Some grantees budgeted for new staff at the state and local levels to coordinate grant activities, but only a small percentage of grant funds support direct ADRC services.

Model Structures

...Slightly more than 60% of all ADRC pilot sites have state-driven management and centralized structures.

Program models vary across three organizational dimensions: (1) management (state vs. local), (2) structure (centralized vs. decentralized), and (3) mode of consumer access (physical setting vs. virtual). Slightly more than 60 percent of all ADRC pilot sites fall at the state-driven end of the management structure and

¹ This figure includes Wisconsin's nine original ADRCs and three open pilot sites in Virginia (2005 grantee).

centralize their organizational structure. The state-driven and centralized cohort divides fairly evenly between physical and virtual models. The next largest group of grantees lies at the locally-driven end of the management scale, but are also centralized in their structure and divided along the consumer access dimension. While decentralized models constitute the minority, some grantees have developed successful decentralized models and more of the recent grantees appear to be adopting decentralized designs.

**Distribution of Pilot Sites across Model Types,
FY 2003 and 2004 Grantees (n = 24 States)**

Management		Structure		Consumer Access		# of Pilot Sites	% of Pilots
State	Local	Centralized	Decentralized	Physical	Virtual		
√		√		√		17	33%
√		√			√	14	27%
√			√	√		2	4%
√			√		√	3	5%
	√	√		√		8	16%
	√	√			√	5	10%
	√		√	√		1	2%
	√		√		√	1	2%
73%	27%	86%	14%	53%	47%	51	99%*

* = Total does not sum to 100% because the results were rounded

Interim Findings

ADRCs began to establish themselves as visible and trusted places in the community and served increasing numbers of individuals

- Consumers and providers made more than 750,000 contacts to ADRCs between March 2004 and March 2006, and the average number of contacts per month per site increased by over 200 percent across all sites and 60 percent for sites reporting in both periods.
- One-third to one-half of ADRC contacts involved the provision of non-LTC information, in part because ADRCs played a vital role in providing the Medicare Part D prescription drug benefit information and enrollment support.
- Consumers constitute 71 percent of contacts, while caregivers represent 17 percent and professionals 12 percent. A slight majority of all contacts came from new consumers, but the substantial number of repeat contacts indicates that ADRCs have begun to establish themselves as a trusted source of information.

...the substantial number of repeat contacts indicates that ADRCs have begun to establish themselves as a trusted source of information.

- For most ADRC pilot sites, younger adults with disabilities represented a new and growing service population (20 percent of contacts for October 2005 through March 2006).
- Grantees and pilot sites strategically marketed the ADRCs using names and messages that were consistent with their model types. Most ADRCs (70 percent) marketed and publicized the ADRC as a new entity, but several grantees implementing decentralized models used their marketing resources to raise visibility and awareness in the community about the enhanced services newly available through existing networks of trusted service organizations.

Strategic partnerships play a key role in establishing ADRCs

- Partnership development among diverse constituencies at both the state and local levels proved critical to successful expansion of the project. Partnering activities ranged from information sharing to co-location of staff.
- ADRCs must foster a strong relationship with Medicaid at the state and local level, which has been a challenge for some. Several grantees reported difficulty partnering with Medicaid, although the input and involvement of Medicaid is necessary to moving forward with plans to streamline access.

- Some grantees encountered difficulty with establishing relationships between aging and disability entities, because of differences in service philosophy and historic divisions between the two service systems at both the state and local levels.

Partnership Activities	State Level (n=211 partnerships in 24 States)	Pilot Site Level (n=288 partnerships in 51 Pilots)
Formal Protocols/MOUs	29%	28%
Co-location of Staff	13%	16%
Information Sharing	42%	44%
Joint Training	19%	25%
Joint Sponsorship of Programs	18%	23%

- Grantees made a special effort to partner with “critical pathway” providers – i.e., common pathways for consumers to the long-term care system, both community-based and institutional, such as hospitals and discharge planners, doctors’ offices, rehabilitation nursing homes, and intake agencies for home and community-based services (HCBS). These types of organizations together accounted for 55 percent of all referrals to ADRCs, suggesting that ADRCs are playing a key role in the process of making consumers aware of available options and assisting consumers make informed decisions (options counseling).

ADRCs built and enhanced the information technology infrastructure for information, referral, assistance, and eligibility

- Seventy-five percent of the 2003 and 2004 grantees are moving toward developing and implementing web-based, centralized data management systems to provide

...75% of the 2003 and 2004 grantees are moving toward web-based, centralized data management systems.

access to information, expedite application and eligibility determinations and facilitate updating, sharing and tracking of consumer information.

- In selected sites, progress has also been made in establishing IT/MIS systems that support self- assessments, client intake, needs assessments, client tracking, case management, service utilization levels and costs.
- The establishment of comprehensive resource databases and the ability to efficiently share information among agencies to make the most effective referrals through enhanced IT/MIS and formal partnerships represents a different way of delivering I&R/A than “business as usual.”
- Grantees found the process of implementing the IT/MIS refinements more time consuming and costly than originally planned and IT/MIS delays were the most commonly reported reason for delays in streamlining access.

Grantees made significant progress in streamlining access to services

Over the course of the three-year grant period, the 2003 grantees undertook at least three of 14 different types of activities to increase the ease with which consumers access information and services and improve the efficiency or timeliness of the process.

Major Activities Undertaken by Grantees to Streamline Access to Long Term Support Services, 2003 grantees (26 pilot sites)

Consumer Ease	Efficiency/Timeliness
Develop Web-based resource database (66%, 16 pilots)	Collect preliminary financial information as part of initial screen (80%, 21 pilots)
Provide online access to programmatic or financial applications or forms (75%, 18 pilots)	Shorten forms (33%, 8 pilots)
Allow electronic submission of applications or forms (69%, 18 pilots)	Reduce duplication (e.g. pre-population of forms with consumer information) (42%, 10 pilots)
Offer online decision support tools (12.5%, 3 pilots)	Integrate forms or develop universal assessment (42%, 10 pilots)
Shorten time from intake to eligibility determination (58%, 15 pilots)	Co-location of staff (61%, 16 pilots)
Reduce number of interactions for the consumer (54%, 13 pilots)	Institute presumptive eligibility or self-declaration of financial resources (16.6%, 4 pilots)
Reduce number of entities involved in the process (21%, 5 pilots)	Integrate MIS/ share information across agencies/ track clients system-wide (66%, 16 pilots)

- Streamlining access often involved establishing standard screening and intake processes across organizations.

- Facilitators for streamlining access include having a strong partnership between the ADRC and the Medicaid agency and pursuing a largely state-driven initiative (planned and managed across all sites at the state level).
- For eight pilot sites in five states that reported consistent data about average monthly enrollment in HCBS, institutional settings and other LTC programs, since instituting an ADRC, these pilot sites experienced a 10.2 percent increase in HCBS enrollment and a 11.8 percent decline in institutional placements.

Grantees faced challenges in realigning systems and building relationships and learned valuable lessons to address these challenges

- All 24 of the 2003 and 2004 grantees reported at least one substantial challenge to planning and implementing their ADRC grant. They reported IT/MIS challenges most frequently. Other frequently reported challenges related to leadership, staffing and turnover, forming and maintaining partnerships with other agencies, streamlining access, and engaging consumers.
- ADRC grantees developed strategies to address these challenges in a variety of ways, some of which included investing time in building partnerships, cross-training staff from partnering organizations, establishing a systematic process for determining IT/MIS user specifications, and effectively managing changes in the political environment, such as changes in administration.

Challenges and Facilitators (24 grantees)

Challenges	Facilitators/ Lessons Learned
IT/MIS (16 of 24, 67%)	
<ul style="list-style-type: none"> • Insufficient staff time/resources set aside for IT/MIS issues • Technical issues linking systems from different agencies • Difficulty procuring IT/MIS vendor • Delays due to other agencies' activities/issues/concerns • Other 	<ul style="list-style-type: none"> • Allowing adequate time and resources for determining IT/MIS needs and procuring a vendor. • Establishing systematic process for determining user specifications. • Tools to facilitate the re-engineering process, such as mobile input devices.
Staffing and Leadership (15 of 24, 63%)	
<ul style="list-style-type: none"> • Administration and leadership changes/agency reorganizations • Delays in hiring key staff due to hiring freezes, budget delays • Turnover of key staff during grant period • Insufficient staff capacity 	<ul style="list-style-type: none"> • Establishing relationships with new leaders early and educating them about the purpose of the ADRC. • Appointing a dedicated project manager. • Cross-training staff from partnering organizations.
Partnerships with Other Agencies (13 of 24, 54%)	
<ul style="list-style-type: none"> • Partnerships between aging and disability agencies • Partnerships with state and county Medicaid agencies 	<ul style="list-style-type: none"> • Involving partners early in the planning process. • Identifying champions in partnering organizations.

Challenges	Facilitators/ Lessons Learned
<ul style="list-style-type: none"> Partnerships with other agencies 	<ul style="list-style-type: none"> Setting clear and realistic expectations for partners. Remaining flexible in determining partner roles. Selecting pilot sites that already have strong partnerships with key agencies.
Streamlining Access Activities (11 of 24, 45%)	
<ul style="list-style-type: none"> Integrating ADRC with other Medicaid system reform efforts/initiatives Fragmentation of eligibility determination processes Privacy concerns related to data sharing between agencies 	<ul style="list-style-type: none"> Coordinating closely with other system reform initiatives and grant programs Taking incremental steps toward streamlining Implementing policies to protect consumer privacy and facilitate data sharing
Consumer Involvement (9 of 24, 38%)	
<ul style="list-style-type: none"> Recruiting consumers from target populations to participate Maintaining active involvement of consumer participants 	<ul style="list-style-type: none"> Involving consumers in meaningful ways, such as direct involvement in marketing and outreach activities Establishing links with existing advisory committees. Creating a separate board for consumers.

Conclusion

The ADRC grantees have begun to create integrated points of entry into long-term care systems; to empower individuals to make consumer-directed, informed choices about long-term care options; and to serve as highly visible and trusted places that people of all ages can rely on for a full range of information and supports regarding long-term care, utilizing four overarching strategies:

- 1) Streamlining access to long-term care information, services and supports;
- 2) Building upon strategic partnerships and consumer empowerment to achieve project goals;
- 3) Establishing and operating replicable models of service delivery consistent with the ADRC philosophy and mission and program objectives; and
- 4) Creating programs that demonstrate the feasibility, effectiveness and value of rebalancing long-term care service systems.

Several characteristics differentiate ADRCs from other long-term care organizations and establish them as leaders in rebalancing systems of care historically oriented toward institutional care. These include:

- Delivery of efficient, simplified access to a wide range of information and supports about community-based options for an array of consumer groups seeking information or access into the long-term care system through diverse entry points.

- Commitment to developing consumer-centric systems based on values of consumer direction, person-centered planning, and individual choice and autonomy.
- Capacity to facilitate effective linkages at multiple junctures involving diverse stakeholders along the long-term care continuum.
- Ability to prevent unnecessary institutional placement by maximizing access to comprehensive, updated and credible information about alternate resources in the community, including access to Medicaid HCBS waiver services.

The ADRC program is a collaborative effort mobilizing both public and private sector resources. It provides states with creative opportunities to effectively deliver long term support resources for providers and consumers in a single coordinated serviced delivery system consistent with the goals of long-term care rebalancing initiatives taking place at all levels. In addition to their role as change agents in producing enduring systems change, the initial experience of the initiative also shows that ADRCs provide the community and state levels capable of playing a critical role in implementing national programs, such as Medicare Part D, and assisting consumers in times of crises, such as responding to the devastation of Hurricanes Katrina and Rita.

The outcomes that ADRCs have achieved over the past three years have had significant impact at the individual, program, community and state levels. The benefits, successes and lessons learned through ADRC experiences have energized and informed policymaking and program development at all levels in the long-term care arena. ADRCs have shown, as demonstrated in the findings in this report, that it is possible to develop more efficient and effective access to information and supports and that these initiatives are widely endorsed by diverse stakeholders involved in the rebalancing enterprise. They have demonstrated that it is possible to achieve economies of scale through decreasing duplication of effort, maximizing existing resources and building new, more effective partnerships.

I. INTRODUCTION

In Fiscal Year (FY) 2003, the Administration on Aging (AoA) and the Centers for Medicare & Medicaid Services (CMS) formed a historic partnership to launch the Aging and Disability Resource Center (ADRC) demonstration grant initiative. The ADRC initiative is part of a nationwide effort to restructure services and supports for people with disabilities, building on the *Olmstead Decision*², a 1999 Supreme Court ruling directing states to provide services in the most integrated setting appropriate to the needs of qualified individuals with disabilities, and the *New Freedom Initiative* (NFI)³, a 2001 presidential initiative aimed at increasing access to an array of supports and promoting participation in daily community life for persons with disabilities. States have largely responded to *Olmstead* and NFI by expanding their use of home and community based services (HCBS) Medicaid waivers and implementing Real Choice Systems Change⁴ projects, another key component of NFI.

Two shortcomings of the current long-term care system that are often cited by consumers, advocates, and policymakers are the confusion and frustration that consumers and their families often experience in trying to access needed information and support, and the over-reliance on institutional care. Consumers may have to take many steps before becoming eligible for a program or service and, in the process, interact with multiple entities, often “telling their story” and providing the same information multiple times. Sometimes consumers get bounced around within an agency or between different organizations with no systematic follow-up and tracking to determine if the consumers’ needs were met. Furthermore, lack of awareness about long-term support options and the difficulty of accessing home and community-based services result in unnecessary institutionalization for some consumers.

An integrated point of entry into the long-term supports and services system commonly referred to as a “one stop shop,” can address many of these problems. Integrated points of entry have the potential to create community-wide systems of services that reduce consumer confusion and build consumer trust and respect by enhancing individual choice and informed decision making. This strategy can also break down barriers to community-based living by offering consumers information about the complete spectrum of long-term care options.

ADRCs were derived from this integrated point of entry concept. The ADRC program seeks to empower individuals to make informed choices about long-term support options and to streamline access for consumers to long-term support services. The federal vision is that there will be ADRCs in every community serving as highly visible and trusted places where people of all ages can turn for information on the full range of long-term support options and for a single point of entry to publicly-funded long-term support programs and benefits. By coordinating and integrating access to all publicly-

² OLMSTEAD V. L. C. (98-536) 527 U.S. 581 (1999)

³ U.S. DHHS, New Freedom Initiative, <http://www.hhs.gov/newfreedom/init.html>

⁴ Information about the Centers for Medicare and Medicaid Services’ Real Choice Systems Change Grants can be found online at: <http://www.hcbs.org/>

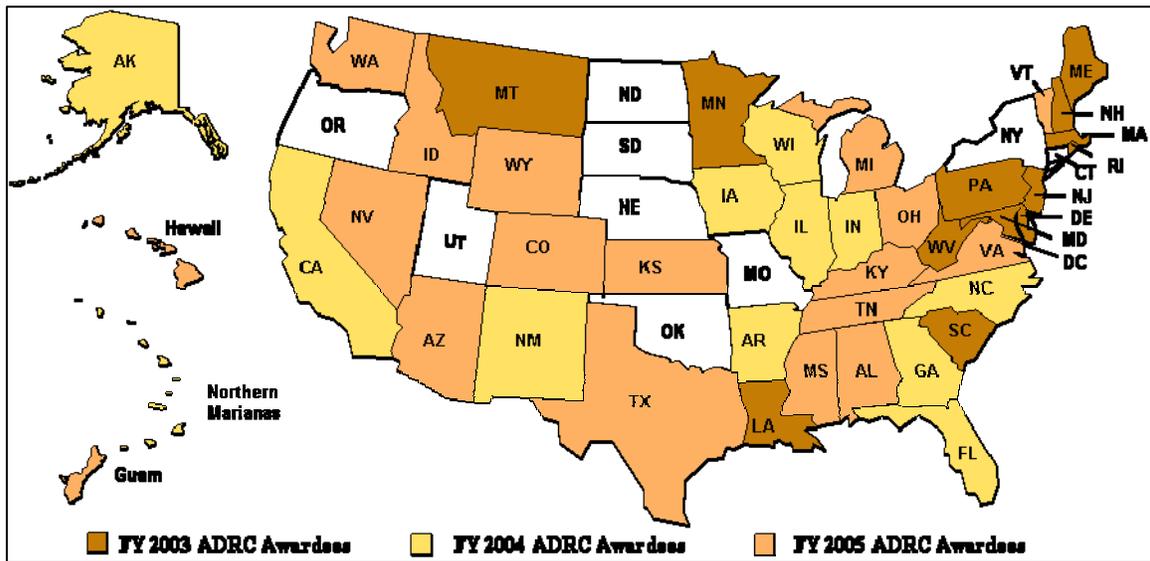
supported long-term care programs, ADRCs should improve the efficiency of government programs and reduce the frustration and confusion that consumers often face when trying to learn about and access the long-term care system.

ADRCs serve as a resource for individuals of all income levels and a range of populations -- older adults, younger individuals with disabilities, family caregivers, as well as persons planning for future long-term support needs. ADRCs also offer resources to health and long-term support professionals and others who provide services to older adults and to persons with disabilities. Since the program launched in 2003, 43 states and territories have received three-year competitive grants from AoA and CMS to design and implement ADRC demonstrations serving the elderly and at least one other target population of adults with disabilities in at least one community.

Twelve states were awarded grants in 2003, 12 states in 2004, and 19 additional states were funded in 2005 to develop ADRC programs (*Exhibit 1*). Currently, many grantees plan to expand the number of ADRC sites in pursuit of operating ADRCs statewide. By the end of 2006, these grantees will operate 109 pilot sites across the country covering almost 22 percent of the U.S. population.

The grantees are supported by the ADRC Technical Assistance Exchange (ADRC-TAE), which is funded by AoA and operates in partnership with CMS via its technical assistance center for the Real Choice grantees. The ADRC-TAE partnership includes The Lewin Group, Rutgers University Center for State Health Policy, the National Academy for State Health Policy, and the National Association of State Units on Aging.

Exhibit 1: ADRC Grantees across the U.S., 2006



Overview

This report presents findings at the state level and the pilot site level on the outcomes, accomplishments, and contributions of the ADRC program over the grant period. It emphasizes the activities of FY 2003 and FY 2004 grantees in the greatest detail. While it is too soon to report impacts of the program, this interim report details more immediate results related to key consumer and program outcomes. It also documents lessons learned and program and policy implications at the pilot, state and national level.

Grantees must serve older adults and at least one other disability target population and meet a broad set of requirements (*Exhibit 2*), including the provision of three main ADRC functions - information & awareness, assistance and access to long-term support services. In addition, federal expectations include: creating a seamless system for consumers; streamlined eligibility; meaningful involvement of consumers and other stakeholders; partnership among aging networks, disability networks and Medicaid agencies; investment in management information systems that support the goals of the ADRC; performance measurement; and sustainability.⁵

The sponsoring federal agencies gave the grantees flexibility to develop ADRC models that best meet their specific needs, as long as these models align with the federal vision. The federal project officers and the ADRC-TAE support team encourage grantees to design and implement programs by leveraging existing resources they employ, either in-house or through partnerships, rather than duplicating or creating new services. As this report highlights, the variability across grantees in terms of political and environmental climates, state and local vision of the program, and existing capacity yielded a range of program models capable of achieving the goals of ADRCs.

⁵ ADRC 2005 Grant Cooperative Agreement available online at: <http://www.adrc-tae.org/tiki-index.php?page=ADRCGrantInfoPublic> and ADRC 2005 Grant Initiative Solicitation online at: http://aoa.gov/prof/aging_dis/ADRC2005solicitation_percent20-percent20final_percent20revised_percent20-percent204-05.pdf

Exhibit 2: Summary of Grant Requirements

Required Functions of an ADRC

Awareness & Information

- Public Education
- Information on Options

Assistance

- Options Counseling
- Benefits Counseling
- Employment Options Counseling
- Referral
- Crisis Intervention

Access

- Eligibility Screening
- Private Pay Services
- Comprehensive Assessment
- Programmatic Eligibility Determination
- Medicaid Financial Eligibility Determination
- One-Stop Access to All Public Programs
- Planning for Future Needs

Target Populations

- Must serve the population aged 60 and over and at least one disability population under age 60 – i.e., physically disabled, severe mental illness, developmental disability
- Must include the private pay population

Research Questions

This report addresses the following research questions related to the initial experience of the ADRC initiative:

1. What is the range of program activity and what progress have grantees made toward:
 - Serving their target populations?
 - Promoting informed decision making about long-term support options?
 - Streamlining access to services and supports?
 - Conducting outreach to critical pathways?
 - Achieving visibility and public awareness/trust?
 - Creating IT/MIS infrastructure to support ADRC functions?
 - Achieving sustainability?

2. What ADRC program models have emerged and which models or model components are related to better outcomes?
3. What makes an ADRC an ADRC? What is their capacity for replication?
4. What role does the ADRC program play in the broader context of long-term support systems reform?

Data Sources and Methods

Data Collection

Findings presented in this report are from six primary data sources:

- **Semi-annual Reports (SART).** Every six months, ADRC grantees submit a progress report through a Web-based instrument called the “Semi-annual Reporting Tool” or SART. The SART contains fields for both state and local level program data and includes narrative sections for the authors to further explain approaches taken, and successes and challenges encountered. This report addresses information from three reporting periods: April 2005, October 2005 and April 2006. Data from the most recent reporting period (April 2006) are emphasized.
- **Sustainability Site Visits.** During the winter and spring of 2006, the ADRC-TAE conducted site visits to Maryland, Massachusetts, Minnesota, New Hampshire, New Jersey, and South Carolina, which represented half of the states receiving ADRC grants in 2003. Grantees were selected for site visits because they were among the first to receive ADRC grants and were in the final year of their three-year grants when they were likely to be focusing on sustainability issues. The particular study states were chosen because they exhibited different model types and represented a range of service delivery strategies and initiatives as well as economic and programmatic settings.

Structured interviews were conducted with project leaders, staff, advisory board members, evaluators, volunteers, and other project partners in the six states, at nine pilot sites and at four ADRC Access Points (in Minnesota). Topics covered in the fieldwork included: (1) *Elements* of the ADRC initiative that are most likely to be sustained and/or replicated; (2) *Strategies* used to achieve sustainability; and (3) *Conditions, features or characteristics* of the different states and ADRC programs that facilitate sustainability. Findings from the site visits are incorporated into the “Achieving Sustainability” section of this report.

- **Grants Monitoring Database.** AoA and CMS conduct calls every six months (off-cycle from the Semi-annual Reports) with each grantee to monitor grant compliance and program development. Grantees report successes and any significant challenges they have experienced. Project officers input notes from these calls into a Web-based database which is shared with the technical assistance team. Data from Grants Monitoring calls for all grantees were analyzed for this report.
- **National Meeting Proceedings.** Grantees attend two national meetings each year focused on the ADRC initiative. The meetings present an opportunity to learn about grantees’ experiences with program design and development, including approaches

taken and lessons learned, at both the grantee and pilot levels. The ADRC-TAE team at Lewin abstracts and synthesizes common themes and posts the proceedings on the ADRC Technical Assistance Exchange (TAE) website.

- **Grantee Teleconferences.** The ADRC-TAE arranges a variety of ADRC-specific teleconferences, including: (1) standing topic-oriented monthly grantee calls (e.g., Options Counseling), (2) peer workgroup calls with themes suggested by grantees (i.e., pilot sites workgroup, evaluation workgroup), (3) individualized teleconferences between the grantee and the ADRC-TAE. Data from these sources were examined and used for the illustrative examples included in this report.
- **TA Tracker and Website resources.** AoA sponsors the ADRC-TAE website, where resources, information about grantees, and numerous examples of grantee materials such as work plans, budgets, intake forms, advisory board minutes, formal agreements, marketing materials, and streamlining access flow charts are found. In addition, the TAE team uses a Web-based tool to track grantee requests for technical assistance and the provided response. Requests for assistance are coded by themes that allow the team to look across grantees for common challenges, which informed several sections of this report. In particular, for the visibility and public awareness subsection of this report, we analyzed marketing materials and tag lines to determine if ADRCs at the pilot level branded themselves as a new entity or an enhanced entity. Likewise, ADRC names were examined to determine if the ADRCs branded themselves as a network/affiliation or a physical center.

Data Analysis

Initially, SART program data pertaining to implementation and outcomes from three reporting periods were coded and analyzed at both the state level (i.e., “grantee”) and local level (i.e., “pilot site”). Data from the Grants Monitoring database and TAE events (i.e., grantee teleconference, national meetings, and TA Tracker) were triangulated to abstract common themes. Finally, data from the site visits were used to vet the secondary data analysis and to inform the findings pertaining to sustainability, best practices and lessons learned.

To analyze grantees marketing and outreach activities (under ADRC Visibility and Marketing), the research team constructed variables that indicate whether the ADRC is being marketed as a (1) New Entity or (2) Existing/ Enhanced Entity based on analysis of their marketing materials.

To analyze the relationship between existing capacity, program model and grantee outcomes pertaining to streamlined access to public programs, the research team constructed variables representing:

- *Existing capacity at the start of the grant* – (1) Partnership between Grantee and Medicaid (less mature, more mature) based on integration and partnership prior to grant, (2) IT/MIS infrastructure (less mature, more mature) based on integration of MIS and use of specialized IT systems.
- *HCBS Spending* – (1) percent of state long-term care spending on home and community based services

- *Different program models based on three dimensions* – (1) Management (State-driven, Locally-driven), (2) Structure (Centralized, Decentralized), and (3) Mode of Consumer Access (Physical, Virtual)
- *Streamlined access*– (1) activities designed to improve Consumer Ease of Access, (2) activities designed to improve Efficiency/Timeliness of process, (3) Post-ADRC Grantee and Medicaid Partnership (less mature, more mature)

Data Limitations

Analysis limited to 2003 and 2004 grantees. Almost all of the analysis in this report is based on the experience of and data reported by the 24 FY2003 and FY2004 grantees only. The findings in this report do not represent the experience of all 43 ADRC grantees. As they complete the first year of their grant period, most of the FY2005 grantees are in the planning and design stages of their projects, do not have fully developed models and have not yet reported outcomes.

Analyzing self-reported data. The primary data used in this report are self-reported by the grantees and pilot sites. Grantees have discretion over the types of information they report in their Semi-annual Reporting Tool (SART) and the depth and detail of the narrative sections of the report varies considerably across grantees. In some cases, grantees are engaged in activities that are not reported on in the SART. Supplementing the SART data with other data sources such as Grant Monitoring calls and grantee teleconference has helped provide a more complete picture, but this report cannot account for all grantee activity.

Differences in capacity for collection and reporting across grantees. The grantees' capacity for collecting and reporting the minimum data set requested varies considerably. The extent to which grantees have been able to report baseline and outcomes data related to service volume, consumer demographics, types of assistance provided, sources of referrals, and long-term outcomes varies according to the data elements their IT systems allow them to collect, their client tracking systems, staff time, and training. Furthermore, differences in data collection processes and definitions of terms across grantees sometimes result in data that are not comparable, which must be excluded from the analysis. The sample sizes (“n” values) for many of the data elements and figures in this report are smaller than the total number of grantees or pilot sites because data were drawn from sub-sets of grantees that were able to report these data elements consistently.

Difficulty comparing consumer satisfaction data across grantees. Although the majority of grantees are conducting surveys of consumers satisfaction, there was no required or standardized survey instrument or data collection routine. Consequently, consumer satisfaction data varies widely across the grantees. Eighteen grantees reported at least some outcome data from their consumer satisfaction surveys. While some grantees submitted the full results of their consumer satisfaction surveys, others reported only a few indicators. It is difficult to compare results as some grantees used Likert scale measures and others multiple choice or yes or no responses. Response rates varied from 5.2 percent to 100 percent, and level of response was not related to the survey method.

Analyzing predictors of program outcomes. The analysis of the relationship between program model type, existing capacity, and streamlined access to long-term support services is based on the early experiences of the first round of ADRC grantees and is an assessment of program performance at a “point in time.” It is too early to measure the extent to which the program can be sustained over time and the true evidence of change; therefore, rather than drawing conclusions about which factors result in streamlined access and other successful outcomes, this report emphasizes the major trends from the data analyses and what the trends may suggest regarding program performance.

Organization of the Report

The remainder of this report is divided into four sections and three appendices as follows:

- **Section II: Grantee Program Models and Characteristics** describes the range of ADRC program models that emerged from the FY 2003 and FY 2004 grantees and reports select characteristics of these programs such as the target populations being served, geographic coverage, program budgets, and staffing composition and training.
- **Section III: Findings** describes the major findings of the ADRC initiative in terms of accomplishments and outcomes, subdivided by consumer and program levels.
- **Section IV: Promising Practices/ Lessons Learned** highlights emerging promising practices related to planning, infrastructure, and access to long-term support and describes key facilitators and barriers to program planning and implementation as reported by the grantees.
- **Section V: Conclusion** synthesizes the major contributions of the ADRC program and reports key program policy implications of the findings for the grantee and federal levels related to future ADRC development and its role within broader long-term care systems reform. This includes discussion implications for replication, challenges and future direction of the program.
- **Appendix A - “Acronyms and Glossary:”** provides a list of commonly used acronyms and definitions of key terms used in the report.
- **Appendix B - “Exhibits:”** provides a chart of all the tables and graphs included in this report with page references.
- **Appendix C - “Examples of Program Resources:”** includes several resources related to ADRC websites, cross-training, partnership development, marketing, and streamlined access developed by grantees.

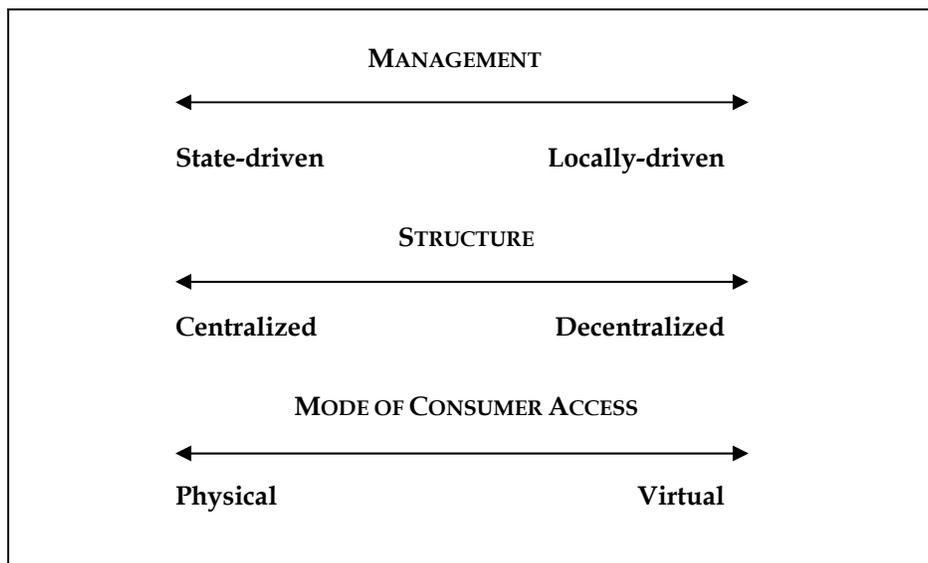
II. GRANTEE PROGRAM MODELS & CHARACTERISTICS

ADRC Program Models

A key intent of the ADRC concept is the development of proactive and responsive systems of information and support that meet the range of needs consumers have regarding home and community-based services and supports. Over the first three years of the ADRC grant initiative, participating states and pilot sites responded to this consumer-centered systems approach by developing and implementing models designed to achieve the goals of the program, while balancing and leveraging factors unique to each grantee, including socio-economic and political contexts, existing infrastructure and capacity, and needs expressed by key stakeholders and consumers. As a result, a range of ADRC models have evolved over the course of implementation. In general, the ADRC models (*Exhibit 3*) vary across three organizational dimensions: (1) management (state vs. local), (2) structure (centralized vs. decentralized), and (3) mode of consumer access (physical setting vs. virtual). One ideal model for delivering ADRC services has not emerged. Indeed, programs with notably different designs have made similar progress in realizing the ADRC vision.

In terms of management, states vary in the extent to which grant planning, design and administrative responsibilities reside at the state or local levels and the extent to which pilot sites have discretion in the implementation of the grant. The second dimension, organizational structure, varied at the pilot site level from centralized to decentralized in terms of how many organizations share responsibility for providing ADRC functions and the extent to which these organizations partner with others in the community. The third dimension, consumer access, pertains to how consumers interface with the ADRC to access information and services in which some pilot sites focus more heavily on physical means of access and other focus more on virtual means.

Exhibit 3: ADRC Model Dimensions



To describe where the grantees fall within the dimensions, four categories were applied to each dimension. The percentage of the pilot sites that fit into each of these four categories and the criteria used to define each category are outlined below.

Management

About three-quarters of the 2003 and 2004 grantee pilot sites are managed primarily at the state level (*Exhibit 4*). This category includes ADRCs that offer services statewide, which are often operated by state level staff. Others in this category are states that developed an overall policy vision and project design at the state level, to be implemented across multiple pilot sites. Pilot sites in these states may benefit from innovative directors and skilled staffs, as well as strong local partners and advisory boards, but major decisions about ADRC policies are made primarily at the state level. Just over one quarter of pilot sites fall toward the locally-driven end of the spectrum. In these cases, the state provides support and technical assistance but otherwise allows pilot sites a great level of discretion to develop and implement the ADRC program. In some cases, states chose pilot sites that had been operating programs with ADRC-like components prior to the grant award and encouraged them to develop their ADRC initiatives locally. Locally-driven projects have demonstrated that ADRC pilot sites can succeed when they have the flexibility to develop programs that meet the needs of their communities, as well as support and guidance from the state.

**Exhibit 4: Management: State-driven to Locally-driven
(n = 51 Pilot Sites)⁶**

27.5% (14)	45.1% (23)	11.7% (6)	15.7% (8)
State-Driven: One or more state agencies have primary responsibility for planning and oversight, with limited input from pilot sites/local level organizations.	State/Local: One or more state agencies share responsibility for planning and oversight, with significant input from pilot sites.	Local/State: Local level organizations have flexibility in ADRC planning and implementation, with significant state involvement.	Locally-driven : Local level organizations have primary responsibility for pilot site planning and implementation, with limited state involvement.

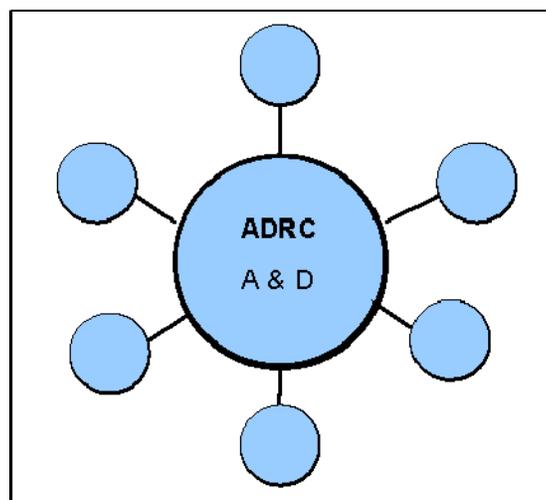
Structure

In centralized models, one organization takes primary responsibility for providing all ADRC functions and serving all target populations, similar to Wisconsin’s original

⁶ The 51 pilot sites are those opened by 2003 and 2004 grantees. It does not include the 2005 grantees’ pilot sites or Wisconsin’s original nine sites, which are not considered pilots in the national initiative.

ADRCs and other single point of entry systems.⁷ However, centralized models still rely heavily on other partnering organizations in the community to serve on advisory boards, help with marketing and outreach, refer clients to the ADRC, and provide direct services for ADRC clients. In decentralized models, two or more organizations partner to provide ADRC services, offering consumers multiple entry points into the long-term care system. Through the coordination of referrals, standardized intake procedures, and data sharing between these primary partnering organizations, consumers can enter into any one of these organizations and receive the same standard set of ADRC services. Decentralized models have a core group of primary partners, organizations that are responsible for offering ADRC services, as well as peripheral partners that play more limited roles, such as assisting with outreach and referring clients to one of the multiple access points. There is variation in how decentralized ADRC models are organized. In some, all of the primary operating organizations serve all the ADRC target populations. In other decentralized models, one partner takes the lead on serving the aging population while another focuses its outreach and services to disability populations. In both centralized and decentralized models, grantees work to simplify the process of accessing services and to impose consistency and uniformity across the intake and eligibility determination processes for long-term care programs. *Exhibits 5, 6 and 7* below illustrate the differences between a centralized model and two different kinds of decentralized ADRC models.

Exhibit 5: Centralized ADRC with one operating organization that serves older adults and younger people with disabilities, with support of Partnering Organizations



⁷ Wisconsin opened Aging and Disability Resource Centers in nine counties as part of the state's Family Care initiative in 1999. More information about the Wisconsin ADRCs and Family Care is available online at: <http://dhfs.wisconsin.gov/LTCare/Generalinfo/RCs.htm>

Exhibit 6: Decentralized ADRC with multiple operating organizations that serve both older adults and younger people with disabilities, with support of Partnering Organizations

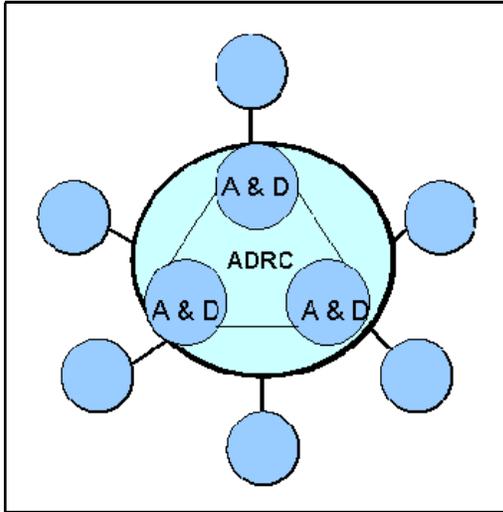
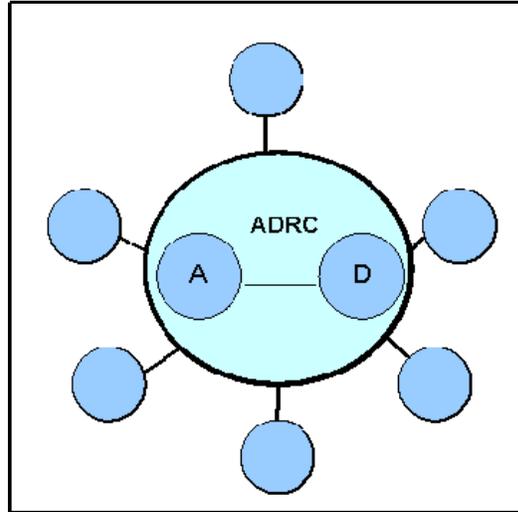


Exhibit 7: Decentralized ADRC with multiple or Disability populations, with support of Partnering operating organizations that focus on either Aging Organizations



Most ADRC pilot sites are working to implement a highly centralized structure, where ADRC functions will be offered by one organization (*Exhibit 8*). Integrating all the ADRC functions into one organization often represents a major change in how these services were offered at the local level. Some highly centralized sites have achieved complete integration, through co-location of entire organizations or hosting staff from other organizations, on a full-time or part-time basis. Other centralized sites are still working to bring all the functions together.

About 20 percent of pilot sites are implementing “somewhat centralized” models, where some ADRC functions remain the responsibility of an outside organization but are closely coordinated with the ADRC. About 14 percent of sites have decentralized structures. These sites are notable in the extent to which they have streamlined access to public and private services through partnerships, coordination, and data sharing.

**Exhibit 8: Structure: Centralized to Decentralized
(n = 51 Pilot Sites)**

64.7% (33)	21.6% (11)	5.9% (3)	7.8% (4)
<p>Highly Centralized:</p> <p>One primary organization offers all ADRC functions; partners play a limited role, referring clients to the ADRC and receiving referrals back for direct services.</p>	<p>Somewhat Centralized:</p> <p>One primary organization offers most ADRC functions, but relies on partners for some functions; partners play a significant role; client information may be shared between ADRC and partners.</p>	<p>Somewhat Decentralized:</p> <p>Two primary organizations offer all ADRC functions; client information is shared between primary partners; other partners play a limited role, referring clients to the ADRC and receiving referrals back for direct services.</p>	<p>Decentralized :</p> <p>Two or more primary organizations partner to offer ADRC functions; many organizations play significant roles; client information is shared among primary partners and peripheral partners.</p>

Mode of Consumer Access

In physical models, consumers’ primary means of accessing information and services is by contacting the ADRC by telephone or in-person. Most of the pilot sites that are designated below as having highly physical modes of access sites also host websites to provide basic information about services and how to connect with them. However, these sites are not a primary mode of consumer access; rather they supplement and direct consumers to access the ADRC in other ways. About half of the 2003 and 2004 pilot sites offer more virtual mechanisms as primary modes of access (*Exhibit 9*). In virtual models, consumers access the ADRC primarily by telephone or by using Web-based searchable databases to access information and resources. Many of these sites operate statewide call centers and websites that connect consumers to local services. Once an initial contact has been made through a virtual mechanism, an in-person appointment for counseling or assessment may be scheduled. In highly virtual models, consumers can use online tools to help them assess their own needs, electronically submit personal information to the ADRC to begin the service process, or complete and submit applications for Medicaid and other public programs.

**Exhibit 9: Mode of Consumer Access: Physical to Virtual
(n = 51 Pilot Sites)**

33.3% (17)	19.6% (10)	19.6% (10)	27.5% (14)
<p>Highly Physical:</p> <p>Consumers access the ADRC mainly by walking in or by calling.</p>	<p>Mostly Physical:</p> <p>Consumers access the ADRC mainly by walking in or by calling; they may find basic (static) information about ADRC and services on a website.</p>	<p>Somewhat Virtual:</p> <p>Consumers access the ADRC mainly by walking in or by calling; they may also use a Web-based searchable resource database; they may be able to download and mail in applications for Medicaid and/or other public programs.</p>	<p>Virtual :</p> <p>Consumers access the ADRC mainly by calling or a using Web-based searchable resource database; they can electronically submit personal information and/or application forms to begin eligibility process for Medicaid and/or other public programs.</p>

Eight Model Types

When the four categories of each dimension are collapsed into two dichotomous classifications (e.g., State-driven versus Locally-driven) and examined across all three dimensions, the grantees fall into eight different model types. *Exhibit 10* shows the distribution of pilot sites across these eight types. Slightly more than 60 percent of the ADRC pilot sites fall at the state-driven end of the management structure and are centralized in their organizational structure. The state-driven and centralized cohort is fairly evenly divided between physical and virtual models. The next largest group of grantees lies at the locally-driven end of the management scale, but are also centralized in structure and divided along the consumer access dimension.

**Exhibit 10: Distribution of Pilot Sites across Model Types,
FY 2003 and 2004 Grantees
(n = 24 States)**

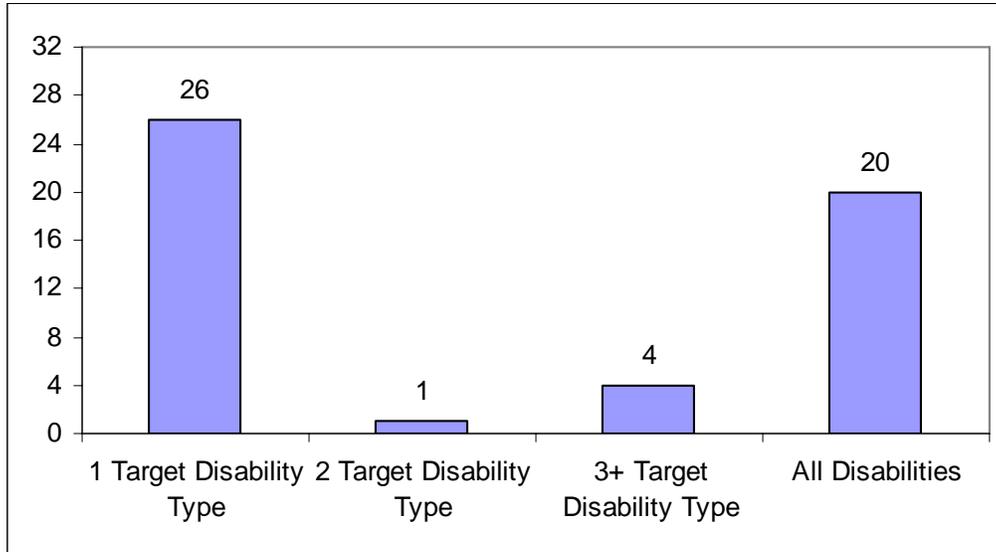
Management		Structure		Consumer Access		# of Pilot Sites	% of Pilots
State	Local	Centralized	Decentralized	Physical	Virtual		
√		√		√		17	33%
√		√			√	14	27%
√			√	√		2	4%
√			√		√	3	5%
	√	√		√		8	16%
	√	√			√	5	10%
	√		√	√		1	2%
	√		√		√	1	2%
73%	27%	86%	14%	53%	47%	51	99%*

* = Total does not sum to 100 percent because the results were rounded.

Target Populations

ADRC pilot sites must serve adults over the age of 60, as well as younger individuals in at least one target disability group. As shown in *Exhibit 11*, nearly half of the pilot sites began by serving one target disability group, such as people with physical disabilities, mental retardation or developmental disabilities, or mental illness. Just less than 40 percent of these pilot sites serve people with all types of disabilities. Most sites serve adults only, while roughly one-third serve people of all ages.

**Exhibit 11: Number of Pilot Sites Targeting
One or More Disability Type
(n = 51 Pilot Sites)⁸**



About 88 percent of all sites serve people with physical disabilities as one of their target populations, with 24 pilot sites in 13 states choosing to target this population specifically and another 21 sites serving people with all disability types (*Exhibit 12*). Approximately 55 percent of pilot sites have chosen to include people with mental retardation/developmental disabilities/intellectual disabilities in their target population. While sites in only two states have chosen target individuals with mental illness exclusively as their one disability group, 53 percent of all sites serve individuals with mental illness.

**Exhibit 12: Number of Pilot Sites Serving Different
Target Populations, 2006
(n = 51 Pilot Sites)**

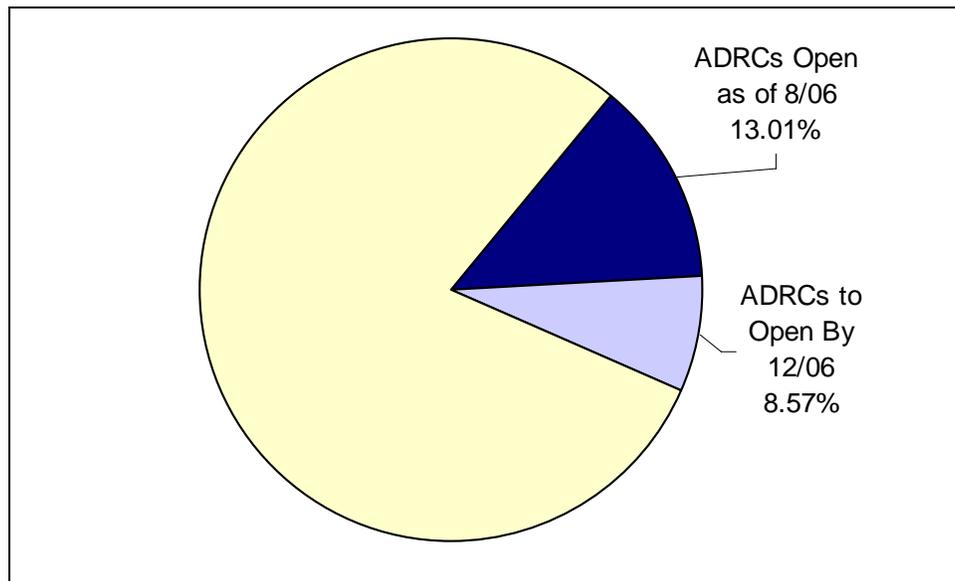
Target Population	No. of Pilots Sites
Physical Disabilities	45 (88%) in 19 states
Mental Retardation/Developmental Disabilities/Intellectual Disabilities	28 (55%) in 13 states
Mental Illness	27 (53%) in 12 states
All Disabilities	21 (41%) in 10 states

⁸ The 51 pilot sites are those opened by 2003 and 2004 grantees. It does not include the 2005 grantees' pilot sites or Wisconsin's original nine sites, which are not considered pilots in the national initiative.

Geographic Coverage

As of August 2006, there are 63 pilot sites operating in 25 states.⁹ Over 38 million U.S. residents in 467 counties across the country live in an ADRC service area (*Exhibit 13*). Approximately 46 additional pilot sites are expected to open by the end of 2006. When all the planned pilot sites to date open, ADRCs will serve 613 counties with a combined population of 61 million, almost 22 percent of the U.S. population.

Exhibit 13: Percent of U.S. Population Living in ADRC Service Areas, August 2006



Most states pilot the ADRC initiative in one to three sites, with grantees opening multiple pilot sites choosing at least one urban/suburban location and one rural location. Iowa, Minnesota, New Mexico, and Rhode Island began their ADRCs as statewide initiatives.¹⁰ The District of Columbia, Guam, and the Northern Mariana Islands are piloting district-wide or territory-wide.¹¹ Among the 59 ADRCs that operate within specific regions of the state, their service areas range from one to 13 counties. The resident population ranges from just over 10,000 for one rural pilot to nearly 3.5 million for one urban pilot. *Exhibit 14* shows the range in pilot site service area populations.

⁹ This figure includes Wisconsin's nine original ADRCs and three open pilot sites in Virginia. (2005 grantee).

¹⁰ Key ADRC functions such as I&R/A are offered statewide; Minnesota and New Mexico are piloting other ADRC functions in Hennepin County and Santa Fe, respectively.

¹¹ The District of Columbia, with a population of 550,521, is categorized as an Urban/Suburban site. Guam and the Northern Mariana Islands, with populations of 154,000 and 69,221 respectively, are categorized as Rural sites.

**Exhibit 14: ADRC Service Areas by Urban/Rural, 2006
(n = 63 Pilot Sites)**

	Rural	Urban/Suburban	Statewide
Avg. Pop. in Service Area	138,306	1,111,502	2,736,863
No. of Pilot Sites, Open and Planned	20 (31% of all Pilots)	39 (61% of all Pilots)	4 (6% of all Pilots)

Note: 63 sites include the original Wisconsin sites and three open pilot sites in Virginia (FY 2005 grantee).

Program Budgets

Grantees received up to \$800,000 in federal funding to design and implement the ADRC initiative over the course of three years. Since the ADRC grant initiative is intended to help states reorganize and streamline existing processes and service delivery, many grantees allocated a significant portion of their grant funds to improve service system infrastructure, such as management information systems (MIS), and to support marketing and outreach activities. On average, grantees planned to spend \$312,000 (from grant funds and other sources) on MIS enhancements over the course of three years. Some grantees budgeted for new staff at the state and local levels to coordinate grant activities. A relatively small percentage of grant funds were budgeted to provide direct ADRC services.

The average annual ADRC pilot site operating budget in rural areas was approximately \$1.4 million and in urban/suburban areas was \$5.5 million (*Exhibit 15*).

Exhibit 15: Staff Levels and Operating Budgets in Rural and Urban/Suburban Pilot Sites, April 2006

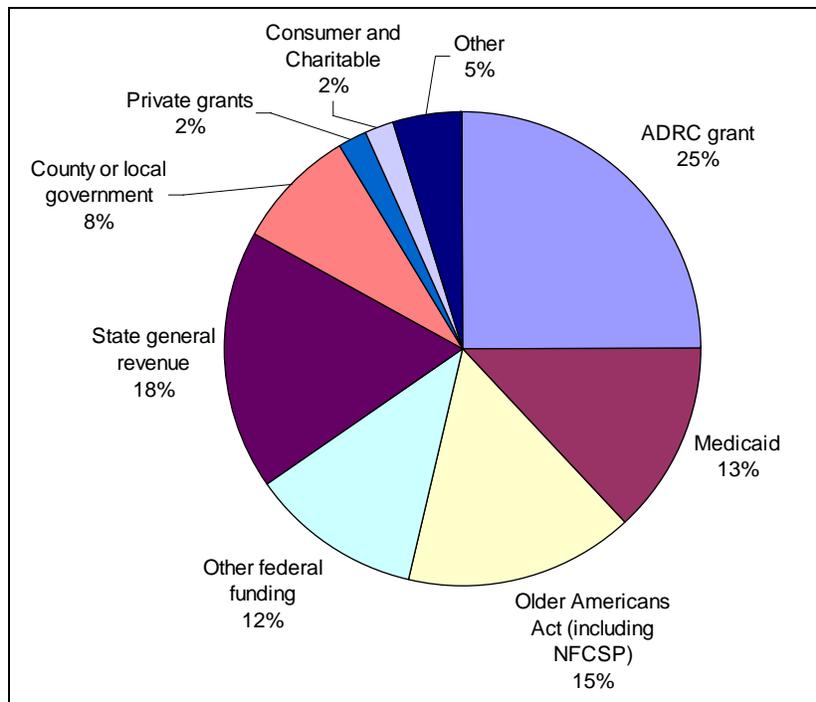
	Rural	Urban/Suburban
Avg. Annual ADRC Pilot Site Operating Budget	\$1,399,129	\$5,542,481
Annual Dollar Amount Budgeted per Resident in Service Area	\$9.77	\$5.14
Avg. Total Full Time Equivalent (FTE)	8.75 FTE	18.96 FTE

Annual operating budgets and staff levels reported by ADRC pilot sites vary considerably, in large part based on how the ADRC defines itself. In some states, when an organization such as an Area Agency on Aging is designated as an ADRC pilot site, the whole organization *becomes* the ADRC. In these cases, the annual operating budget is more reflective of the entire organization's budget. In other cases, pilot site organizations will designate a few staff members, or a smaller division within the larger organization, to serve as the ADRC and the annual operating budget will reflect the amount budgeted for the ADRC division only. Budgets and staffing levels in rural and

urban/suburban sites also vary considerably from one another, due in large part to differences in staff size. Urban pilot site budgets are more than three times the size as rural site budgets; however, rural sites budgeted 90 percent more per capita than urban/suburban sites, reflecting a level of fixed costs associated with ADRC activities.

Given the size of the average ADRC operating budget, it is clear that pilot sites draw from funding sources other than federal grant dollars. In fact, ADRC pilot sites reported that 75 percent of their annual budgets come from sources other than the ADRC grant, such as the Older Americans Act (OAA), Medicaid, state and local revenue, and other grants. *Exhibit 16* illustrates the average proportion of total annual budgets across different revenue sources for the ADRC pilot sites.

Exhibit 16: Proportion of ADRC Pilot Site Budgets from Different Revenue Sources, April 2006 (n = 37 pilot sites)



Staffing Composition and Qualifications

Staff positions and job roles are defined differently across ADRC pilot sites. For the purposes of grant reporting, grantees were asked to use the following job categories based on key functions (*Exhibit 17*). However, in many cases one staff person performed cross-functional work and therefore devoted time to more than one position.

Exhibit 17: ADRC Staff Positions and Job Functions

Position	Key Job Functions
I&R/A Specialists	<ul style="list-style-type: none"> • Answering telephones and meeting with in-person visitors • Offering initial information, referral and assistance on a variety of topics (caregiver support, home care, adult day care, employment, housing, transportation, financial counseling, prevention and wellness programs, etc.) • Triaging emergency situations • Determining if a home visit or an appointment for options counseling, or referral to case worker is necessary • Assisting with populating and maintaining resource database
Case Workers (Nurses and Other)	<ul style="list-style-type: none"> • Providing clinical consultation and/or health promotion services (for Nurse Case Workers) • Performing assessments • Determining LTC level of care (LOC) • Conducting LTC options counseling via phone or in person • Interacting with Medicaid eligibility workers • Confirming eligibility approval
Training and Outreach Staff	<ul style="list-style-type: none"> • Training and providing outreach to workers along critical pathways to LTC (e.g., hospital discharge planners, physicians, community "gatekeepers") • Developing and/or selecting training materials and training ADRC staff • Attending health and promotional fairs • Implementing ADRC outreach and marketing plans • Assisting with identifying community resources for resource database
Benefits Counselors	<ul style="list-style-type: none"> • Offering information about available benefits • Providing technical assistance to consumers about how to access benefits • Assisting consumers in applying for benefits • Advocating for/ assisting with the appeal process for benefits denial • Consulting with legal counsel when appropriate
Financial Eligibility Workers	<ul style="list-style-type: none"> • Making financial eligibility determinations for publicly funded programs, such as Medicaid • Assisting consumers through the financial eligibility determination process • Providing technical assistance to consumers with gathering financial information and filling out eligibility forms
IT/ MIS Staff	<ul style="list-style-type: none"> • Developing and/or maintaining Management Information Systems • Developing and/or maintaining ADRC website • Managing network systems, hardware and software used by ADRC • Training ADRC staff on the use of data systems and trouble shooting • Assisting with program reporting • Assisting with populating and maintaining resource database
Administrative Support Staff	<p>Providing administrative assistance for all functions of the ADRC</p>

Position	Key Job Functions
Management	<ul style="list-style-type: none"> Managing ADRC grant requirements Coordinating reporting requirements Assembling and coordinating advisory committees Hiring, scheduling and supervising clinical and administrative staff Developing and managing policies and procedures for ADRC Overseeing all ADRC activities
Consultants	These individuals may provide consultation on an as-needed basis regarding medical, psychological, behavioral, public policy or other issues.
Others	Examples of other positions within ADRCs are LTC Ombudsman, Caregiver Advocate, and Behavior Health Specialist.

Exhibit 18 shows the number of pilot sites reporting any full-time equivalent staff (FTEs) devoted to these positions and the average number of FTEs across pilot sites, classified by urban/suburban or rural. Over 90 percent of ADRC pilot sites had at least one I&R/A Specialist on staff and the average number of full-time equivalent (FTE) I&R/A Specialists across all sites was three. Those sites that did not report having an I&R/A Specialist on staff did report staff in the Case Worker or Benefits Counselor categories and therefore some of these staff members may be performing I&R/A functions.

**Exhibit 18: Pilot Site Staffing Averages, April 2006
(n = 49 Pilot Sites)**

Staff Position	Percent of Pilot Sites Reporting Any FTE	Avg. No. FTE Across Rural Sites	Avg. No. FTE Across Urban/Suburban Sites	Avg. No. FTE Across All Grantees
I&R/A Specialists	92%	2.7	4.1	3.0
Nurse Case Worker	33%	1.6	3.9	2.7
Case Workers	47%	4.6	6.6	5.8
Training and Outreach Staff	49%	1.1	3.8	2.5
Benefits Counselors	51%	2.2	3.1	2.6
Financial Eligibility Workers	24%	0.2	3.4	1.8
IT/ MIS Staff	55%	0.5	1.4	1.0
Administrative Support Staff	80%	1.4	2.2	1.6
Management	86%	1.3	2.6	1.8
Consultants	22%	1.5	0.9	1.0
Others	22%	2.5	1.5	2.3
Total	49	Average: 8.6 (Range: 1 – 22)	Average: 19.0 (Range: 1 – 122)	Average: 12.7

Note: 49 of 51 pilot sites from FY 2003 and FY 2004 grantees reporting.

Many ADRCs required minimum qualifications for certain staff positions (*Exhibit 19*). For example, almost half of pilot sites required I&R/A Specialists to hold Bachelors degrees at a minimum; nearly seven percent require a Masters degree for this position. In addition, thirteen of these sites (representing five states) required I&R/A Specialists to be certified through the Alliance of Information and Referral Systems (AIRS).

**Exhibit 19: Minimum Qualifications Required for ADRC Staff Positions,
April 2006**

Pilot Site Staff Positions	% of Pilot Sites Reporting Any Min. Requirement	% of Pilot Sites Requiring Bachelors Degree	% of Pilot Sites Requiring Masters Degree
I&R/A Specialists	63.3%	48.3%	6.7%
Case Workers	23.3%	20.0%	1.7%
Training and Outreach Staff	35.0%	21.7%	6.7%
Benefits Counselors	20.0%	16.7%	1.7%
Financial Eligibility Workers	25.0%	20.0%	3.3%
IT/ MIS Staff	26.7%	25.0%	1.7%
Administrative Support Staff	33.3%	20.0%	3.3%
Management	56.7%	35.0%	21.7%
Consultants	26.7%	15.0%	8.3%
Other	20.0%	11.7%	8.3%

Note: 49 of 51 pilot sites from FY 2003 and FY 2004 grantees reporting

III. FINDINGS

Consumer-level Accomplishments & Outcomes

This section of the report describes the accomplishments and results of the ADRC initiative in relation to immediate consumer outcomes. It addresses the following areas:

- Demographics of the populations served by ADRC Programs
- Consumer satisfaction and access to long-term support
- The receipt of information, assistance, and informed decision making about long-term support options
- Prevention and health promotion opportunities for consumers

Demographics of Populations Served by ADRC Programs

ADRCs provided information and long-term support to more than 750,000 contacts between March 2004 and March 2006 and the average number of contacts per month increased by over 200 percent during this period. Between March 2004 and March 2006, grantees reported responding to a total of 752,789 contacts.¹² During this same period, the average number of contacts per month per pilot site grew from 401 to 1,315 (*Exhibit 20*).

**Exhibit 20: Total ADRC Contacts March 2004 to March 2006
(n = 49 Pilot Sites)**

Reporting Time Period	No. of Pilot Sites Reporting	Total No. of Contacts	Total No. of Contacts Per Month	Total No. of Contacts Per Month Per Site
March 2004-March 2005 (13 months)	22	114,759	8,828	401
April 2005-September 2005 (6 months)	37	251,324	41,887	1,132
September 2005-March 2006 (6 months)	49	386,706	64,451	1,315

It is important to note that for reporting purposes, grantees have been asked to distinguish between the number of times they were called and or had a consumer walk in and the number of individuals they served. It is not always necessary or appropriate for I&R/A providers to ask callers for identifying or demographic information, so they may not know the actual number of unduplicated individuals served or very much information about the individuals they serve. The “contact” was chosen as the primary unit of service about which ADRCs report, because it provides a more realistic picture of

¹² Across 49 pilot sites that reported contacts for at least one period.

overall service volume. When a contact comes from an individual who needs more comprehensive services, such as short-term case management or intake for public programs, ADRC staff will collect more detailed information, which can then be reported.

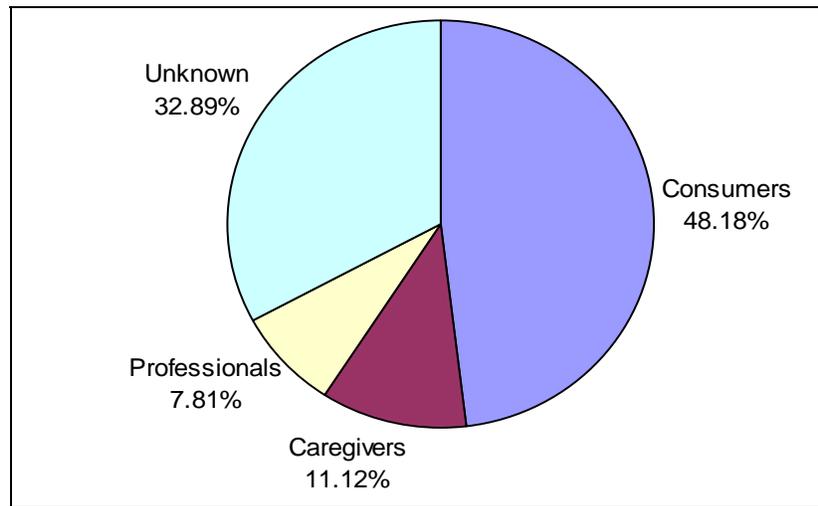
The sites reporting verifiable contact information for all three periods showed a significant increase in contact volume over a two year period; the average number of contacts the grantees received per month increased by over 60 percent (*Exhibit 21*). Seventeen pilot sites in 12 states were able to report verifiable contact information in all three reporting periods and these sites experienced a significant increase in contact volume over a two year period.

**Exhibit 21: Change in Contact Volume for Grantees Reporting
Over Three Periods
(n = 17 Pilot Sites in 12 States)**

Reporting Time Period	Total No. Contacts Per Month	Total No. Contacts per Month Per 1,000 Residents in Service Area
March 2004-March 2005 (13 months)	1,501	2.34
April 2005-September 2005 (6 months)	1,692	2.89
September 2005-March 2006 (6 months)	2,426	3.99

Consumers contact ADRCs more frequently than caregivers and professionals. On average, grantees collected information about caller type for about two-thirds of the contacts made to the ADRC. Many ADRC contacts involve the provision of basic information and because the calls are brief, staff do not collect this information (33 percent). For the contacts about which these data were collected, consumers constitute 71 percent, while caregivers represent 17 percent and professionals 12 percent (*Exhibit 22*).

**Exhibit 22: Percent of All Contacts by Consumers, Caregivers, Professionals and Unknown, April 2006
(n = 33 Pilot Sites)**



Note: The “unknown” contacts include contacts involving provision of basic information, where staff may not ask the caller about themselves.

New customers represent a slim majority of ADRC contacts. Grantees were asked to track the number of contacts from first-time callers and the number from repeat consumers. This measure is intended to demonstrate the extent to which ADRCs are attracting new consumers and the extent to which they are responding to the same consumers over time. For those grantees that have the data collection capacity to track new and repeat callers, it also serves as a rough estimate of how many contacts are provided with in-depth services, in which enough identifying information is collected to determine if the consumer has contacted the ADRC before.

As seen in *Exhibit 23*, during the most recent reporting period, over half of ADRC contacts were with new individuals and roughly 30 percent were with repeat customers. This ratio of new to repeat contacts may result from the newness of the initiative and the increased marketing activity that pilot sites have undertaken with the grant. As time goes on, it will be important for ADRCs to maintain a steady stream of repeat customers. Repeat contacts demonstrate consumers’ trust and consumers’ willingness to contact the ADRC again as their needs change over time.

**Exhibit 23: New and Repeat Contacts, April 2006
(n = 32 Pilot Sites)**

	Percent New Contacts	Percent Repeat Contacts	Percent Unknown Contacts
All Contacts (October 2005-March 2006) n = 32 pilots	55.7%	33.0%	11.3%

Note: Guidance provided to grantees on how to report New and Repeat Contacts changed in April 2006; data from prior reporting periods are not incomparable.

The proportion of all ADRC consumers who report they are under the age of 60 or calling on behalf of someone under the age of 60 increased slightly since initial launch. More than half of all ADRC pilot sites focused primarily on serving the aging population prior to becoming an ADRC and younger adults with disabilities represented a new service population for them. During the last reporting period (October 2005 through March 2006), an average of over 20 percent of all contacts came from someone under the age of 60 or on behalf of someone under the age of 60 (*Exhibit 24*). The increase in the proportion of contacts with unknown age from the first to second period is due in part to the launch of the 2004 grantee pilot sites in the second half of 2005. By October 2005, these new sites were better able to collect and report this information.

**Exhibit 24: Proportion of Contacts by Age Group over Time
(n = 30 Pilot Sites)**

	Number of Pilot Sites Reporting	Consumers 60+	Consumers ≤ 60	Age Unknown
All Contacts (March 2004-March 2005)	18	72.90%	13.12%	13.98%
All Contacts (March 2005-September 2005)	20	60.38%	8.80%	30.82 %
All Contacts (October 2005-March 2006)	30	66.48%	21.11%	12.41%

Grantees have had difficulties collecting and reporting data about contacts by disability type, sometimes because individuals who call do not identify themselves as someone with a disability or do not explain what type of disability they have. The grantees that have been able to collect and report these data found that between 8 and 15 percent of their contacts come from their primary disability target population under age 60. Most grantees report that they frequently serve individuals with all types of disabilities, even those outside their primary target populations. For example, South Carolina’s first pilot site reported an increase in the number of contacts from people with disabilities under age 60 of over 100 percent between April 2005 and April 2006. This pilot site’s primary target population is people with physical disabilities but this increase in contacts includes individuals with MR/DD, mental illness, and other disabilities. They also served a significant number of individuals over age 60 with physical disabilities. Some grantees have been able to capture information about their consumers through consumer satisfaction surveys. For example, Maryland found that about half of their survey respondents had contacted them about either a disability-related or a disability-related and aging-related issue.

**Maryland Access Point Consumer Satisfaction Survey
March 2005-February 2006
260 completed surveys**

Maryland's two pilot sites focused primarily on serving the aging population prior to the ADRC grant. However, they report that 27 percent of their calls come from individuals 64 or younger. Their consumer survey found that 16 percent of respondents had called the ADRC to ask for help with something "disability-related" as opposed to aging-related. The survey question and response rates are outlined below:

Question: Are you asking for help for disability services, aging services, or both?

Response:

Aging-related services -----	36%
Both disability and aging-related services -----	35%
Disability-related services -----	16%
No response given -----	14%

Consumer Satisfaction and Access to Long-term Support

Grantees were required to establish measurable performance goals related to consumers' interface with the ADRC program as well as indicators to track progress. The federal expectation was that, at a minimum, grantees be able to assess the following elements of consumer satisfaction: (a) *Trust* on the part of the public in the objectivity, reliability, and comprehensiveness of the information and assistance available at the ADRC, (b) *Ease of Access* (e.g., reduction in the amount of time and level of frustration and confusion individuals and their families experience in trying to access long-term support), and (c) *Responsiveness* to the needs, preferences, unique circumstances, and feedback of individuals as it relates to the functions performed by the ADRC. This section focuses on grantees' approaches to assess trust, responsiveness and ease of access and reports preliminary results pertaining to consumer satisfaction.

The most common technique for assessing consumer satisfaction was the use of a consumer satisfaction survey. All twenty-four 2003 and 2004 grantees conducted some form of consumer satisfaction survey, using either telephone or mailed surveys or a combination of these methods. While the content and administration of the instruments varied considerably, in general, the surveys captured data in three main areas in addition to basic demographic information:

- Customer Service
 - Clarity and usefulness of information
 - Wait time
 - Quality of interaction with staff
- Application for Services
 - Subsequent application for services
 - Ease of application
 - Timeliness of services
- General Experience/Overall Satisfaction
 - Quality of interaction with the ADRC
 - If consumer would recommend the ADRC to others

Examples of Approaches to Assess Consumer Satisfaction

Maryland. Between March 2005 and February 2006, Maryland mailed 1,088 surveys to consumers from both its pilot sites. The Maryland Access Point Consumer Satisfaction Survey fielded nine questions, including whether the consumer was able to speak with a staff member within one business day of first contact, and whether the information and help the consumer received from Maryland Access Point helped that consumer make a decision and/or find appropriate services.

New Mexico. New Mexico implemented a telephone survey of consumers who spoke with a Resource Center counselor, collecting information on access (“Was your telephone call answered quickly?;” “Was your telephone transfer to a counselor completed smoothly?;” “Are our hours of operation sufficient to allow you to call us conveniently?;”); trust (“Do you feel your counselor listened to what you wanted?;” “Was your counselor courteous to you?”) and satisfaction (“How would you rate your overall experience with the Resource Center?;” “Will you recommend the Resource Center to others who may need this kind of assistance?”). The survey is conducted immediately after the consumer has spoken with a resource counselor. New Mexico plans to conduct this survey one month per quarter in order to compare responses over time and make ongoing quality improvements.

North Carolina. In Forsyth County, the ADRC fielded questions with consumers about overall satisfaction and quality of service in a written survey. The survey included additional questions about call outcome (“Did the information you received from [agency name] help you make a decision or find the service you needed?”) and operational processes (“Were you told to go to, or to call, any other place for a service or for more information?;” “If you contacted [agency name] for services, are you receiving the service that you were seeking?”) in order to measure the effect of streamlining in the transition to an ADRC model.

There were eighteen survey instruments available to examine for this report. Of the 18 instruments, 16 fielded questions about the consumer’s general experience, 15 about customer service, and nine included at least one question about subsequent application for services. Many grantees expanded or revised existing consumer satisfaction surveys for the ADRC grant initiative. The text box above highlights several examples of grantees’ efforts to assess consumer satisfaction.

Grantees reported high levels of consumer satisfaction. While it is difficult to compare survey results due to the variability of instruments in terms of methods, metrics, and measurement scales, grantees reported overwhelmingly positive feedback from individuals who had contacted the ADRC on measures such as: whether the information was clear and understandable; whether the information helped them with the issue they contacted the ADRC about; and whether the staff listened carefully, was courteous and respectful, and took into account the callers’ wants and needs. The most consistently reported measure of overall satisfaction was whether callers would recommend the ADRC to others (*Exhibit 25*). Seventy-five percent of ADRCs who asked this question reported that over 90 percent of respondents would recommend the ADRC to others.

**Exhibit 25: Percent of Consumers Who Would Recommend ADRC
(n = 22 Pilot Sites)**

Percentage of Respondents Who Would Recommend the ADRC to Others	Percentage of Grantees with this Level of Positive Responses
90-100%	75%
80-90%	13%
70-80%	6%
60-70%	6%

Consumers gave high praise for ADRC programs, such as:

“I was surprised at the wealth of information offered to me. This is a wonderful service.”

“In this day and age, it is a wonderful resource to have all information in one central place. It certainly made my quest easier.”

“I was very pleased with the person who assisted me. She offered to send information that would help us make decisions and it arrived quickly.”

“I feel the counselor will do everything she can for me.”

“I like to get answers and this is where I know I can come for them.”

“I got information I would not have otherwise known about.”

Some consumers expressed levels of dissatisfaction, which underscores the need to continue to refine the system to improve consumers’ experiences:

“I initially called and waited fifteen minutes on hold, then called back and got right through.”

“After many calls they finally got back to us and then after one month sent someone to our home to ask a lot of questions to two very sick people and to say they don’t have enough funds to help us.”

“Basically the woman I talked to said she’d send me a book that would have all the information I needed – she didn’t seem interested in providing information over the phone. I waited a few days for the book. When it arrived all it contained was a list of programs with very brief descriptions and phone numbers. If the purpose of [the ADRC program] is to serve as a single point of contact to assist citizens.... in identifying appropriate services and facilitate their securing services, then the program has failed in my case.”

“Hopefully we will receive some assistance eventually. It takes time to work through the [unreadable] system.”

Grantees’ assessment of consumer satisfaction focused largely on evaluating the quality of consumers’ experience at initial contact and how easily consumers could contact the ADRC, less so on measures of streamlined access to services. Most surveys assess consumers’ front-end experience in gaining long-term support information and assistance, and very few assess consumers’ experience with going through the system including eligibility determination and access to public programs (*Exhibit 26*).

However some grantees, such as North Carolina, did use consumer satisfaction surveys to track consumers’ experience as it relates to streamlined access to services and supports by including queries about whether the consumer is receiving services, whether those services are useful, and whether the services were received in a timely manner. Eleven grantees asked at least one question about access to services and supports beyond the initial contact with the ADRC. Arkansas and Pennsylvania included questions about how long it took a consumer to receive services from the time when the consumer first contacted the ADRC. Ten states included questions about whether the consumer was receiving services, whether those services were appropriate to their needs, and whether those services were useful in increasing or maintaining independence.

Exhibit 26: Consumer Satisfaction Survey Questions by Type of Question

Question	No. of Grantee Surveys (n=22)
Quality of Information:	
Was the information you received from <i>organization name</i> clear?	10
Will the information you received from <i>organization name</i> be helpful in dealing with the issue you called or came to our offices to talk about?	19
Response Time:	
If you called, how quickly was your call answered?	18
If you left a message, when did the person call you back?	10
General Experience:	
Were you told to go to or call any other places for a service or more information?	12
If you came to our offices, how long did you wait to see someone?	8
Overall, did the person you talked with listen carefully to what you wanted?	12
Did you feel they took into account your wants and needs?	11
Were there any problems with the service provided by <u><i>organization name</i></u> ?	11
What could we do differently to make it better?	11
Would you tell a friend or relative to call <u><i>organization name</i></u> ?	22
Information About Responder:	
Did you call or come to our offices for yourself or someone else?	18
Are you or the person you called about aged 60 or over? Do you or the person you called about have a disability?	11
Race/ethnicity	8
Male or Female	9
Age	8
Home zip code	6
Household Income	1
Streamlining Access to Services:	
Did you apply for apply for services?	7
The steps to apply for services were easier than I expected/about what I expected/harder than I expected.	2
If you needed help, did the people who work at organization name help you with your paperwork?	3
Did the person you spoke with explain the steps clearly?	7
If you were approved for services, how long did it take to receive services from when you first contacted organization name?	3
Timeliness	3
Appropriateness	4
Services received/useful	9

Information, Assistance and Informed Decision Making about Long-term Support Options

Grant requirements included designing an ADRC that engaged in “Awareness and Information” and “Assistance” to empower consumers to make informed decisions about their long-term support options. For most grantees, this meant coordinating or integrating with other community agencies to offer a range of functions, from public education and information on long-term support options to community referrals and crisis intervention (see text box below). This section describes grantees’ accomplishments in providing information, referral and assistance (I&R/A), identifying what makes the delivery of I&R/A through ADRCs different than “business as usual.” It also addresses the extent to which ADRCs are empowering consumers to make informed decisions.

Awareness and Information & Assistance Functions of an ADRC

Awareness and Information

- Public education
- Information on long-term support options

Assistance

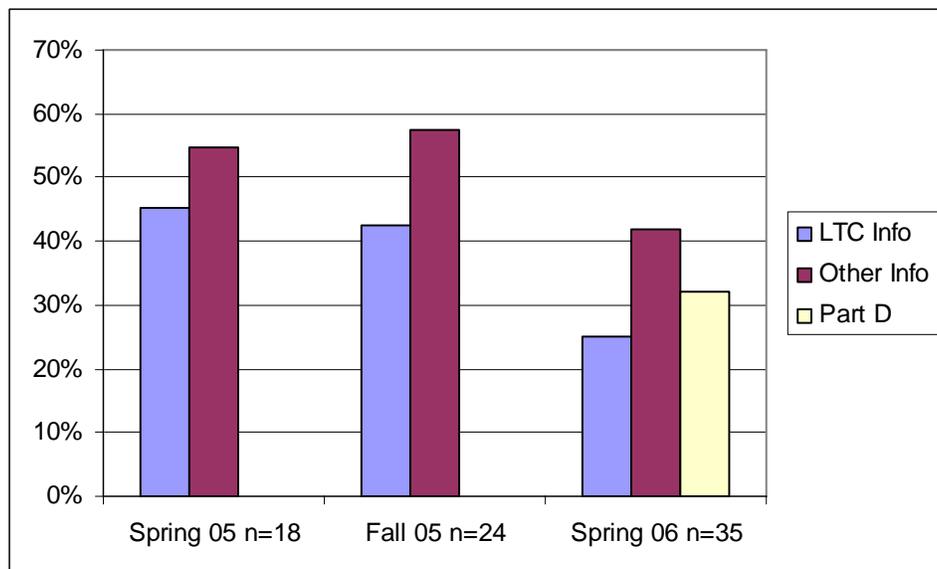
- Long-term support options counseling
- Benefits counseling
- Employment options counseling for people who are interested in or may be interested in such counseling; Grantees would be expected to coordinate with other sources funding employment counseling in their state, such as the Social Security Administration and/or the Department of Labor, to ensure access and prevent duplication
- Referral to other programs and benefits that can help people remain in the community, including programs that can assist a person in obtaining and sustaining paid employment
- Crisis intervention
- Helping people to plan for their future long-term support needs

The highest proportion of contacts with the ADRC involved the provision of non-LTC information and ADRCs played a vital role in providing the Medicare Part D prescription drug benefit information and enrollment support. As seen in *Exhibit 27*, the majority of ADRC contacts involved the provision of non-LTC related information. Non-LTC related information includes information about other services or resources such as Low-Income Home Energy Assistance Program (LIHEAP), county tax relief, local libraries, food stamps, or other kinds of public assistance. The proportion of non-LTC related information provision compared to LTC related information increased each reporting period.

Information related to Medicare Part D impacted a significant portion of ADRC activity from October 2005 to April 2006. The massive initial enrollment process in the new program meant that, in addition to the 1-800-MEDICARE line and the CMS funded State Health Insurance Assistance Program (SHIP) which focuses on assisting Medicare beneficiaries with health insurance issues, nearly all other agencies providing information and assistance felt the impact. Of the 35 pilot sites that were able to report contact figures for the most recent SART, on average, 32 percent of contacts were provided information about Part D. In fact, during the peak of enrollment period, pilot sites reported limited capacity to engage in other ADRC planning and implementation activities. By offering objective information and beneficiary enrollment support, ADRCs clearly played a vital role in the successful roll-out of Medicare Part D.

ADRCs played a large role in the Part D enrollment efforts, in part, because grantees proactively coordinated and collaborated with their respective SHIPs to meet consumers' needs prior to the launch of Part D. The majority of pilot sites (64 percent) co-locate with SHIP. In 17 states, the ADRC and the SHIP program reside in the same agency at the state level. In the remaining seven states, ADRCs and SHIPS partner at either the state or local levels. In Pennsylvania, for example, ADRC and SHIP are part of the same agency at the state level, but are not co-located at the local level. In this instance, the Cumberland County, PA pilot site reported that the state SHIP identified partners at the local level and provided education and information. In Iowa, the ADRC and SHIP reside in separate agencies and the State Unit on Aging, Area Agencies on Aging, and Social Security Administration all coordinated with SHIP to offer Medicare Part D outreach and education activities.

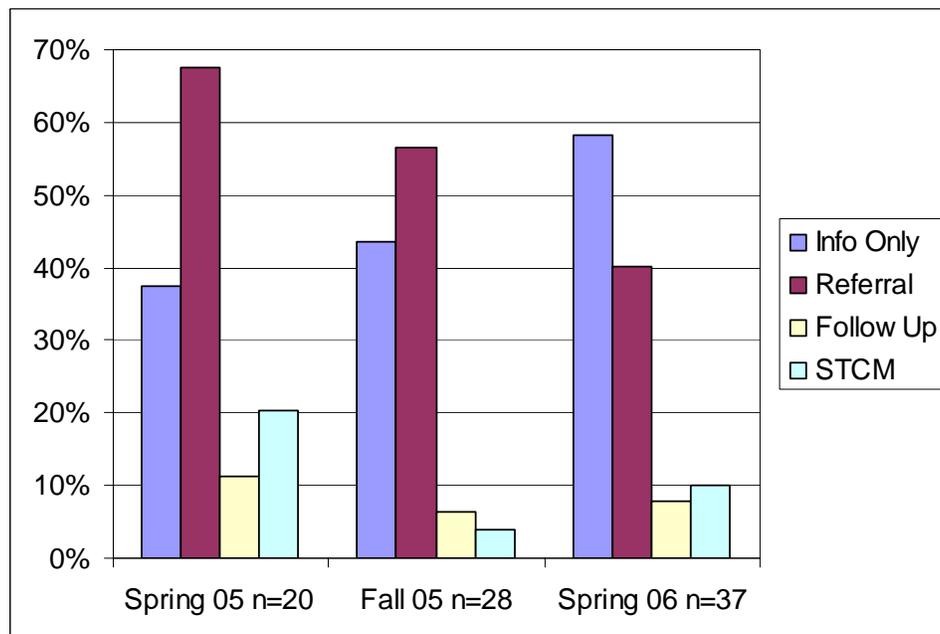
Exhibit 27: Average Percent of Contacts by Type of Information Provided – Related to LTC, Other than LTC and Medicare Part D



The establishment of comprehensive resource databases and the ability to efficiently share information among agencies to make the most effective referrals through enhanced IT/MIS and formal partnerships represented a different way of delivering I&R/A than “business as usual.” Most ADRCs established comprehensive Web-based resource databases for use by consumers, community providers and program staff (see IT/MIS section of the report for more detail). In this effort, many ADRCs also broadened their scope of I&R/A to include more information geared to the private pay population and persons with disabilities than the network traditionally offers. Many pilot sites also worked with key partners to cross-train and establish protocols for referrals and information-sharing (see Partnership section) which reduced the likelihood of “empty referrals” in which consumers bounce from agency to agency with no accountability for whether the individual receives the necessary information or assistance. In addition to being better equipped to make appropriate referrals, ADRCs increased their in-house capacity to provide comprehensive information, thereby reducing a lot of back-and-forth.

As *Exhibit 28* displays, the average percentage of information-only contacts increased from 37 percent in the first reporting period to 59 percent in the spring of 2006, while the average percentage of referrals decreased from 68 percent to 41 percent. The lower percentage of referrals is consistent with the experience of well-established ADRCs in Wisconsin in which the majority of contacts require basic long-term care information and assistance rather than program access.

Exhibit 28: Average Percent of Contacts by Type of Assistance Provided – Information Only, Referral, Follow Up, and Short Term Case Management



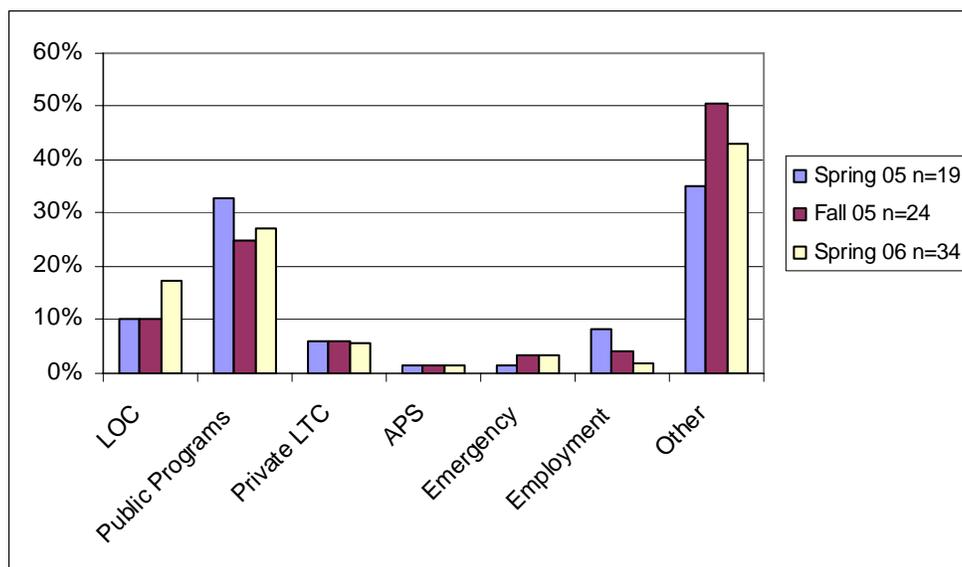
Note: STCM stands for Short-term case management

In addition to providing information and making a referral on behalf of consumers, ADRCs engaged in: 1) short-term case management (STCM), characterized as intensive assistance to stabilize a consumer's situation to enable the individual to remain in the community and 2) follow up to ensure that consumers' needs were met. Short-term case management often serves as a bridge connecting an individual with formal or informal long-term case management. It can be provided at different junctures or settings, such as in the home, upon hospital discharge, or in nursing facilities to assist individuals transitioning to the community. In La Crosse County, Wisconsin, for example, ADRC staff provide short-term case management until the particular situation has been stabilized. Once the situation is stabilized, the worker checks in with the consumer via telephone and maintains basic case management notes to track activity. If the individual needs long-term case management and does not qualify for state or Medicaid funded long-term case management, the ADRC may recommend that he or she privately purchase case management. Often a family member will assume general coordination of services and then call the ADRC when an issue or problem arises. In this case, consumers use the services of the ADRC numerous times along a continuum of service need.

Grantees also developed methods to ensure consumers' needs were met in making referrals. For example, South Carolina incorporated a simple case management design in their database system that allows an individual case manager to track consumer goals and that features a tickler that reminds the case manager when to complete the necessary tasks by a certain date.

As seen in *Exhibit 29*, the most common type of referral reported by pilots during all three reporting periods, aside from the "other" classification was "applications to public programs." Level of Care (LOC) referrals accounted for the next largest category of referrals and actually spiked in the third period which may indicate that pilot sites made progress in streamlining access. Other major types of referrals included employment, privately purchased LTC, emergency services, and Adult Protective Services (APS). The proportion of referrals for private LTC (roughly five percent of referrals) remained at the same level over time; the proportion of referrals for employment decreased each reporting period which may be indicative of some of the challenges pilot sites faced in connecting the aging and disability communities.

Exhibit 29: Average Percent of Contacts by Type of Referrals Made by Pilot Sites



ADRCs emerged as critical components of state and local communications networks that will invariably be accessed during emergencies and disasters. The early experience of ADRCs demonstrated that they are a ready infrastructure to provide essential information about the availability and location of life-saving resources such as food, shelter, and medical care for vulnerable populations. ADRCs played a critical role in supporting their communities as a result of the devastation of Hurricanes Katrina and Rita. When Hurricane Katrina hit Louisiana, the pilot ADRC was serving eight parishes in the south central region of the state, which did not include New Orleans. Nevertheless, state and local officials chose to use the ADRC toll-free number as the central resource in the state for information about evacuees, victims, and their families. As a result, the ADRC program expanded to cover 42 parishes in southern Louisiana. Between August and September 2005 during Hurricane Katrina and its aftermath, contacts to the Louisiana ADRC jumped from 107 to 486. Of those calls, 221 were identified as having come from evacuees and it is likely that the remaining 261 contacts were from individuals impacted by the hurricane. ADRCs in other states assisted in serving evacuees. For example, the ADRC pilot site in Atlanta, Georgia area contracted with Jewish Family and Career Services to provide case management services for individuals affected by Hurricane Katrina who located either temporarily or permanently to the metro Atlanta area.

Grantees are in the early stages of establishing systematic processes for empowering consumers and their families to make informed decisions about long-term support options. Much of the role of the ADRC involves information and referrals, but a significant goal of the ADRC initiative extends beyond traditional assistance to support individuals and families with informed decision making about long-term support options, or “options counseling.” Most grantees offer aspects of options counseling, often through follow-up or short term case management activities.

Assessing grantees’ accomplishments with providing options counseling presents a challenge. A survey of ADRC grantees conducted by the ADRC-TAE (Lewin and NASUA) in 2005 demonstrates that grantees interpret the term “options counseling” in a variety of ways. *Exhibit 30* represents the responses of 25 ADRC respondents at either the state or local level when asked the question, “What activities are included in Options Counseling?” While all respondents reported that options counseling constituted information and referral activities, only 60 percent reported that it constituted assessing an individual’s needs.

**Exhibit 30: Activities Included in Options Counseling
(ADRC-TAE Options Counseling Survey, Fall 2005)**

Activities Included in Options Counseling	Percent of Respondents
Information Giving	100%
Referral Giving	100%
Explaining Documentation for Applications	96%
Assistance Contacting Agency	92%
Advocating	92%
Making a Home Visit	76%
Providing Short-Term Case Management	68%
Conducting Functional Needs Assessment	60%
Conducting Consumer Reassessments	52%
Providing Long-Term Case Management	20%

Similarly, grantees provided a variety of responses when asked, “What distinguishes options counseling from other ADRC services?” However, as displayed in *Exhibit 31*, a majority of grantees reported similar topics discussed during options counseling, such as the range of long-term care settings (i.e., nursing homes, adult family care homes, assisted living facilities, board and care facilities). *Exhibit 32* shows the different kinds of topics that grantees reported discussing during options counseling. Other resources discussed with consumers included: senior centers, food stamps, drug discount programs, Medicaid eligibility agencies, support groups, and companion visits. Most grantees also mentioned that they linked with other agencies in their communities to provide options counseling. For example, grantees partnered with SHIP, Ombudsmen, legal programs, estate planning attorneys, school systems, independent living centers, and protection and advocacy programs to offer specialized options counseling.

**Exhibit 31: Topics Discussed During Options Counseling
(ADRC-TAE Options Counseling Survey, Fall 2005)**

Topics	Percent of Respondents
Home Health	96%
Personal Care	92%
Assisted Living	88%
Adult Day Care	88%
Homemaker	88%
Chore	88%
Nursing Home	84%
Adult Family Care Homes	60%
Escort	56%
Board & Care Facilities	52%
Other	56%

**Exhibit 32: Supported Services for In-home Long-term Care Services
(ADRC-TAE Options Counseling Survey, Fall 2005)**

Supported Services for In-home Long-term Care Services	Percent of Respondents
Transportation	96%
Nutrition Services	88%
Nutrition Counseling	56%
Special Diets	40%
Other	40%

A few grantees began to establish formal processes to refine and deliver options counseling through ADRCs. This activity often resulted from a state-driven initiative. Wisconsin used part of their ADRC grant money to develop an options counseling tool kit including a video which details the process of options counseling from both the consumer and staff perspective. New Hampshire created the position of Long-term Supports Counselors at the ADRC to provide pre-screening for eligibility as well as provide comprehensive options counseling to individuals who are looking for long-term supports, regardless of funding source or an individual's financial situation.

Despite the variability in the organization and delivery of options counseling, most grantees reported that supporting consumers in long-term support decision making is an on-going *process* which requires relationship development. Pilot sites reported that providing consumers with information may not be enough to help people come to important decisions on long-term care. Rather, it takes time, trust, and relationship building for people to work through the concomitant issues associated with LTC planning and obtaining resources. Over time, grantees will be able to assess their efforts in offering objective, reliable, and comprehensive information and supporting consumer

decision making. A few grantees have begun to measure these objectives through consumer satisfaction surveys.

ADRCs also provide assistance to individuals and families with planning for future LTC needs. Some of the 2003 and 2004 grantees hope to use ADRC supplemental funding to continue to implement some future planning initiatives. Some grantee states have received funding from HHS/AoA's Own Your Own Future Campaign to target individuals with a letter from the Governor encouraging LTC planning.¹³ ADRCs can play a critical role in this effort, providing information and support to those interested in planning for their future long-term care needs.

For many organizations involved in ADRCs, a focus on consumers who can privately finance services requires both procedural and cultural changes. Prior to ADRCs, many information and referral systems only included services provided by government and non-profit organizations. As a result, many ADRCs needed to develop defensible criteria for including for-profit providers in their databases, which may be more likely to serve consumers with higher incomes. Expanding beyond publicly financed consumers also requires ADRC staff to re-orient their approach to advising individuals about their options often necessitating changes in organizational culture.

Wisconsin Options Counseling Toolkit

Wisconsin has created an options counseling toolkit to continue to educate new and current ADRC pilots about the details of providing options counseling. The toolkit contains introductory material, a DVD, a series of recorded web casts, and discussion questions to support training new ADRC staff and provide opportunities to re-visit key aspects of the provision of this service.

A state-wide Information and Assistance workgroup developed, filmed, and produced a 37 minute DVD featuring an overview of the options counseling process. The DVD details discussions of why Information and Assistance is a central function of the ADRC and of how the process works through scenarios featuring county representatives and clients.

Currently available web casts cover legal decision making tools, residential/housing options, benefits for people with disabilities, etc. The web casts pair presentations by experts in subject matter important to long-term care options counseling with materials to retain for ongoing reference.

The toolkit will also be included as part of the materials provided for the next phase of statewide managed care expansion, currently in progress.

Wisconsin describes the options counseling in the following way:

¹³ ADRC grantees that received Own Your Own Future funding include: AR, ID, NV, NJ, VA, KS, MD, RI, WA, GA, MA, MI, and TX.

“The Relationship between I&A and Long-Term Care Options Counseling:

Long-term care options counseling is an extension of the I&A process. This service is focused on consumer education and is often provided when an individual is planning for or currently experiencing a life change. These life changes may include surviving a traumatic event such as a car accident, a medical event such as a stroke, or the transition from school-based services to programs for adults with disabilities. To be effective in providing this service, it is important to take the time needed to fully understand each individual’s strengths as well as needs. In order to ensure continuity in service delivery, options counseling can be provided by the same I&A Specialist that began the process with the individual.”

Source: Planning for Information and Assistance (I&A) Service. Aging and Disability Resource Center Development Technical Assistance: Wisconsin Department of Health and Family Services, Division of Disability and Elder Services. August 1, 2006.

Prevention and Health Promotion

Although not a grant requirement, the solicitation encouraged grantees to incorporate health promotion and disease prevention activities into the ADRC initiative. The emphasis on health promotion and disease prevention is to assist consumers in enhancing and sustaining a higher quality of life, reduce acute and long-term care crises, and lessen the burden of costly medical care. There are a number of terms related to health promotion and disease prevention that are commonly used to describe these types of activities, such as disease management, chronic disease self management, behavior change intervention, geriatric care management, and health management.

ADRCs’ role as community gateways to information, education and assistance position them well to offer health promotion and disease prevention. By identifying and linking consumers with individualized resources and tracking consumers over time, ADRCs have the ability to provide optimal support at the right time which may assist in preventing unnecessary institutionalization, chronic disability due to disease, and acute crises resulting in emergency room visits or hospitalization. In addition, partnerships with community health providers offer greater opportunity to collaborate on health promotion activities. This section describes the health promotion and disease prevention activities that grantees pursued during the three-year grant period.

Grantees have started to consider health promotion and disease prevention, but many grantees remain in the planning stages for such initiatives. As shown in *Exhibit 33*, a few grantees articulated prevention/health promotion goals in project work plans, evaluation plans, and/or Semi-annual Reports. Many grantees remain in the beginning stages of these initiatives. However, the first generation ADRCs in Wisconsin continue to engage in special prevention projects, such as fall prevention, nutrition screening, and preventative health care which are detailed in *Appendix C*.

The range of health promotion and disease prevention activities spans from partnering with health and wellness agencies, to engaging in specific ADRC initiatives, to participating in larger community-based initiatives such as the Chronic Care Management program in North Carolina. Several grantees made concerted efforts to include representatives from the Department of Public Health on the ADRC advisory boards.

Exhibit 33: Examples ADRC Health Promotion/ Disease Prevention Activities

State	Goal	Type of Model	Progress/Outcomes
New Jersey State-level	Evaluation plan goal: “Become the gateway to programs that connect consumers to basic human need resources: <i>work/volunteer opportunities, insurance programs, financial support services, health promotion/disease prevention, crisis intervention (county)</i> ”	Health Promotion	“A directory of disability services, telephone access programs, Social Security disability, as well as some disease specific materials have been added to the center’s collection of resource material.” April 2006 SART
California Pilot-level	“Develop a module on Falls Prevention to be housed on the ADRC website ¹⁴ to be tested with consumers, caregivers, physicians and other health and social service providers. Fall Prevention will be used as an initial focus to support effective community, client and provider education around effective problem identification and solution. “ SART April 2006	Disease Prevention	“Based on findings, learning strategy will be expanded to the broader array of chronic care conditions/problems faced by older and disabled adults.” April 2006 SART
Maine Pilot-level	ADRC partners with the Healthy Community Coalition (HCC), Franklin County	Health Promotion	HCC acts as the Coalition leader, providing staffing, dissemination of materials, and partnering in designing and delivering ADRC activities with Coalition partners.
Maryland Pilot-level	Grant to Howard County Office on Aging from Horizon Foundation (ADRC is intake point)	Chronic Disease Self Management	“Howard County is running the CDSM using the ADRC as the intake point. Consumers sign up for the prevention program and can be assessed for other programs and services. The ADRC is screening and attracting consumers by conducting community outreach around the program. As part of their outreach efforts, the ADRC collects information about needs that area consumers identify and informs them about both I&R and evidence-based programs. Maryland has invested in a video as well”.

¹⁴ Available at <http://sandiego.networkofcare.org/aging/library/articleList.cfm?cat=180> Accessed August 17, 2006.

State	Goal	Type of Model	Progress/Outcomes
North Carolina <i>State and pilot-levels</i>	The ADRC participates with the Chronic Care Management Steering Committee to help to ensure that I&R is part of the CCM model which brings together local health departments, hospitals, and social service agencies to better manage the care of 650,598 Medicaid enrollees.	Disease Management/ Chronic Care Self Management	The ADRC has presented, to the eight Community Care Networks, on the strengths of the aging network, Home and Community Block Grant Planning Committees and the role of I&A in chronic care management and self management. One of the Networks (Surry County) overlaps with the ADRC site and will be closely linked. Cumberland County, another CCM site, overlaps with the NC Carelink pilot and has a strong Aging I&A system. The State will be working directly with these two sites to support emerging models/partnerships related specifically to I&A and the aging network.
Massachusetts <i>(state or pilot)</i>	Massachusetts is involved with the Chronic Disease Consortium, which is a group of service providers who are trying to start a program based on the CDSM model.	Chronic Disease Self Management	The Consortium has had some trouble finding group leaders and getting them qualified as trainers, ADRC suggested reaching out to the disability community. There are around 40 people who come to Consortium meetings.

Some grantees use health promotion and disease prevention language to market ADRC services. A few grantees market health promotion and disease prevention to portray the focus of ADRCs in a more positive light. For example, in New Jersey, the term “healthy living” is used as opposed to “long-term care” in reference to ADRC offerings. In Maryland, the tagline is “Your Link to Health and Support Services.”

Grantees also report that showcasing health promotion/disease prevention to market the ADRC can attract consumers into the system who may benefit from other services the ADRC has to offer. For example, an ADRC in Wisconsin partnered with the local health department to purchase a bone scan machine. They offered free screenings and reported that the machine offered a mechanism for people to feel comfortable beginning a conversation with ADRC staff. Thus, many contacts began by discussing bone density and then moved into long-term care options counseling and/or futures planning.

Program-level Accomplishments & Outcomes

This section of the report describes the accomplishments and results of the ADRC initiative in relation to immediate program outcomes. It addresses the following areas:

- Strategic Partnerships
- ADRC Visibility and Public Awareness
- Outreach to Critical Pathways
- IT/MIS Infrastructure to Support ADRC Functions
- Streamlined Access
- Sustainability

Strategic Partnerships

As described earlier in this report, the ADRC grant requires that grantees serve the elderly population and at least one population from the disability community, and that access to all publicly-funded long-term care programs serving aged and disabled populations, including OAA, state-funded, and Medicaid programs, be integrated or closely coordinated across the organizations involved. Serving individuals across populations and integrating or coordinating such a broad set of services requires substantial cooperation and contribution from state and local organizations.

This section describes grantee accomplishments and outcomes in developing strategic partnerships to fulfill the information, assistance, and access functions of ADRCs in general, and analyzes partnership at three levels: (1) Partnership among core entities – i.e., the state’s main Aging, Disability, and Medicaid entities; (2) Partnership with community-based organizations, including providers, advocacy organizations and public/private partnerships; and (3) Partnership between the ADRC state grantee and the ADRC pilot.

Grantees invested significant time and energy in strengthening and building partnerships with a broad spectrum of agencies and providers. As of April 2006, there were a total of 211 partners across the twenty-four 2003 and 2004 grantees at the state level, and 282 partners across the 51 pilot sites at the local level (*Exhibit 34*). The states with the highest number of

partners were Pennsylvania with 60, California with 55, and New Jersey and West Virginia with more than 30 partners each. Overall, ADRCs averaged 20 partners per grantee.

**Exhibit 34: State and Local Partnerships
FY 2003 and 2004 Grantees, April 2006**

	State Level N=24	Pilot Site Level N=51
Total No. of Partnerships	211	282
Avg. No. of Partners	8.8	5.5
Range of Partners	1-23	1-27

Grantees reported that rather than approaching partnership building as one step or a single grant activity, they needed to involve stakeholders from initial planning through implementation. Most grantees began ADRC program development by assessing which stakeholders were critical to involve in the design of the ADRC and inviting them to partner. At the state level, grantees worked to develop or strengthen partnerships between the State Unit on Aging, State Medicaid Office, and agencies that operate disability services programs (e.g., State Independent Living Council). Most pilot sites developed several local level partnerships and some benefited from the partnerships developed at the state level that extended to them.

Partnership manifested differently across the grantees, with data sharing and formal protocols/MOUs as the most common components of partnership. Of the different activities, data sharing was the most common activity of ADRC partnerships (42 percent of partnerships at the state level, 44 percent at the local level) and co-location of staff was the least common activity (13 percent of partnerships at the state level, 16 percent of partnerships at the local level). ADRC partnerships also involved developing formal written agreements for working with a partner (29 percent at state level, 28 percent at local level); conducting joint training activities (19 percent state, 25 percent local); and jointly hosting or sponsoring events or programs for consumers (18 percent state, 23 percent local). *Exhibit 35* displays partnership activities reported by grantees in the SART.

**Exhibit 35: Proportion of Partners with Formal Agreements
and Other Components of Partnership, April 2006**

	State Level (n=211 partnerships in 24 States)	Pilot Site Level (n=288 partnerships in 51 Pilots)
Formal Protocols/MOUs	29%	28%
Co-location of Staff at Local Level	13%	16%
Information Sharing	42%	44%
Joint Training	19%	25%
Joint Sponsorship of Programs	18%	23%

In general, the most commonly reported benefits of strategic partnership were being able to reach different and broader audiences, support sustainability, and offer a stronger network of

services than existed without partnerships in place. Partners also serve on ADRC advisory committees, assist ADRCs in developing and implementing outreach and marketing strategies, and refer their own clients and constituents to the ADRC. Some grantees also involved partners in program evaluation activities.

Grantees reported that, in some cases, partnerships led to unexpected and positive outcomes. For example, one South Carolina pilot site was approached by a faith-based organization interested in starting a medication assistance program (MAP) in the community to help consumers access discounted prescription drugs from private pharmaceutical companies. The pilot site invited the MAP to share office space with the ADRC. The MAP has reportedly been enormously successful at recruiting volunteers, who are now familiar with the ADRC and its services and who regularly refer the consumers they serve to the ADRC. The MAP has also built strong connections with physicians' offices in the community by assisting their patients in accessing their prescribed medications, raising the visibility of the ADRC along this critical pathway in the process.

Aging and Disability Organization Partnerships

The capacity and focus areas of the grantees and pilot sites prior to receiving the grant influenced the types of partnerships developed to implement the ADRC program. While over 90 percent of the 2003 and 2004 grants were awarded to State Units on Aging, only a slight majority of their pilot sites (53 percent) focused exclusively on serving the aging population prior to becoming an ADRC pilot (*Exhibit 36*). In Alaska, Centers for Independent Living operate the pilot sites. Almost 10 percent of pilot sites used more than one organization to develop the ADRC partnership, characterized as joint efforts involving both an aging-focused and a disability-focused organization. For example, a partnership between the Atlanta Regional Commission (an AAA) and the Atlanta Alliance on Developmental Disabilities operate Atlanta's ADRC and Massachusetts' ADRC is based on a partnership between an Independent Living Center (ILC) and an Aging Services Access Point. Another 25 percent of pilot sites are operated by a single organization that already served both aging and disability populations prior to receiving the grant.

Exhibit 36: Pilot Site Population Focus Prior to Grant and Aging and Disability Partnerships after Grant, FY 2003 and 2004 Grantees (N = 51 Pilots)

Pilot Site Population Focus Prior to ADRC Grant	No. of Pilot Sites	At Least One Aging Partner Reported	Formal Agreement with Aging Partner	At Least One Disability Partner Reported	Formal Agreement with Disability Partner
Aging Focused (AAA or other Aging Organization)	27	19	9	17	15
Disability Focused (ILC or other Disability Organization)	5	5	5	5	5

Pilot Site Population Focus Prior to ADRC Grant	No. of Pilot Sites	At Least One Aging Partner Reported	Formal Agreement with Aging Partner	At Least One Disability Partner Reported	Formal Agreement with Disability Partner
Focused on Aging and Disability Populations Through Two Separate Organizations (now partnering to operate ADRC)	6	6	1	6	2
One Organization Focused on Aging and Disability	13	10	1	13	6
Total	51	40	16	41	28

Given that so many pilot sites are operated by aging-focused organizations, it is not surprising then that over 80 percent of pilot sites reported at least one disability-focused partner, such as a Center for Independent Living, disability council or task force, or advocacy organization, at either the state or local level.¹⁵ Over 78 percent of pilot sites also reported at least one outside aging-focused partner at either the state or local level such as an AAA, senior center, AARP, or other advocacy group.¹⁶ Of those that reported having at least one disability partner, 68 percent had a formal agreement with a disability partner, compared to 40 percent of those with aging partners.

Many grantees experienced challenges building strong partnerships between the aging and disability networks because of differences in service philosophy and historic divisions between the two service systems at both the state and local level. One of the most commonly reported barriers was developing a working partnership between the main aging entity and main disability entity. Grantees reported that it takes commitment and patience on the part of both aging and disability organizations to overcome cultural and organizational differences and to work together productively.

¹⁵ Among those with at least one disability-focused partner, the median number of disability-focused partners is three.

¹⁶ Among those with at least one aging-focused partner, the median number of aging-focused partners is three.

Examples of Aging and Disability Networks Working Together

Massachusetts Disability and Aging Cross Training. Massachusetts' ADRC model is based on an equal partnership between an Independent Living Center and an Aging Services organization. The two organizations maintain their own identities but through membership in the consortium, they partner to increase and streamline access to services for older adults and people with disabilities in the community. Staff in both organizations have been cross-trained about the different service philosophies of the aging network and disability network, the needs and values of the different populations, and the different resources available to them. Staff in both organizations report that through this partnership, they have developed a new understanding and appreciation for the different populations, as well as the two service systems and their philosophies has been achieved in both partner organizations. The partnership has created a safe learning environment in which staff from both organizations can exchange ideas, make mistakes, be forgiven, and keep working toward common goals.

Maine's Partnership with Independent Living Center. Based on ADRC connections, the Eastern Area Agency on Aging's Executive Director developed a partnership with Alpha One (an Independent Living Center) to provide financial assistance for at-home installation services for wheelchair ramps for elders with physical disabilities. Alpha One had been pursuing banks and other financial entities for support, but through an ADRC presentation learned of opportunities for people with physical disabilities to qualify for small grants that need not be repaid. At least three consumers have been served through these grants since late February 2006, meaning easier and direct access and shorter time in securing such assistance.

North Carolina's Partnership with Family Support 360 Grant. Family Support 360 (FS 360) is a grant initiative of the U.S. DHHS Administration of Children and Families and Administration on Developmental Disabilities, designed to create one-stop centers that assist families of individuals with developmental disabilities. In North Carolina, the Family Support Network recently transferred their pilot site from eastern North Carolina to Forsyth County (also an ADRC pilot site county). ADRC staff at the state and local levels have attended FS 360 grant collaborative team meetings, and the evaluators of the ADRC and FS 360 grant have met to determine commonalities and to learn from each other. The state ADRC team and the Family Support Network plan to meet jointly with their pilot sites to more fully develop collaborative activities. They have already made plans to partner on serving grandparents raising grandchildren and providing I&R.

Despite the challenges they faced in coordinating program development activities, grantees' experience showed that there are many opportunities when aging and disability networks partner and that the different resources, skills, and strengths that each network brings can be leveraged to provide better access and better services for consumers. Several examples of successful aging and disability partnerships are highlighted in the text box above.

Medicaid

As part of the overall federal vision, ADRCs are to provide the following functions to enhance access to long-term support: (a) one-stop access to all publicly funded programs for community and institutional long-term support services administered by the state under Medicaid; (b) programmatic Eligibility Determination (level of care determination) for publicly funded long-term support services; and (c) Medicaid Financial Eligibility Determination that is either integrated or so closely coordinated with the Resource Center that each individual applicant experiences a seamless interaction. Achieving these goals requires strong partnerships between the grantee and Medicaid at the state and local levels.

The structure of state government and the type of Medicaid functions that were being performed at the pilot level prior to the grant influenced the way grantees approached their partnerships with Medicaid and role that Medicaid played in the ADRC initiative. As shown in *Exhibit 37*, all 24 grantees partnered with Medicaid to some extent, at the state or local levels or both. Overall, 13 grantees have formal agreements with Medicaid at either the state or local level. For 10 grantees, the Medicaid agency and the grantee agency are in the same umbrella department at the state level. In these states, Medicaid staff played an active role in grant planning and implementation, often without the need for a formal agreement.

Exhibit 37: Integration of Grantee Agency with Medicaid Agency Prior to ADRC Grant and Partnership Post-ADRC (n = 24 States)

Level of Integration Prior to ADRC	No.	State	Post-ADRC Partnership					
			Formal Agreement at State Level	Formal Agreement at Pilot Level	Formal Agreement at Either Level	Co-location at Pilot Level	Info Sharing	Joint Training
Different Departments at State Level and No Integration at Pilot Level	8	AK, FL, IA, LA, NM, NC, SC, WV	4	2	4	1	6	3
Same Department at State Level but No Integration at Pilot Level	3	ME, NH, CNMI	2	0	2	1	3	1
Different Departments at State Level but Co-located at Pilot Level	6	CA (1 Pilot), PA, NJ, IL, MD, GA	3	3	4	6	4	1

Level of Integration Prior to ADRC	No.	State	Post-ADRC Partnership					
			Formal Agreement at State Level	Formal Agreement at Pilot Level	Formal Agreement at Either Level	Co-location at Pilot Level	Info Sharing	Joint Training
Same Department at State Level and Integration at Pilot Level	7	IN, MT, WI, MA, MN, AR, RI	3	1	3	7	6	0
Total	24		11	6	13	14	19	5

States where the grantee agency and Medicaid are in separate departments typically experienced challenges engaging Medicaid leadership and staff in grant activities, at least in the initial phases of planning and implementation. However, at least eight of the grantees that are not in the same department as their Medicaid agencies have enjoyed a high degree of involvement from Medicaid facilitated by a formal agreement. For example, New Jersey’s Medicaid Director regularly attends ADRC state management meetings and Medicaid staff play leading roles in designing new assessment and eligibility determination processes. The Pennsylvania grantee coordinates closely with Medicaid Agency staff to align the ADRC grant with other state rebalancing efforts. The Florida grantee established formal agreements with Medicaid that facilitated co-location of Medicaid staff in one pilot site and data sharing across all sites.

Some grantees strategically selected ADRC pilot sites that had prior experience with Medicaid programs and eligibility processes. Nine grantees chose pilot sites that were already performing case management for Elderly and/or Disabled Medicaid waivers. Six states had already implemented “single points of entry” at their pilot sites for at least one Medicaid waiver program. However, for eight grantees, the grantee agency and the Medicaid Agency are in different departments at the state level and no Medicaid functions had been performed at the pilot site level prior to the grant. Of these eight grantees, four have since established formal relationships with Medicaid at either the state or pilot site level, one has co-located eligibility workers at the pilot site, six are now sharing client information with Medicaid, and three are conducting joint trainings. In addition, in many cases, the ADRC grant has assisted states in expanding on or continuing long-term care reform initiatives that started in the Medicaid agency, such as Real Choice Systems Change initiatives.

Partnerships with Other Community-based Providers

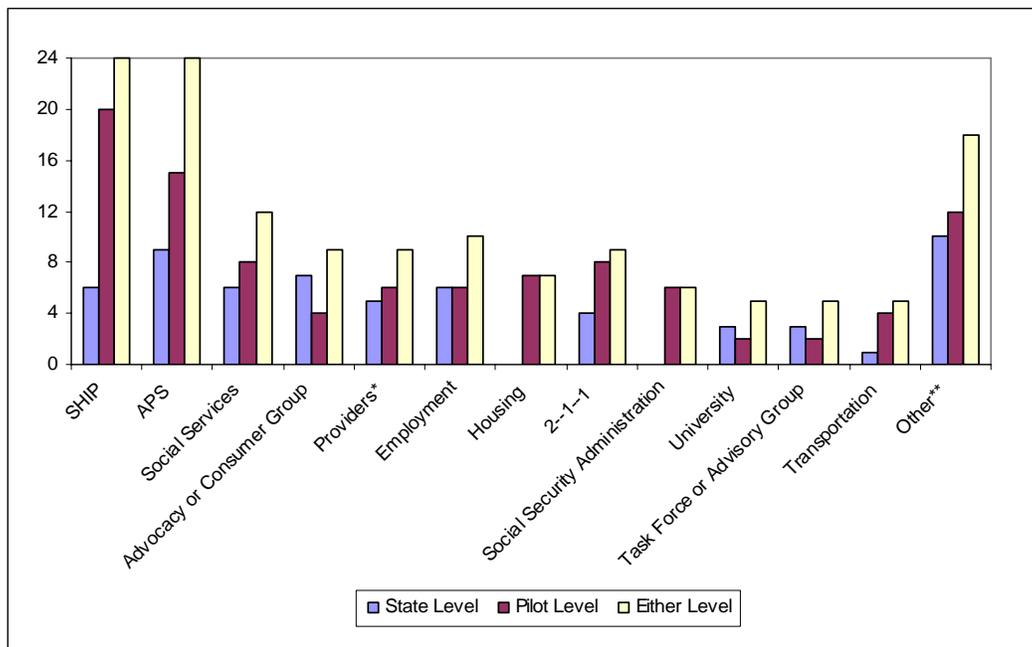
Throughout the first three years of the ADRC grant program, grantees strategically partnered with an array of provider and community-based organizations, with State Health Insurance Assistance Program (SHIP) and Adult Protective Services (APS) being the most common type of partner. Aging-focused, disability-focused, SHIP and APS partners combined represented over half of all ADRC partners. The grant announcement specifically encouraged grantees to partner with SHIP. The majority of pilot sites (64 percent) are co-located with SHIP. In 17 states, the

ADRC and the SHIP program are in the same agency at the state level. In the remaining seven states, ADRCs and SHIPS are partnering at either the state or local levels. Co-location and partnership with SHIP has been particularly important in the last year, when ADRCs and SHIP collaborated closely to provide assistance with Medicare Part D.

ADRCs are required to be able to link consumers to emergency services, including APS. Of the 24 grantees, 16 are in the same department at the state level as the APS program. Representatives from APS serve on grantee Advisory Committees, and ADRCs refer consumers to APS services as needed. Of the 51 pilot sites, 23 are co-located with APS and the remainder are partnering with APS at either the state or pilot level. In some cases, states worked out formal referral protocols with APS and worked to train staff on correct APS procedures. For example, New Hampshire and Wisconsin provided training to ADRC staff on recognizing and handling emergency cases appropriately.

In addition, grantees partnered with employment, housing, and transportation service providers and other social and human service organizations, including local and state health boards, rural services, community centers, and community assistance networks (*Exhibit 38*).

Exhibit 38: Number of Grantees Partnering with Different Types of Partners at State and Local Levels



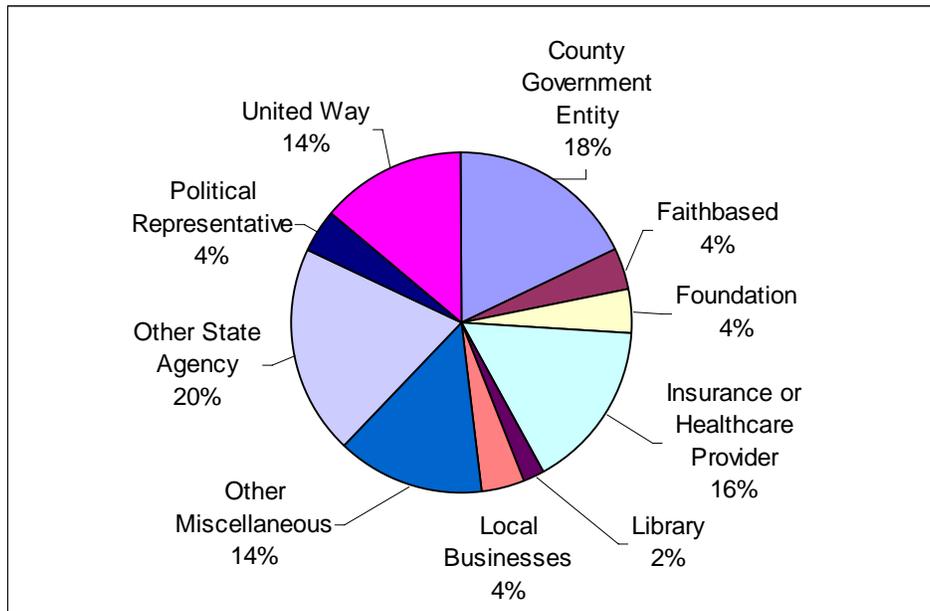
Note: Providers include hospitals, home health agencies, nursing facilities, and provider associations. "Other" includes United Ways, County Health Departments, Faith-based organizations, and others.

- **Critical pathway providers.** Grantees made a special effort to partner with “critical pathway” providers – common pathways for consumers to the long-term care system, both community-based and institutional. Examples of critical pathway providers include hospitals and discharge planners, doctors’ offices, rehabilitation nursing homes, and intake agencies for home and community-based services. Grantee outreach approaches to critical

pathway providers are described in more detail in the “Outreach to Critical Pathways” section of this report.

- **Non-profit and for-profit sector.** ADRCs also involved a variety of non-profit and for-profit private sector partners to strengthen their activities (*Exhibit 39*).

Exhibit 39: Breakdown of Types of Partners Included in “Other” Category



Private sector partners often served on the ADRC advisory board and were reportedly a valuable asset to the ADRC. For instance, some private partners operate entities where individuals with long-term care support needs are likely to come on a regular basis, such as grocery stores, banks, and libraries; ADRCs leave marketing materials and brochures in these locations for individuals to take home. In some states, ADRCs placed electronic Internet kiosks in public places where consumers can search the Resource Directory to find services and health information (see IT/MIS section of the report for more detail).

Non-profit agencies assisted with in-kind support or sharing costs for certain activities. For example, Minnesota, New Mexico, and North Carolina partnered with AARP to recruit volunteers who can assist with ADRC counseling. Illinois partnered with AARP tax preparation volunteers who help ADRC consumers file taxes. For-profit businesses were also strategic partners for a minority of grantees and have been particularly valuable in helping to disseminate information to privately paying consumers.

For-profit businesses also contributed financially to ADRC programs. In Virginia (FY 2005 grantee), ADRC pilots are operated using a public-private partnership model that incorporates local multi-disciplinary coalitions of public-private service providers. Each pilot site community receives in-kind public relations expertise from the Dominion Power (a Virginia power company) corporate public relations office. Dominion is also providing a \$50,000 cash match for the project. ADRCs have also received grants United Ways, banks, hospitals, and

local health systems. At least one grantee has made a particular effort to include foundation representatives on their local Advisory Committees.

At least nine pilot sites developed partnerships with local 2-1-1 operators, an Information and Referral service that connects people with health and human services in their communities. Where there is both a 2-1-1 and an ADRC operating in the same region, the ADRC typically maintains a separate telephone number and the two entities make referrals to one another. At least five ADRCs have formal agreements with the local 2-1-1 that outline how each entity will share resource databases and/or make mutual referrals. A few pilot sites have made arrangements for 2-1-1 to answer after-hours and weekend calls. In this case, consumers who call the ADRC number after business hours are routed directly to 2-1-1. ADRCs reported that 2-1-1 staff have been pleased to refer callers that need more detailed information about aging and disability services. See text box below for specific examples of partnerships with 2-1-1.

Some grantees report that there has been some concern in their states that the ADRC and 2-1-1 offer duplicative services and might potentially compete for limited resources. However, for the most part, states where 2-1-1 and ADRCs both operate have reported that the two entities play very different roles in the community. 2-1-1 is an easy-to-remember number for consumers, and another potential pathway into the ADRC and long-term care system. While 2-1-1 differs across the country (i.e., some offer general I&R, some are crisis responders, some offer both) they do not specialize in long-term care. ADRCs are positioned to go much more in depth with callers and have expertise in aging and disability services. In addition to basic I&R, ADRCs often provide supplemental information given the caller's circumstances that may not be directly asked for, make preliminary assessments on the phone, offer referrals, conduct long-term support options and benefits counseling, and provide follow-up and short-term case-management.

Examples of Partnership with 2-1-1

New Jersey's Atlantic County pilot site (2003 grantee) operates both the 2-1-1 and the ADRC. In addition, the grantee and NJ 2-1-1 have partnered at the state level to conduct orientation sessions for the two pilot counties about both initiatives as well as for the other counties that are served by NJ 2-1-1 call centers.

Iowa (2004 grantee) is building a virtual ADRC based on the existing I&R capacity of 2-1-1, the aging network and the disability network. In Iowa, 2-1-1 is statewide and offers information tailored toward the general public, while the aging and disability I&R systems maintain the specific information about programs and agencies that provide services to their populations. All the systems have some overlap but each has their own unique set of data. Iowa is establishing MOUs between all the I&R services to assure that referrals are made to the appropriate I&R. This type of relationship helps to eliminate duplication because the clients are directed to the appropriate source versus each source answering the same question. They plan for the ADRC Website to allow web users to access all three databases.

In **Idaho** (2005 grantee), the 211 CareLine functions as the single point of entry to long-term care services. The CareLine is a toll-free, bilingual service available to link consumers with health or human service providers and programs. Consumers will be connected to an Integrated Access Team consisting of four full time staff persons serving all three communities. A Community Resource Team, composed of volunteers from local agencies, will be established in each of three pilot communities, to provide information and assistance to the Integrated Access Team and consumer as needed.

ADRC Visibility and Public Awareness

The federal vision is to have ADRCs in every community serving as *highly visible and trusted* places. Visibility can be defined as the extent to which the public is aware of the existence and functions of the Resource Center. Grantees are required to establish measurable performance goals for their programs, including the goal of *visibility*. In addition, public awareness is a component of the "Information and Awareness" function of an ADRC that all grantees are required to implement.

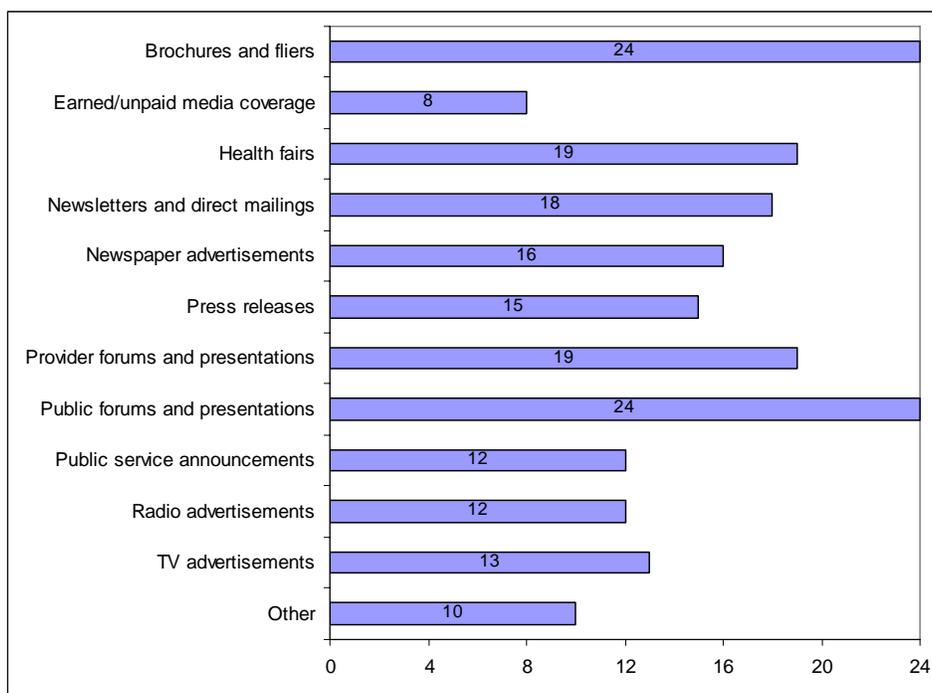
Increasing the visibility and awareness of the ADRC can be achieved through a variety of marketing strategies and activities, such as developing outreach materials, logos, and taglines; launching or enhancing a Web-based resource directory that includes both non-profit and for-profit providers; or developing a marketing plan. Successful branding and marketing may assist grantees in promoting ADRCs as a trusted source of information and assistance, where consumers can receive a full range of long-term support options and information to public long-term support programs and benefits.

This section describes the range of methods and strategies grantees employed to market the ADRC to different populations and includes an analysis of the relationship between the program model and how the ADRC was branded.

Grantees and their pilot sites employed a variety of strategies to successfully market ADRCs. Grantees reported using between three and twelve different marketing methods each, with

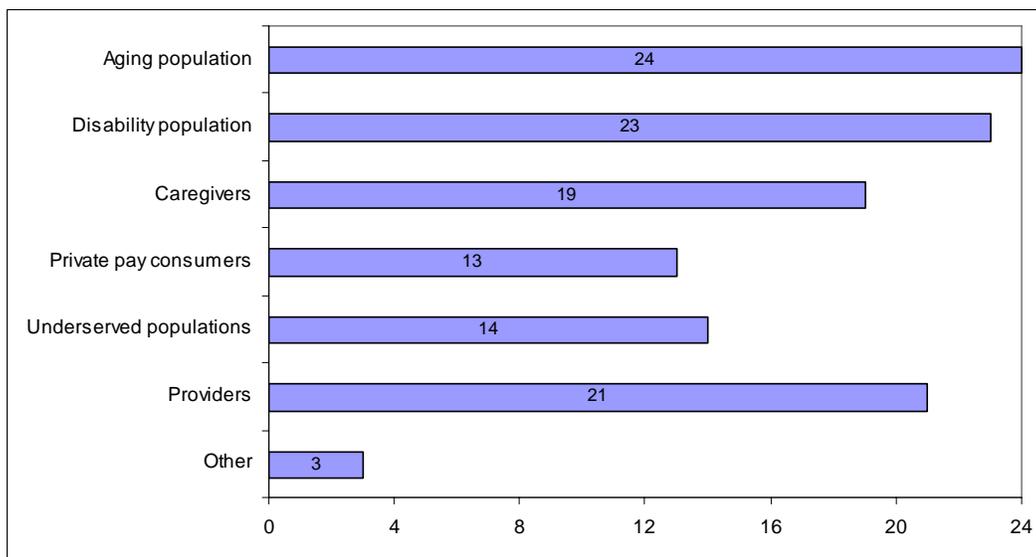
most grantees using a combination of eight. Pilot sites, in particular, were actively engaged in marketing activities. *Exhibit 40* presents the frequency of marketing methods as reported at the state level. In addition to the specific methods grantees were prompted to report about, 40 percent used “other” marketing activities and strategies to promote and brand the ADRC— other activities included advertising on billboards and posters, disseminating promotional souvenirs (e.g., cups, magnets, pens, business cards, etc.), and developing CDs and DVDs for distribution.

Exhibit 40: Number of Grantees Using Different Marketing and Outreach Activities (N=24 Grantees)



Grantees tailored some of their marketing activities for particular audiences, with aging, disability and provider populations as the most commonly targeted audiences. Nearly all grantees developed marketing materials specifically for aging and disability populations. Providers along critical pathways were specifically targeted by 87 percent of grantees (21), and caregivers by 80 percent of grantees (19) (*Exhibit 41*). In addition, several states chose to design marketing materials and activities to reach historically underserved populations as well as consumers with the ability to pay privately for services. “Other” audiences that grantees specifically reached out to included advocacy organizations, minority groups, and state legislators.

Exhibit 41: Number of Grantees Tailoring Marketing Strategies to Specific Populations (N = 24 Grantees)



The extensive effort grantees made to market the ADRC to providers was important for reaching “critical pathway” providers as evidenced by the number of referrals these providers made to the ADRC. The most common sources of referrals to ADRCs, accounting for an average of 55 percent of all referrals across reporting pilot sites, were along critical pathways, including HCBS or social services organizations, doctors or health professionals, hospitals, nursing facilities, ICFs/MR, Senior Centers, ILCs, and alternative residential centers (see *Outreach to Critical Pathways* section of the report for more detail).

Friends and neighbors referred more than a quarter of all ADRC consumers. Overall, marketing materials and efforts such as brochures, websites, and radio, television and newspaper ads account for approximately 17 percent of all referral sources. Sources of referrals identified as ‘other’ by grantees include libraries, AARP, disaster response agencies, government agencies, first responders, telephone books, and public utilities who serve as gatekeepers.

Overall, 60 percent of the 2003 and 2004 grantees are using a name other than “Aging and Disability Resource Center” for their ADRCs. Twelve grantees chose and branded unique names for their ADRCs, and three grantees created new names by modifying existing brand names in their states. For example, New Hampshire built on their existing I&R system called *ServiceLink* to create *ServiceLink Resource Centers*. Several grantees, including Iowa, Maryland, Louisiana and Rhode Island, hired marketing consultants and conducted stakeholder surveys to assist them with the process of choosing program names and tag lines that would resonate and appeal to consumers in their communities. Rather than using the term *center*, three states chose the term *point* and two chose *station*. Two grantees replaced the term *resource* with *information*. Several grantees departed from the concept of a *center* by using terms like *network*, *connection*, and *coalition*. Six grantees incorporated the term *link* into their program’s name or tag line. In all cases where a new name was chosen, states use the same basic name for all their pilot sites. See *Exhibit 42* for a list of the ADRC names and “tag lines”.

Exhibit 42: ADRC Names and Tag Lines

State	No. of Pilot Sites	ADRC Public Name	Tag Lines
Alaska	5	Aging and Disability Resource Center (all 5 pilot sites)	Information for Alaskans
Arkansas	1	Aging and Disability Resource Center	
California	2	Aging and Disability Resource Center	
Florida	3	Aging and Disability Resource Center of (County name)	Pointing You in the Right Direction!
Georgia	2	Georgia's Aging and Disability Resource Connection	
Illinois	2	Starting Point	Your Aging and Disability Resource Center
Indiana	2	Link-Age	Aging Resource Connection - the Point for All the Answers
Iowa	1	LifeLongLinks	Connecting You to Iowa's Aging and Disability Resources
Louisiana	5	Aging and Disability Information Station	Louisiana Answers
Maine	1	DASH Network (Disability and Aging Hotline)	Getting You Connected to Services
Maryland	2	Maryland Access Point (MAP) (County name)	Your Link to Health and Support Services
Massachusetts	2	Aging & Disability Resource Consortium of Northeastern Massachusetts Partnering orgs: Elder Services of Merrimack Valley and Northeast Independent Living Program continue to use these names publicly.	
Minnesota	1	Minnesota Help Network (Senior Linkage Line, Disability Linkage Line, and MinnesotaHelp.info)	Connecting Minnesotans to Community Resources
Montana	1	Yellowstone County Council on Aging Resource Center	
New Hampshire	5	Service Link Resource Center of (County name)	Connections for Independent Living and Healthy Aging
New Jersey	2	New Jersey EASE Aging and Disability Resource Connection	Your Doorway to Information and Assistance
New Mexico	1	Aging and Disability Resource Center	
North Carolina	2	(County name) Aging and Disability Resource Connection	

State	No. of Pilot Sites	ADRC Public Name	Tag Lines
Northern Mariana Islands	1	Aging and Disability Resource Center	
Pennsylvania	2	(County name) Link to Aging and Disability Resources	
Rhode Island	1	The POINT	Rhode Island's Resource Place for Seniors and Adults with Disabilities
South Carolina	2	Aging and Disability Information Center	SC Access - A Program of The Lower Savannah Council of Governments
West Virginia	2	ADRC of (County name)	
Wisconsin	3 (new and open)	Aging and Disability Resource Center of (County name) ¹⁷	

Grantees selected names reflective of the chosen ADRC program structure and design. Every one of the pilot sites with decentralized structures named their ADRCs using words like *connection, network or link*, whereas centralized models more frequently chose names with words such as *center, point or station (Exhibit 43)*. It is important to note that these words were chosen for different reasons and have meanings that are unique to the grantees' environmental context. For example, Maryland chose Maryland Access Point, which connotes a physical place. However, they deliberately chose this name and use the acronym MAP to communicate that the ADRC can help consumers get where they want to go. This message is enforced by their logo that includes an image of a bridge.

Similarly, for Pennsylvania's two pilot sites that are somewhat centralized (as opposed to completely centralized), choosing the word *Link* for their name reflects their strong commitment to partnership building at the local level. In fact, their two sites have more formal partnerships in place with different organizations in the community than any of the other ADRC pilot sites. Interestingly, the percentage of virtual and physical models was fairly evenly mixed in comparing the terms used to represent their initiatives.

¹⁷ Some of Wisconsin's original nine ADRC sites do not use this naming convention.

Exhibit 43: Key Words Chosen by Structure Type

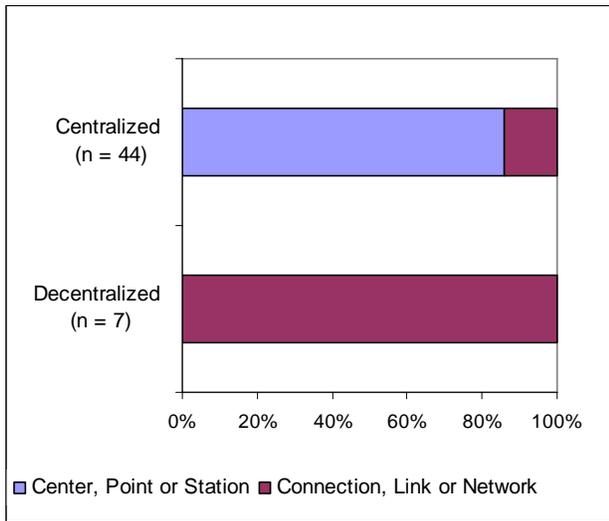
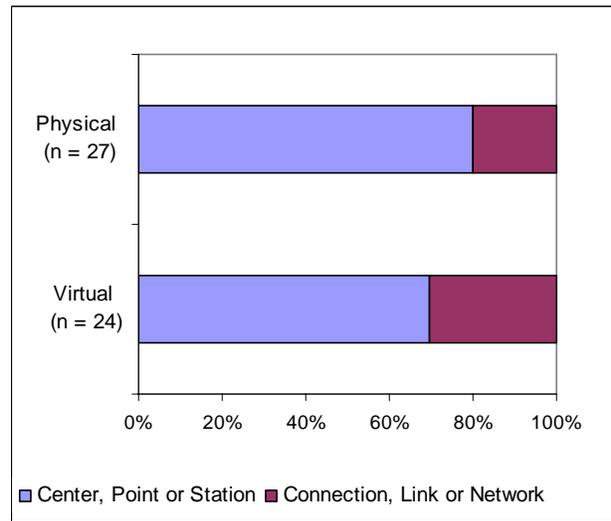


Exhibit 44: Key Words Chosen by Access Type



Most grantees marketed and publicized the ADRC as a brand new entity. While most grantees were building pilot sites within pre-existing organizations, such as Area Agencies on Aging, county government entities, and Centers for Independent Living, 17 of the 24 grantees (70 percent) decided to publicize their ADRC initiative as a new entity with its own name and identity. Five grantees chose not to market the ADRC as a new entity, but to advertise the ADRC initiative as an *enhancement* to existing entities. For example, Massachusetts decided that the two lead organizations piloting the ADRC were so well-known and well-trusted in the community that changing their names would not make sense. Rather, their marketing materials emphasize that enhanced services are available through a new partnership between these well-established organizations.

Those grantees that chose words implying a physical place, such as *center, point* or *station*, tended to market their initiatives as new entities, while almost half of those who used words like *connection* or *network* marketed their ADRCs as enhancements to existing organizations. Two grantees chose not to advertise the ADRC initiative and instead expanded and increased their marketing efforts to raise the visibility of existing entities.

Exhibit 45: Marketing New or Enhanced Entities by Key Words Chosen (n = 24 States)

Key Words in Name	New	Enhanced	Total
Center, Point or Station	12	1	13
Connection, Link or Network	5	4	9
No Unique Branding	0	2	2
Total	17	7	24

Grantees and pilot sites collaborated on marketing efforts. While many states took the lead on branding the initiative statewide, pilot sites were closely involved in planning and implementing marketing activities.

Examples of Marketing Strategies at the Grantee and Pilot Levels

Maryland – Maryland Access Point. At the state level, the grantee was responsible for developing a marketing campaign to rename the project, selecting two website addresses, determine a target audience, and issuing a request for proposal for a marketing and outreach contractor. A marketing firm assisted the Maryland Access Point (MAP) in developing a logo and tagline appropriate and reflective of the program. Additionally, it developed a statewide marketing and outreach plan that was comprehensive to educate the public, targeted populations and internal stakeholders about MAP. The grantee also organized and conducted consumer focus groups and surveys in order to gather input from pilot sites and key stakeholders to assist in renaming the initial name of the ADRC program. At the pilot site level, pilots were responsible for outreach activities. These activities included attending health fairs; presenting at long-term care facilities; creating flyers and brochures; direct mailings to hospitals, physician’s offices; and advertisements in local newspapers and newsletters, among other activities. Maryland’s most successful marketing activities were reportedly presentations to HCBS and senior centers, which accounted for 20 percent and 14 percent of referrals made to the pilot sites respectively.

Louisiana – Information Station. Louisiana had a unique marketing approach which included developing a tagline and organizing a campaign to promote the opening of Louisiana’s ADRC. The campaign involved outreach and mailed invitations to local elected officials and advisory committee members. Louisiana also ran advertisements through the local media. Specifically, ads were placed in local newspapers, a string of radio public service announcements were broadcasted, and a paid TV PSA was aired during the day of opening. They coordinated demonstrations and presentations of the new ADRC website to key stakeholders and long-term care agencies. Louisiana’s most successful marketing activities included public and private presentations to HCBS organizations and senior centers, TV PSA, the Internet, and activities marked as ‘other.’ On average, pilot sites reported receiving 27 percent and 12 percent of referrals from HCBS organizations and senior centers. The internet and TV PSA accounted for 18 percent and 16 percent of referrals.

Georgia – The Aging and Disability Resource Connection. Georgia, at the pilot site level, was responsible for developing a marketing plan and branding the ADRC, with the assistance of a marketing consulting firm. The marketing plans goal was to push the awareness and use of the ADRC through existing channels, including professional referral networks, business referral sources, and consumers and caregivers who are currently in the system. The pilot site developed flyers and brochures, and incorporated the use of CD’s and DVD’s to distribute to providers, board members, and consumers. Marketing and outreach activities also focused on individuals with brain and spinal cord injuries. The pilot site is also building partnerships with local TV stations to expand its outreach. Georgia’s marketing strategy has enabled to ADRC to reach groups outside its target population, such as grandparents raising children, caregiver groups, hospitals, school transition teams and consumer groups. On average, the pilot site reported receiving 45 percent and 17 percent of their referrals from HCBS organizations and family members.

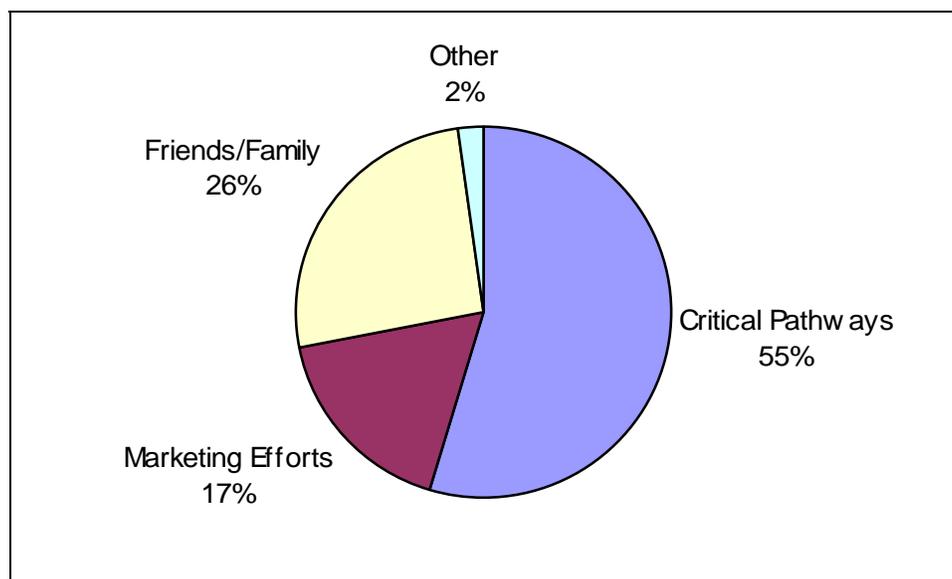
Outreach to Critical Pathways

In an effort to steer consumers to the right information or service at the right time and to prevent or delay unnecessary institutionalization, ADRCs are expected to form linkages with “critical pathways” – i.e., providers that serve as the major pathways to long-term care, such as hospital discharge planners, rehabilitation facilities and health clinics. Critical pathways provide information to individuals at a key decision making juncture. Outreach to critical pathways generally involves increasing providers’ knowledge about services that are available through the ADRC and promoting appropriate referrals to the ADRC. The participation of critical pathways in referring individuals to ADRCs is thought to be vital for advancing the goals of consumer empowerment through informed decision making and serving as the entry point to all publicly-administered long-term supports.

Outreach to critical pathways is especially purposeful for identifying and intervening with individuals at-risk of institutional placement. All too often, individuals enter the long-term care system at a point of crisis when they face limited options and when assistance is time-intensive and care is costly. Therefore, in addition to assisting individuals with urgent needs, a long-term objective of performing outreach to “critical pathways” is to identify and assist individuals earlier on before they reach a point of crisis. This section describes grantees’ approaches to performing outreach to various critical pathways and the extent to which critical pathways are referring individuals to ADRCs.

“Critical pathway” providers play an important role in connecting individuals to the ADRCs. HCBS or social services organizations, doctors or health professionals, hospitals, nursing facilities, ICFs/MR, Senior Centers, ILCs, and alternative residential centers together accounted for 55 percent of all referrals to ADRCs (*Exhibit 46*).

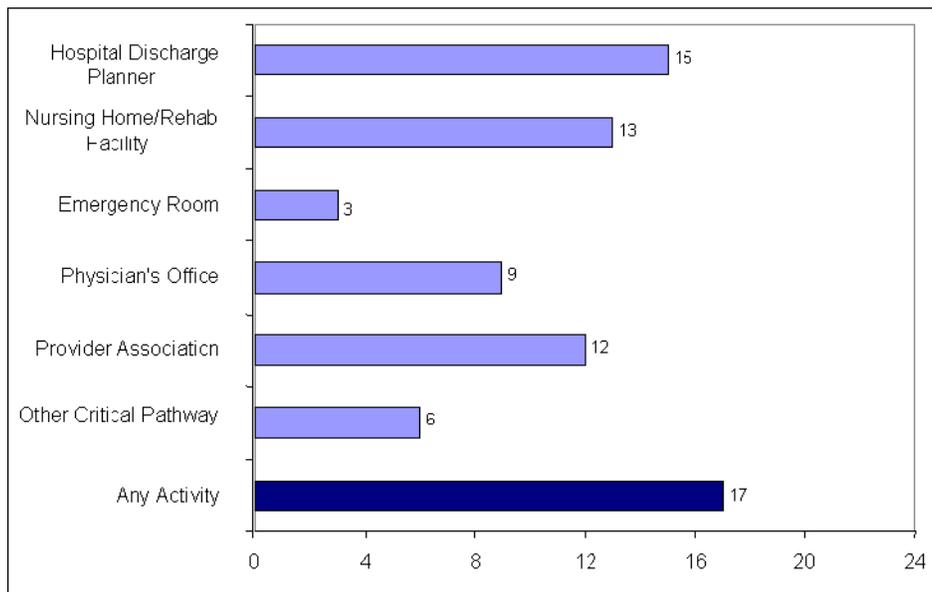
Exhibit 46: Average Percent of Referrals from Different Sources, April 2006 (n =35 Pilot Sites)



As providers of critical pathways become more familiar with the services of an ADRC, they will likely play an increased role in providing information about resources and referring individuals in need of long-term care to ADRCs. Further, as grantees' IT/MIS infrastructure matures, grantees will be better positioned to track the effectiveness of outreach activities and the relationship between referrals and consumer outcomes.

Grantees conducted outreach to a variety of critical pathways, with hospital discharge planners representing the most common type. As shown in *Exhibit 47*, grantees performed outreach to different types of critical pathways with the majority of grantees reporting activities with hospital discharge planners, provider associations and nursing and rehabilitation facilities. Also, nearly half of the grantees conducted outreach with physician offices and a few grantees linked with emergency room providers. Other pathways included pharmacies, senior centers, elder law attorneys, libraries, and employers.

**Exhibit 47: Outreach to Critical Pathways by Provider Type, April 2006
(n = 24 Grantees)**



Grantees engaged in a number of marketing, training, and educational activities targeted to different types of critical pathways. In general, ADRCs offered training on the availability of community long-term support and the ability of ADRC staff to help link individuals to these services. Although some training was conducted in a group setting, ADRCs more commonly provided training and education on a one-on-one basis. ADRCs also provided an array of written materials (e.g. brochures, business cards, magnets, ADRC newsletters) about the ADRC to critical pathway providers that were then disseminated to consumers. Specific activities by provider type are described below:

- **Hospital Discharge Planners.** Acute hospital stays represent times of crises in which patients and their families may have an urgent need for information about available options. Critical decisions at the time of discharge can have a significant impact on an individual's ability to remain in the community. For nearly half of the grantees, hospital representatives served on the ADRC advisory board or stakeholder coalition. A few grantees, such as Indiana and the District of Colombia, assigned ADRC staff to specific hospitals as a strategy to develop relationships with those providers. Others, such as Georgia, reached out to the statewide hospital association. Two states reported mandatory referrals from hospital providers to the ADRC for persons of the designated ADRC target population who are in need of long-term care (Illinois and New Hampshire). Wisconsin currently practices mandatory referrals from long-term care facilities to the ADRC, but discontinued mandatory referrals from hospitals because of the overwhelming volume of inappropriate referrals.¹⁸ Despite these efforts, a fairly small percentage of referrals came from hospitals (grantees reported an average of less than three percent).

In general, ADRCs located in rural areas or small service regions, such as Alaska and Arkansas, reported an easier time developing relationships with discharge planners than ADRCs serving larger metropolitan areas. The main challenges grantees faced in conducting outreach to discharge planners were developing a single point of contact at hospitals due to high hospital staff turnover and, given the hurried pace at the hospital, limited availability of the hospital discharge planner to meet with ADRC representatives.

- **Nursing or Rehabilitation Facilities.** Another critical time for decision making occurs when individuals are completing therapy at nursing or rehabilitation facilities and must determine a discharge plan and next steps. This transitional period offers an opportunity for the ADRC to provide individualized information and counseling to consumers about their options for long-term support. Additionally, ADRCs have an opportunity to target some individuals residing in institutional settings who wish to return to the community and who may be unaware of their options. This cohort could benefit from learning about home and community-based support options, although affordable housing can pose a significant barrier.

A majority of ADRCs involved nursing facility representatives on their advisory boards, leadership teams, or coalitions. Some grantees, such as New Mexico, worked with the nursing home ombudsman. Other strategies included assigning ADRC staff to specific facilities (Indiana) accounting for 10 percent of referrals in one pilot, offering options counseling to nursing facility residents (Indiana), assessing nursing facility residents for possible return to the community (Maryland) accounting for 6 percent of referrals. However, grantees have reported that reaching out to this group of provider can be a slow and time-intensive process, often requiring an ongoing effort. One of Illinois' pilot sites (Macon County) serves as the county Case Coordination Unit and has responsibility for conducting all nursing home prescreen assessments for individuals over age 18 in the county. They also conduct de-institutional screens when someone is preparing to leave a nursing facility, interim assessments and conversion screenings when a nursing home resident transitions onto Medicaid. Having responsibility for these functions gives this

¹⁸ Hospital discharge planners reportedly referred everyone for fear of the financial penalty associated with failure to refer.

ADRC a direct link to nursing facilities, in addition to having administrators and discharge supervisors serve on their local advisory board. It also helps to create a seamless experience for the consumer from their initial assessment to when the ADRC helps to find them appropriate services in the community when they discharge.

- **Emergency Rooms.** Only four grantees reported any activity during the most recent reporting period in performing outreach to emergency room providers. Examples of approaches included providing sensitivity training to emergency room staff on working with older adults (Florida) and education about prescription plans (South Carolina).
- **Physicians.** Physicians tend to have great influence on consumer decision making and many medical providers are unaware of the full range of long-term support options for their patients, including home and community-based support. Although some grantees reported that physicians' busy schedules presented a challenge for the ADRC in making connections, many have been able to reach out through a variety of approaches. Some approaches included distributing ADRC brochures, mailing letters, and conducting educational presentations to physicians and their office staff. Maine and Illinois reported that meaningful involvement of physicians through ADRC-related coalitions and networks. Three innovative practices are described in the box below.

Examples of Outreach to Physician Offices

Florida. "In one pilot site, a geographical database of physicians was created to target those serving indigent and multi-cultural populations. As a result, over 950 letters were mailed with information about the ADRC and long-term care resources for older persons. An offer to attend a staff meeting was included. Of the physician offices identified, over 350 were targeted for high priority follow-up due to their location in rural, poverty-stricken and underserved areas. To date, 139 offices received follow-up calls and 23 offices have been visited with resource materials distributed. Another pilot site has established a working relationship with a multi-disciplinary team composed of nurses, physicians and other medical professionals. This team staffs geriatric assessment clinics in the community and has provided an opportunity to increase awareness of the ADRC in the local medical network." *Florida SART April 2005 (reporting 19.38 percent of all referrals from physicians)*

Tennessee. "The First Tennessee pilot site has developed a prescription pad type info sheet to distribute to physicians. The physician can give a patient needing in-home services a page from the prescription pad that tells how to get in touch with the AAAD. This concept was developed by the First Tennessee ADRC Advisory Committee." *Tennessee SART April 2006*

Illinois. "Rockford: The ADRC has a number of linkages with local physician offices including local medical clinics, which refer clients to the ADRC for assistance. We have had good coordination with the Federally Subsidized Health Clinic in our area, Crusader Clinic, which serves low-income clients and those who are uninsured. Crusader offers a Memory Diagnostic Center. The director attends monthly network meetings at the ADRC. ADRC staff communicate with Crusader's pharmacy staff to help clients who have difficulty paying for their medications. We coordinate with three local audiologists to help low-income clients obtain free hearing aides through the HEAR NOW program." *Illinois SART April 2006*

- **Provider Associations.** Outreach to provider associations offers an opportunity for ADRCs to educate a base of individuals who have links to many critical pathways within the state. Nearly two-thirds of grantees reported outreach to provider associations during the most recent reporting period. In general, ADRCs provided education to provider associations about services offered by the ADRC and a few ADRCs provided specialized education concerning Medicare Part D.

Reportedly, a major benefit of outreach to provider associations was that it offered an avenue to the privately paying population and better access to special provider types, such as those serving persons with mental health needs and developmental disabilities. Some of the main challenges included managing contacts for a large rural state and provider perception of competition between their services and the services provided by the ADRC. In addition, grantees connected with the local housing authority or the state chapter of the Association of Homes and Services for Aging. One grantee also worked with the state trooper association.

Grantees leveraged or enhanced existing outreach efforts that were part of other grants, particularly the state’s Real Choice Systems Change grant activities. Many grantees reported that outreach to hospital discharge planners was an agenda for the state prior to implementing their ADRC program. Some grantees, such as Maine, Minnesota, North Carolina and Rhode Island, reported targeting discharge planners through additional grant funds such as Alzheimer’s Disease Demonstration Grants and Nursing Home Transition Grants.

New Jersey implemented a hospital Pre-Admission Screening (PAS) program as part of a larger system-wide transformation in three counties (two of which had ADRCs). The program enables hospital staff to assess level of care for individuals entering a nursing facility or a Medicaid waiver program, which is then authorized by a Community Choice counselor. The purpose of the preadmission screening pilot was to coordinate processes between the hospital discharge planners, nursing homes, Community Choice counselors and Boards of Social Services (State regional Medicaid offices). ADRC staff facilitated the planning process trained hospital discharge planners and provided the state screening tool. A major goal of training hospital discharge staff was to free ADRC staff to focus more on options counseling (see *Information, Assistance and Informed Decision Making about Long-term Support Options* section of this report).

The Nursing Home Transition grants, part of President Bush’s New Freedom Initiative, were awarded by CMS to states to assist in helping individuals move from nursing facilities into community-based residences. In several states, connections with nursing and rehabilitation facilities were borne out of these already existing Nursing Home Transition programs. For example, in Wisconsin, the grant funded the Homecoming Project, in which Wisconsin's Department of Health and Family Services (DHFS) contracted with Independent Living Centers (ILCs) to transition nursing home residents in their service area to community settings. During the duration of the program, 150 people transitioned from nursing facilities to community-based settings and an additional 150 people began the transition process. This preexisting relationship between DHFS, the ILCs and the nursing facilities provided the foundation for ADRC relationships with nursing facilities.

In New Jersey, Nursing Home Transition grant staff developed a “Round Table/ Interdisciplinary Team” model, which is a consumer-driven forum, coordinated by the state’s Office of Community Choice Options and nursing home discharge planners. ADRC staff have

adopted this model for developing comprehensive service plans that identify housing options, formal and informal services, frequency of services, special needs and cultural preferences. The Round Table/Interdisciplinary Team also includes family members, health care professionals, a care management organization, and community service providers who are instrumental in carrying out and monitoring the service plan.

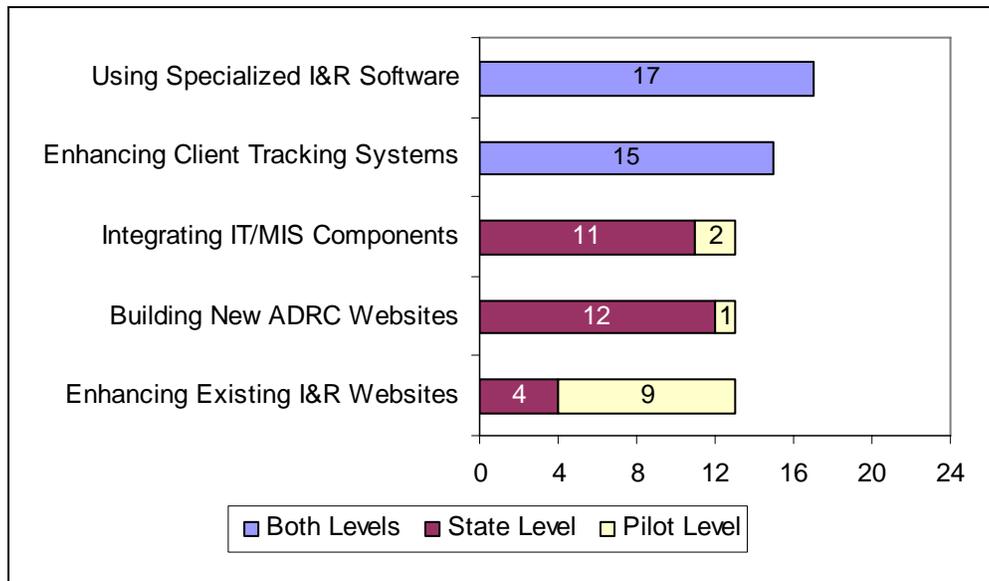
Louisiana's ADRC team has collaborated with several other grant initiatives. The state received a Real Choices Systems Transformation Grant in 2005 and one of the goals of this grant is to explore technology that will allow data sharing between separate agencies. They hope that this technology will allow client information to be shared between Medicaid and the ADRCs to coordinate service delivery. Their Alzheimer's Disease Demonstration Grant has provided funding to expand their web-based resource database, LouisianaAnswers.com, beyond the original pilot site area.

IT/MIS Infrastructure to Support ADRC Functions

A key program element for an ADRC is an information technology and management information system (IT/MIS) that supports the functions of the program, including client intake, needs assessment, care plans, tracking, utilization and costs. Information technology can support ADRC functions in a range of ways, from increasing public awareness and providing information through public websites, to streamlining access to services through online applications and electronic data-sharing between partner agencies. Traditionally, many health and human service organizations have used information technology primarily to collect, monitor, and report program data. The ADRC initiative brings many opportunities, as well as a host of challenges, for these agencies to refine and expand the use of technology. This section describes the variety of ways that grantees enhanced their IT/MIS infrastructure to support the functions of the ADRC and addresses the role that IT/MIS played in improving access to long-term support and other program activities.

Grantees focused on enhancing information technology capacity in four major areas: information and referral, client tracking, development of public websites, and IT integration. Grantees assessed their pre-existing infrastructure and worked to identify and fill the gaps in their data systems. Several grantees used ADRC funding to purchase specialized I&R software to help them better manage their resource databases and keep track of I&R calls, and 17 of 24 grantees now use specialized I&R software. Most grantees already had some kind of client tracking system in place for intake, care planning and services tracking activities when the grant began and have used the grant to integrate their client tracking with a specialized I&R package. Building new websites or enhancing existing websites has been a major activity at both the state and local levels with 22 of 24 grantees building new or enhancing existing websites.

**Exhibit 48: MIS Activities and Enhancements,
Implemented or Planned
(N=24 Grantees)**



IT/MIS decision making predominantly takes place at the state level for the majority of ADRC grantees, often in coordination with other state agencies and local partners. Decisions about IT/MIS tend to be locally-driven in states' long-term care systems. With the ADRC initiative, IT/MIS has become elevated such that states are thinking more strategically about the role of IT/MIS in long-term care reform and how to coordinate IT/MIS between state and local systems. For 21 of the 24 grantees who received ADRC awards in FY 2003 and 2004, the state took the lead role in IT/MIS design and implementation in conjunction with partners at the state and local level. Louisiana, for example, contracted with a vendor to build a statewide website and searchable I&R resource database for all their pilot sites to use. In Alaska, the State Centers for Independent Living coordinate with the Division of Senior and Disability Services and the Senior Housing Alliance to adapt its current IT/MIS system for ADRC requirements. Rhode Island and South Carolina enhanced statewide client tracking and I&R systems that were originally developed through Real Choice Systems Change grants.

Half of the 24 grantees built or purchased new management information systems, and just fewer than half pursued enhancements or improvements to their existing data systems. A number of factors determined whether an ADRC chose to use an "off the shelf" software package or created or customized a system, including: available resources, intra-agency IT/MIS compatibility, and whether a commercially available software package could meet the organization's ADRC-specific needs. In addition to building systems, another major area of focus for grantees was MIS integration. At least 14 grantees worked to integrate different MIS or implement electronic data sharing between systems.

The majority of grantees chose to use or purchase commercial software, but customized (or are in the planning stages to customize) the software for ADRC use. Iowa, for example, is building on the data storage and exchange protocols set up under the "Seamless Project" which created a software package to streamline elder case management. The same vendor is also building the

Iowa ADRC’s web portal which creates greater coordination of resources.

Under the ADRC initiative, South Carolina enhanced an existing Web-based information and assistance system, SC Access, by building an electronic bridge to link its system to other databases, including the Medicaid Waiver Case Management system, the Office on Aging Family Caregiver system, and the Aging Information Management system. Maryland developed a Request for Proposal for a statewide MIS infrastructure that will link its existing aging and disability information systems and create an integrated application and tracking tool.

Eighteen of the 2003 and 2004 grantees (75 percent) chose Web-based systems for either professional or consumer use or both. In web-based systems, data are centralized and can be accessed and updated by multiple agencies, allowing for greater integration both within the ADRC and across partners. Georgia and Illinois, for example, use Elder Services Program (ESP) software, but are converting from a Microsoft Access version of the software to a Web-based version. Montana modified an existing Web-based Information and Assistance MIS program for ADRC program purposes. Montana also plans to make the resource database portion of its system accessible to the public in 2007.

Web-accessed systems have several advantages for ADRCs including ease of updating the application and the ability to provide access to multiple users. The grantees’ experience shows the value of Web-based MIS systems in facilitating electronic data sharing and advancing efforts to streamline access to long-term care services. One of the grantees’ primary strategies to streamline access was the development and use of online applications for benefits and programs. Sixteen of the 24 grantee states (67 percent) have Medicaid application forms posted online, but the majority must be printed out, filled in, and mailed or delivered to the local Medicaid agency (*Exhibit 49*). Three states, Florida, Pennsylvania, and South Carolina, allow consumers to fill out and submit applications online, including an electronic signature function. North Carolina is piloting online submission of its Medicaid application, however, consumers in the pilot area must still print out and mail in the signature page. In addition to consumer-accessible online Medicaid application forms, seven grantees implemented online application forms that are accessible only to staff. Staff in both Iowa and Wisconsin, for example, can fill out and submit functional assessments for the HCBS waiver or other long-term care programs electronically. Grantees’ experience also showed that their ability to streamline access depended in large part on the participation and cooperation of the State Medicaid agency.

Exhibit 49: On-line Medicaid Application Systems in ADRC Grantee States

State	Medicaid Application Available Online	Submission Method
Alaska	Form is online for download.	Mail or in-person.
Arkansas	Form is online but must be printed and mailed or dropped off.	Mail or in-person.
California	Form is online but must be printed and submitted.	Mail or in-person.
Florida	Form is online through ACCESS Florida.	Online using electronic signature, mail or in-person.

State	Medicaid Application Available Online	Submission Method
Georgia	Using supplemental funding to put Georgia's Medicaid form 700 online, with public access. Form 700 is the instrument used to determine initial financial eligibility for all aged, blind and disabled categories of Medicaid. This form will be a consumer-friendly interactive tool that can be filled out by consumers, caregivers, professionals or other representatives and will be located on several easy access public sites. Currently, the Medicaid application is online for download. The website indicates applicants can apply by email, but there is no signature information.	Mail, fax, phone, or in-person.
Illinois	Rockford: Using Real Benefits, a computer program which takes client information and puts this information directly onto an application form for Medicaid, Food Stamps, LIHEAP, and soon, Circuit Breaker. Macon County: The ADRC has the ability to complete Medicaid applications for clients but can't determine eligibility. The application and documentation can be mailed to the local office to determine eligibility without the client going into the Medicaid office. Medicaid forms can be downloaded, but must be printed and mailed or dropped off.	Mail or in-person.
Indiana	An "Eligibility Modernization" Request for Proposal (RFP), which includes online Medicaid applications, was officially released February 9, and vendors have responded with proposals to rehabilitate the current system. Form is currently online. Applicants can enter information into the online form but cannot save it.	Mail or in-person.
Iowa	The Iowa Department of Human Services (DHS) continues to test and refine a combination application for several social service programs, including Medicaid. The combination application would be available both through the enhanced Iowa COMPASS website and through the Seamless application for all HCBS waiver clients. Case managers can currently electronically send level of care information to the Iowa Foundation for Medical Care for the level of care determination, but determining financial eligibility is still a paper-based system. Form is online for download.	Mail or in-person.
Louisiana	Forms are online for download. Cannot save information in form.	Mail or in-person.
Maine	The pilot and the other Coalitions continue to advocate for publicly-funded services applications to be offered online. Much discussion has also centered on the need for face-to-face assistance given the complexity of some application processes. MaineCare application online for download.	Mail or in-person.
Maryland	An on-line application work group has met twice and has begun compiling spreadsheets for all applications for all publicly-subsidized programs providing long-term support services. Work on the application was delayed until DHR participation could be developed. Forms are not currently online.	In-person only.

State	Medicaid Application Available Online	Submission Method
Massachusetts	The Virtual Gateway is being used to facilitate online financial eligibility determinations. Virtual Gateway is available only to health care providers. Forms are available online that can be filled out online or downloaded.	Mail or in-person.
Minnesota	Online form may be filled out online and downloaded.	Mail or in-person.
Montana	No online forms.	In-person only.
New Hampshire	Forms online for download.	Mail or in-person.
New Jersey	No online forms for long-term care programs.	In-person only.
New Mexico	No online forms for long-term care programs.	In-person only.
North Carolina	Form online for download for Medicaid waiver. Forsyth County DSS reports an increase in the number of mail-in applications received since implementation began in October 2005.	Mail or in-person.
CNMI	No online forms.	
Pennsylvania	Medicaid application online with e-sign. Users can also print and send in signature page.	Online using electronic signature or mail.
Rhode Island	No online forms for long-term care programs.	In-person only.
South Carolina	Form that can be filled out and submitted online is available in pilot site service area.	Online. Must mail signature page.
West Virginia	Online screening for LTC programs but no online application forms. Forms must be picked up at DHHR office.	Mail or in-person.
Wisconsin	The system's online eligibility calculator is now used as virtual application option for some consumers who apply for public benefits. Forms are online for download.	Mail or in-person.

In addition to focusing on Web-based IT/MIS infrastructure, ADRC grantees are also using the Internet to increase public awareness and provide access to resources through websites.

Twenty-two grantees built or plan to build public websites; grantees' activities in this area ranged from making minor changes to existing organization websites and adding some additional information about the ADRC (Alaska) to building new websites with interactive searchable resource databases (Iowa, Louisiana and Indiana) to making major enhancements to existing interactive websites (Minnesota and South Carolina). For a complete list of ADRC websites with descriptions of features, see *Appendix C*.

In addition to public websites, grantees pursued other consumer accessed Web-based applications and data integration. Minnesota's ADRC model, for example, is a combination of a virtual and human network, the "MinnesotaHelp Information Network" – a network of information and assistance access points, known as ADRC Access Points (see text box). Two other grantees, New Mexico and Michigan, also plan to use public Internet kiosks to make ADRC services more accessible to consumers.

Several ADRC grantees use the capability offered by Web-based network systems to adopt mobile technology and offer consumer assessments and other services in the home setting. Arkansas, for example, uses a Web-based case management system that includes a

comprehensive database, an Information and Referral Contact Record and a Consumer Assessment Referral and Enrollment (CARE) tool (see text box).

Examples of Web-based Applications to Improve Consumer Access

Minnesota's ADRC model is a combination virtual and human network, the MinnesotaHelp Information Network, a network of information and assistance access points, known as ADRC Access Points, which include an interactive online resource database for consumers and providers (www.MinnesotaHelp.info), written materials, toll free telephone assistance through the Linkage Lines, and referrals for long-term care consultation with a social worker or public health nurse. Access to the Network is available in places where people currently seek and receive information such as health clinics, community agencies, hospitals, pharmacies, libraries, senior centers, faith communities, social service and public health offices, and places where they work, in addition to the Web or the telephone. One of the Hennepin County Access Points is located in the Brookdale Library. Four computer terminals have been configured to feature aging and disability resources and the ADRC has trained librarians to access long-term care information through MinnesotaHelp and the Linkage Lines. The critical component to the resource center is the availability of a new web based tool that helps users complete an informal assessment of long-term care needs. Once the user has entered information, a community resource plan can be developed and then saved or printed at the resource center allowing the user to then seek further assistance in implementing the plan either by self directing access to the services, or seeking the services of a long-term care consultant.

Arkansas' Web-based case management system includes a comprehensive database, an Information and Referral Contact Record and a Consumer Assessment Referral and Enrollment (CARE) tool. The Contact Record enables I&R staff to record consumer contact and demographic information, referral requests, referral outcomes and follow-up summaries. The CARE Tool, which functions as a single entry point for LTC services, enables multiple agencies to enroll clients and record and track client information using the single system. Case managers are using laptops in the field to fill out and submit level of care assessment forms. They are also using portable printers with scanner capability to copy financial documents for eligibility determinations so that clients no longer have to entrust the originals of their personal documents to a third party for copying. However, in a 12-county rural area of Southwest Arkansas, where Arkansas' first pilot site operates, Internet access is not always available. This is especially true in areas case managers travel to for home visits. To meet this technological challenge, this grantee's IT contractor created PC versions of the online applications to enable case managers to enter data while in the field. The data can later be uploaded into the online system. The application of mobile technology, such as cell phones, notebook computers, and portable printers/scanners has reportedly enhanced communications between case managers and provider agencies, saved time and travel expense, and sped up the eligibility process for clients.

The process of refining IT/MIS is time-intensive and was the most commonly reported reason for delays in streamlining access. For many grantees, the process of refining IT/MIS involved assessing existing IT/MIS capacity, meeting with partners, establishing goals, determining compatibility and interoperability issues, developing specifications, addressing any data sharing privacy requirements, selecting and meeting with vendors, and testing and monitoring the implementation of software applications. The grantees' experience showed that IT/MIS infrastructure development is an inherently time-intensive process, and that participants often underestimate both the time and resources necessary to achieve their goals. Eight grantees have reported delays in meeting their IT/MIS goals, including the contracting and procurement processes (4 grantees), having to wait for the state or other agencies to make decisions (3 grantees), and the sheer complexity of the issues involved (5 grantees.) As described in the following section of the report, IT/MIS played a major role in grantees' efforts to streamline access to long-term care services and support and therefore IT/MIS delays experienced by grantees contributed significantly to grantees' progress in streamlining access.

Streamlined Access to Services and Support

A major focus of the ADRC initiative is to create a seamless experience for consumers and their families in accessing needed long-term care support. The federal vision is for ADRCs to provide one-stop access in the community to all publicly-funded long-term support programs and benefits such as Medicaid, state-funded, OAA, and other home and community-based services (HCBS). Therefore, the aim is to streamline the process to access services to long-term care services and support in which eligibility screening, comprehensive assessment, programmatic and financial eligibility determination, and entry into programs are either integrated or so closely coordinated that entry into programs for consumers and their families is as simple and efficient as possible.

By the end of the third year, ADRC pilot sites are expected to perform all the "Access" functions of an ADRC, which include screening and determining eligibility for public programs.¹⁹ As mentioned above, in addition to serving individuals eligible for publicly funded services, ADRCs are intended to serve individuals who can pay privately by linking them with available support in the community. This section describes grantees' progress toward streamlining access and illustrates how some ADRCs were positioned to *integrate* several of these screening and eligibility functions across programs, with Medicaid and other entities, while others were more apt to streamline the process by *closely coordinating* with their partners.

Grantees pursued several different strategies designed to accomplish at least two major goals: 1) improving the ease with which consumers initially access services and support and, 2)

¹⁹ Eligibility screening, providing assistance in gaining access to long-term support service that may be paid with private funds, performing comprehensive assessment of long-term support needs and care planning, conducting programmatic eligibility determination for long-term support services, Medicaid Financial Eligibility Determination that is either integrated or so closely coordinated with the Resource Center that each individual applicant experiences a seamless interaction, One-Stop Access to all public programs for community and institutional long-term support services administered by the state under Medicaid, and those portions of Older Americans Act programs that the state has determined will be devoted to long-term support services and any other publicly funded services which the state determines should be accessed through the Resource Center.

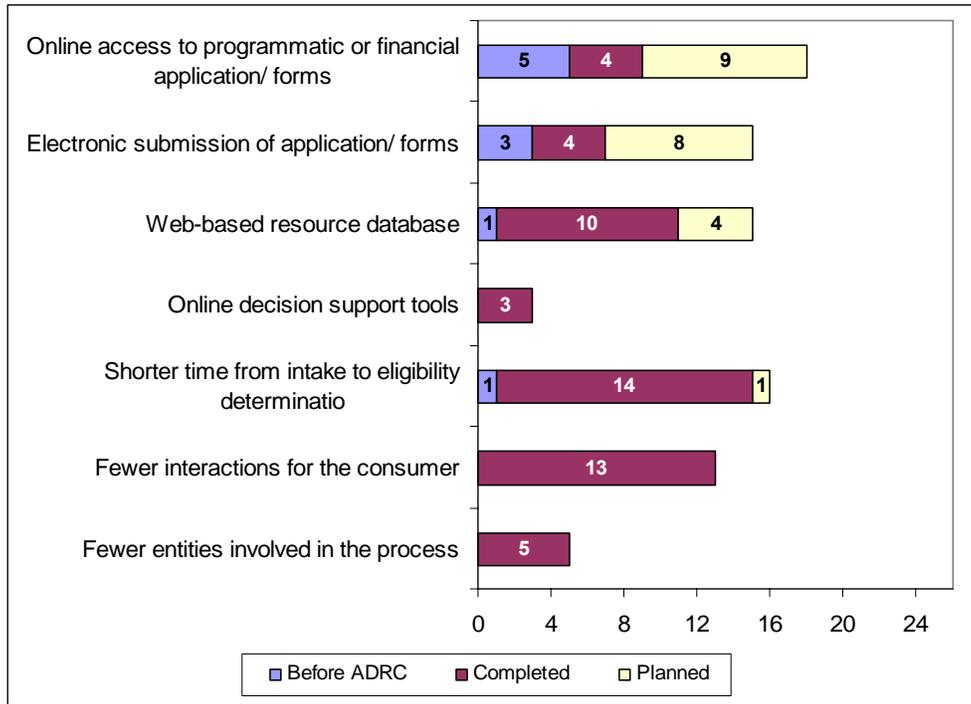
improving the administrative efficiency and timeliness of the process. *Exhibit 50* outlines the major activities that grantees completed or are planning to implement for each of these goals. These steps to streamline access centered on the use of IT/MIS and collaborative relationships among the Aging and Disability Networks and Medicaid.

Exhibit 50: Major Activities Undertaken by Grantees to Streamline Access to Long-term Support Services

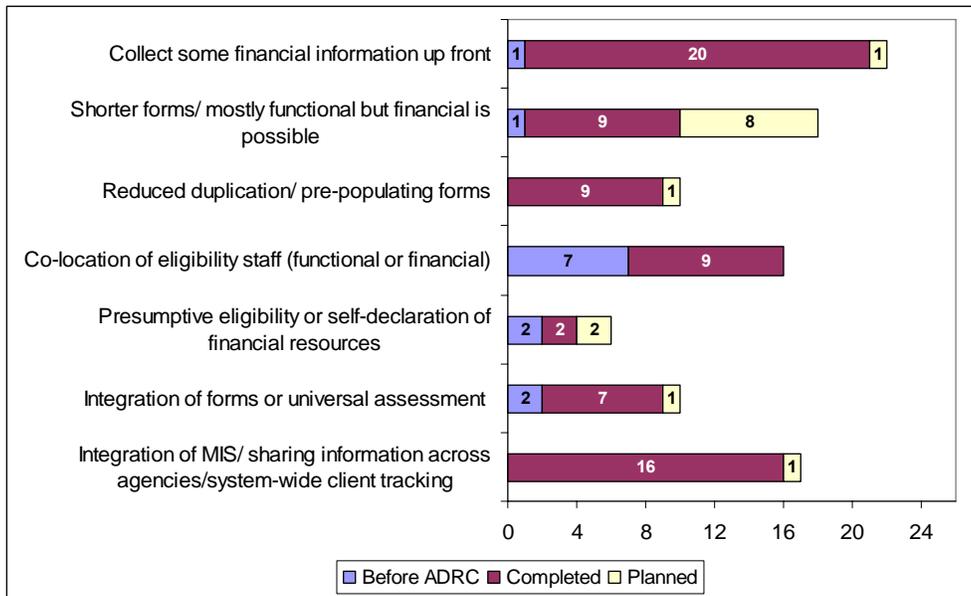
Consumer Ease of Access	Efficiency/Timeliness
Develop Web-based resource database	Collect preliminary financial information as part of initial screen
Provide online access to programmatic or financial applications or forms	Shorten forms
Allow electronic submission of applications or forms	Reduce duplication (e.g. pre-population of forms with consumer information)
Offer online decision support tools	Integrate forms or develop universal assessment
Shorten time from intake to eligibility determination	Co-location of staff
Reduce number of interactions for the consumer	Institute presumptive eligibility or self-declaration of financial resources
Reduce number of entities involved in the process	Integrate MIS/ share information across agencies/ track clients system-wide

FY 2003 grantees made progress in streamlining access, completing six activities on average, ranging from three to ten. All together, grantees completed more activities related to improving administrative efficiency and timeliness than activities related to improving consumer ease of access. See *Exhibits 51* and *52* below for more detail on streamlining activities. In working toward greater ease of access for consumers, over half of the pilot sites (15 of 26) have already shortened the time it takes between initial intake and eligibility determination. Eventually, 69 percent (18 of 26) will offer online access to program applications. Towards improving the efficiency and timeliness of the eligibility determination process, 80 percent (21 of 26) have begun collecting preliminary financial information from consumers at the beginning of the intake process to help determine whether a full financial eligibility determination is appropriate as well as to quicken the determination process. Sixteen pilot sites (61 percent) have functional or financial eligibility staff co-located with the ADRC.

**Exhibit 51: Completed and Planned Activities Designed to Improve Consumer Ease of Access
(2003 Grantees Only, n=26 Pilot Sites)**



**Exhibit 52: Completed and Planned Activities Designed to Improve Efficiency and Timeliness
(2003 Grantees Only, n=26 Pilot Sites)**



The strength of the partnership between the ADRC grantee and the Medicaid agency is closely correlated with streamlining access. While it is too soon to determine which factors result in streamlined access, early analyses suggest that having a strong partnership between the ADRC and the Medicaid agency is an advantage to achieving streamlined access. Our analyses show that pre-existing capacity is positively correlated with the achievement of streamlining activities.²⁰ It was determined that eight states had substantial pre-existing ties with Medicaid. Similarly, the strength of the relationship that developed during program development and implementation is positively correlated to streamlining outcomes.²¹ Our analysis of the post-ADRC relationship found seven grantees to have a strong working partnership with Medicaid and that this variable has a statistically significant influence on the achievement of streamlining outcomes (five of the original eight with pre-existing capacity and two that had minimal pre-existing capacity).

The current division of responsibilities for eligibility determination makes achieving the streamlining access goal more difficult. By law, different staff can be assigned to perform financial and functional eligibility determinations.²² Some grantees perform financial and functional screens for publicly-funded programs within their ADRCs. For others, eligibility determinations are handled by an ADRC partner organization (e.g., agency handling nursing home pre-admission screenings, HCBS Medicaid waiver services). One grantee reported that programmatic eligibility for waivers services and LOC determinations are performed by the local waiver staff, but that ADRC staff are able to coordinate the application process for consumers electronically. However, some grantees report that large waiting lists for services still remain, thereby prolonging the time between application and enrollment.

In general, ADRC model type moderately influences the implementation of streamlining activities; the management dimension has the strongest correlation with streamlined outcomes. When examining the three different dimensions of model type (State-driven vs. Locally-driven Management, Centralized vs. Decentralized Structure, and Virtual vs. Physical mode of access) and controlling for the strength of the partnership with Medicaid, the

²⁰ To measure grantees' existing capacity or *potential* for a strong partnership with Medicaid, we considered whether the grantee agency is situated in the same department as Medicaid at the state and local levels and whether the pilot sites were already performing some Medicaid functions prior to the ADRC grant period.

²¹ In considering the strength of the *post-ADRC* relationship with Medicaid, we first looked at the level of Medicaid staff involvement in ADRC planning and management activities. If grantees report a high degree of participation and active involvement in ADRC planning and management activities by Medicaid staff, we considered this a strong partnership. In the absence of a high degree of Medicaid participation in planning and management, we considered whether there was a formal agreement in place between the grantee and Medicaid, whether information about consumers is shared, and whether joint trainings have been conducted.

²² Section 1905(a) of the Social Security Act and regulations at 42 CFR 431.10(c), stipulates that the final determination of Medicaid eligibility shall be made by the State or local agency administering the State plan, the agency administering the supplemental security income (SSI) program, or the agency administering the State plan approved under part A of title IV. If ADRC staff are not part of the same agency as the Medicaid single state agency, then Medicaid agency staff must approve their determinations of eligibility. If they are part of the same department, they may be able to establish procedures to meet the Medicaid agency requirements and be permitted to make the determinations. Specifically, unless otherwise delegated by regulations at 42 CFR 431.10(e)(3), employees of the State Agencies other than the State Medicaid Agency can only perform initial processing activities. As stated in regulations on the use of outstation locations to process Medicaid applications, at 42 CFR 435.904 (e)(3)(ii), non-Medicaid agency employees at the outstation location can only perform "initial processing" functions.

dimension with the greatest correlation to streamlined access is Management. On average, grantees with initiatives that have been largely state-driven (planned and managed across all sites at the state level) have pursued and completed a greater number of streamlining activities. This may be partly due to during the initial phase of ADRC implementation, locally-driven sites faced more challenges planning and implementing streamlined processes given the limited control or influence over state Medicaid policy by pilot site staff.

When examining the effect of ADRC model type on the two major groupings of streamlining activities (consumer ease and efficiency), having a decentralized structure is positively related to the completion of streamlining activities designed to improve *consumer ease* of access, of small scale. While there are centralized models that have made great progress toward improving consumer ease, decentralized models may offer more options and/or familiarity in where and how to access services.

Whether the initiative is state-driven or locally-driven had a significant influence on achieving *efficiency*. State-driven initiatives were more likely to complete activities to improve the efficiency and timeliness of the process than locally-driven initiatives. In addition, we analyzed what effect a state's annual home and community-based spending as a percentage of Medicaid LTC spending had on achieving streamlined access and found that having a higher proportion of HCBS spending was a slight advantage for grantees. It is important to understand that we cannot draw conclusions from these early analyses about which models are most successful and what are the necessary components to have in place especially given the small sample size and the lack of trend data available to determine sustainability and true evidence of change.

Eight pilot sites in five states reported consistent data about average monthly enrollment in HCBS, institutional settings and other LTC programs. Over time, these pilot sites experienced a 10 percent increase in HCBS enrollment (Medicaid and other state funded programs). These grantees experienced a similar reduction in institutional enrollment between Fall 2005 and Spring 2006 in their service areas (*Exhibit 53*). Enrollment in other programs such as state-funded or OAA programs has also increased by 50 percent. In order to measure the impact of streamlining access to Medicaid and other public LTC programs, grantees are asked to report data about average monthly enrollment in HCBS, institutional settings, and in other LTC programs. At this time, however, few consumer-level outcomes in this area have been reported. It is either too early for grantees to report these outcomes or they do not yet have the capacity to track individual clients this far through the system. However, eight pilot sites in five states have been able to report consistent data and show an increase in HCBS enrollment and a decrease in institutional enrollment. It is important to note that these grantees reported overall enrollment in these programs, not enrollment specifically of ADRC consumers. Also the trend toward HCBS may reflect current trends in these states rather than the ADRC initiative, although the national annual average decline in Medicaid nursing facility residents was only 1.1 percent compared to 11.8 percent for the ADRCs able to report.²³

²³ The Lewin Group analysis of Annual Nursing Home Statistics Yearbooks for 1994 and 2005.

**Exhibit 53: Average Monthly Enrollment in HCBS,
Institutional Care, and Other LTC Program per 1000 Residents
in Service Area (n=8 Pilot Sites in 5 States)**

	Fall 2005	Spring 2006	Percent Change
HCBS	1.37	1.51	10.22%
Institutional	4.57	4.03	-11.82%
Other Program	8.77	13.23	50.86%

Note: Numbers based on enrollment per 1,000 residents in the pilot site area.

Achieving Sustainability

Achieving sustainability is an important activity for ADRCs since grantees are expected to implement systems change goals that improve the delivery of long-term care services that: involve multiple stakeholders, are dependent upon diverse partnerships, and impact state and local systems in both the public and private sectors. This section describes progress that ADRCs have made in ensuring sustainability of project initiatives after funding has ended.

Sustainability has been defined as “ensuring that the values, ideas and processes of the effort are widely shared and deeply felt; that important relationships are nurtured and remain strong; that policy and practice innovations are institutionalized and become the norm; and that needed financial and human resources are secured for the long term.”²⁴ Characteristics contributing to sustainability may differ among funded organizations but typically include:

- Availability of resources;
- Flexibility in response to change or in meeting challenges;
- Commitment to the project’s vision and mission by staff at all levels of the organization;
- Identification of a program or project “champion”;
- Institutional or organizational “fit” of the project within the mission of the grantee organization and/or in the broader environment;
- Measurable perception of the benefits of the program by staff, stakeholders and the broader community; and
- Support and “buy in” by related stakeholders.²⁵

²⁴ Ira Cutler. (2002). “End Games: The Challenge of Sustainability.” The Annie E. Casey Foundation, MD.

²⁵ Scheirer, M.A. (2005). “Is Sustainability Possible? A Review and Commentary on Empirical Studies of Program Sustainability. American Journal of Evaluation, Vol. 26, No. 3, pp. 320-347.

ADRCs have focused their efforts to achieve sustainability on: 1) maximizing resources; 2) developing sustainable programmatic infrastructures to ensure sustainability; and 3) identifying and addressing future challenges to sustainability in their long-range plans. In addition, they have embedded many of the aforementioned characteristics in their programs' operational infrastructure and have used a various strategies to achieve sustainability and ensure long-term program impact.

Maximizing Resources to Achieve Sustainability. ADRCs reported using three key approaches to increasing the availability of resources to augment and sustain project activities. These included: seeking public-sector financial resources; developing partnerships with other organizations, thereby leveraging the capacity of staff to provide services as well as to obtain space and equipment for their operations; and exploring other venues for program sustainability (*Exhibit 54*). Along with sustainability strategies, ADRCs also identified implementation challenges in each of these areas. To meet these challenges some ADRCs have established Sustainability Committees to focus on identifying potential resources, to pursue funding opportunities in both the public and private sectors, and to strategize new approaches for leveraging resources involving creative partnerships, in-kind resources.

Exhibit 54: ADRC Sustainability Strategies

Activity	Strategies	No. of ADRCs (n=24)	Challenges
Seeking Public Sector Financial Resources			
Securing Medicaid reimbursement	<ul style="list-style-type: none"> • Seek Medicaid match for ADRC functions (i.e., waiver services, case management, assessment, counseling, quality initiatives, managed care processes and client tracking through eligibility processes) • Pursue Medicaid Federal Financial Participation (FFP) • Collaborate with Systems Transformation Grant and incorporate/partner with other state and federally funded programs (i.e., medication management, transportation, mental health services) • Pursue state funds for ADRC initiatives 	19	<ul style="list-style-type: none"> • Working around Medicaid priorities • State budget constraints • Fixed number of waiver slots • Time intensive to develop policies • May be difficult to establish alignment of ADRC core functions within state government structure
Pursuing/ implementing cost-sharing	<ul style="list-style-type: none"> • Pilot cost sharing • Incorporate in new waivers • Pilot sliding scale fee system • Partner with ILCs that have cost sharing in place • Request voluntary donations 	8	<ul style="list-style-type: none"> • Introducing new concept to providers and consumers • Developing equitable policies for diverse consumer groups

Activity	Strategies	No. of ADRCs (n=24)	Challenges
Developing Partnerships			
Building Private-Sector Partnerships	<ul style="list-style-type: none"> Enhance volunteer involvement with business sector and community groups Engage in outreach strategies to the business community – for funding and volunteers Involve other agencies and organizations in joint activities 	9	<ul style="list-style-type: none"> Staff resources limited for recruiting and training volunteers Concerns about conflict of interest
Exploring Other Venues for Funding/ Supporting Program Sustainability			
Engaging in sustainability-specific strategic planning	<ul style="list-style-type: none"> Develop sustainable interagency infrastructure Form Sustainability Committee Pursue legislation to codify ADRC activities and mission 	9	<ul style="list-style-type: none"> Time- and staff-intensive Long-term commitments uncertain
Seeking Private Sector Investment Opportunities	<ul style="list-style-type: none"> Seek funding/grants from private foundations with similar goals Maximize use of community volunteers Share resources with organizations and businesses in the community 	9	<ul style="list-style-type: none"> Time and staff intensive Private foundations may have their own priorities, may not fit precisely with ADRC goals

Notes: Chart lists the most-commonly cited sustainability strategies and concerns of the 24 2003 & 2004 grantees. Not all ADRCs reported on sustainability initiatives; numbers represent ADRCs that indicated they were planning to or had implemented sustainability strategies; individual ADRCs may have utilized several strategies and may be represented in multiple categories.

Developing Sustainable Programmatic Infrastructure: Case Studies. In the winter and spring of 2006, ADRC-TAE team-members conducted site visits to six 2003 Aging and Disability Resource Center grantees to discuss site-specific program elements and project activities related to sustainability of project outcomes beyond the funding period.²⁶ Grantees discussed the following topics related to sustainability: (1) Elements of the ADRC initiative that are most likely to be sustained and/or replicated; (2) Strategies used to achieve sustainability; and (3) Conditions, features or characteristics of the different states and ADRC programs that facilitate sustainability. A summary of the findings from each site-visited state in each of these areas is provided in *Exhibit 55*.

Challenges to Sustainability. ADRCs reported that their most critical area of concern in ensuring project sustainability was obtaining funding and resources. Other primary challenges

²⁶ Study states included: Maryland, Massachusetts, Minnesota, New Hampshire, New Jersey, and South Carolina which represented half of the states receiving ADRC grants in 2003. Structured interviews were conducted with project leaders, staff, advisory board members, evaluators, volunteers, and other project partners in the six states, at nine pilot sites and at four Access Point sites (in Minnesota).

to sustainability, reported by many of the ADRCs, included:

- Continuing operations
- Maintaining services already in place and provide ongoing training for staff
- Improving existing infrastructure, especially in the area of IT/MIS
- Developing and expanding effective partnerships
- Ensuring quality in the services and supports they provide
- Supporting expansion and replication of project activities to all areas of the state

Of the twenty-four 2003 and 2004 ADRC grantees, three grantees had to significantly modify or eliminate a pilot site. In two states, decisions were made not to continue pilot site operations in specific localities and one state relocated an ADRC pilot site in order to reduce overall project costs. Strategic, funding and/or consumer service concerns were the primary reasons for altering expansion plans at these ADRCs. Lessons learned from the experience of these three states underscore the critical importance of program monitoring and proactive assessment of successful model elements for replication and statewide expansion.

Exhibit 55: Sustainability Site Visits Summary of Findings

State & ADRC Name	Elements Most Likely to be Sustained	Strategies Used to Ensure Sustainability	Facilitators of Sustainability
New Hampshire Service Link Resource Centers	<ul style="list-style-type: none"> - Uniform statewide standards - IT/MIS improvements - Streamlined access through staff co-location - Statewide network of <i>ServiceLinks</i> 	<ul style="list-style-type: none"> - Integrate project with broader systems reform - Involve diverse stakeholders in project activities - Educate policymakers and demonstrate beneficial outcomes 	<ul style="list-style-type: none"> - Develop ADRC as integral component of ongoing systems change - Maximize ADRC relationships within state government structure - Strike balance between state oversight and local flexibility
Massachusetts Aging and Disability Resource Consortium	<ul style="list-style-type: none"> - Decentralized approach to LTC service delivery - Joint/Collaborative management - Alignment of service philosophies among different service systems - Collaborative development of tools and resources 	<ul style="list-style-type: none"> - Build on existing infrastructure - Heed lessons learned from other systems change initiatives - Establish trust between aging and disability partners - Identify shared values 	<ul style="list-style-type: none"> - Engage partners in strategic planning at outset of project - Promote “give and take” among project collaborators - View partnership-building as a project goal
New Jersey Aging and Disability Resource Connection	<ul style="list-style-type: none"> - Standardized screening and eligibility determination processes - Commitment to consumer-centered policies and programs - Commitment to quality monitoring and improvement 	<ul style="list-style-type: none"> - Engage large and diverse workgroups in planning project activities - Leverage expertise of external consultants - Strive for consensus among stakeholders - Expand responsibility for project success across stakeholder groups and agencies 	<ul style="list-style-type: none"> - View ADRC as an ongoing activity within the state - Develop a “can do” attitude in working around challenges and managing change - Implement policy directives from the “top down” while recognizing local needs
South Carolina Aging and Disability Information Center	<ul style="list-style-type: none"> - Improved consumer access to streamlined services - Close coordination between ADIC and CLTC Medicaid waiver program - Visibility and focus on consumer and provider education - Strengthened state and local-level partnerships 	<ul style="list-style-type: none"> - Build upon prior initiatives - Find a niche for the ADRC - Improve utilization of scarce resources through collaboration - Leverage the potential of partnerships and clout of “project champion” 	<ul style="list-style-type: none"> - Demonstrate and practice visionary leadership - Remain open to developing creative partnerships - Establish clear expectations of staff roles; maintain staff capacity and morale

State & ADRC Name	Elements Most Likely to be Sustained	Strategies Used to Ensure Sustainability	Facilitators of Sustainability
Maryland Maryland Access Point	<ul style="list-style-type: none"> - Streamlined access to services through co-location and/or coordination - Commitment to consumer-centered policies and programs - IT and MIS improvements - Interagency partnerships 	<ul style="list-style-type: none"> - Earn support of diverse stakeholders - Enter into formal partnership agreements with collaborating agencies and organizations - Develop a cohesive marketing strategy to raise awareness of ADRC activities - Track and document programmatic outcomes 	<ul style="list-style-type: none"> - Recognize opportunity for ADRC project to shape state's broader long-term care reform agenda - View the ADRC as a catalyst for positive systems change - Cultivate participation of "natural" as well as unexpected partners in project activities - Integrate ongoing staff training into project activities as a component of quality services
Minnesota MinnesotaHelp Information Network	<ul style="list-style-type: none"> - Multiple approaches for consumers to access streamlined services - ADRC Access Points established in diverse community locations for easy access to services and information - Consumer Decision Tools which are easy to use and readily accessible - Close working relationships that have increased coordination between state and local service delivery systems 	<ul style="list-style-type: none"> - Engage in strategic planning as a critical "first step" in project implementation - Use flexible "give and take" management strategies to foster collaboration - Develop products and resources that have multiple applications and can be used in different settings - Prepare to adapt to policy and political changes ongoing in the state. 	<ul style="list-style-type: none"> - Staying "on message" and focused on the ADRC initiative - Leverage commitment and expertise of "project champions" at the state and local levels - Utilize staff expertise in overcoming bureaucratic barriers to project implementation

IV. PROMISING PRACTICES/ LESSONS LEARNED

This section describes the most commonly reported challenges the ADRC grantees encountered during planning and implementation phases, as well as facilitators that have supported the ADRCs in overcoming challenges and achieving their goals.

Key Challenges

During the planning and implementation of the ADRC grants, grantees encountered a number of challenges that affected the implementation of their programs. *Exhibit 56* lists the most frequently reported barriers that ADRCs have encountered. All 24 of the 2003 and 2004 grantees reported that they encountered at least one substantial challenge to planning and implementing their ADRC grant.

**Exhibit 56: Challenges to Planning and Implementing ADRC Grants
(n = 24 grantees)**

Challenges	No. of Grantees	Percent of Grantees
IT/MIS challenges	16	67%
Insufficient staff time/resources set aside for IT/MIS issues	7	29%
Technical issues sharing data and/or linking different systems	7	29%
Difficulty procuring IT/MIS vendor	4	17%
Delays due to other agencies' priorities/issues/concerns	3	13%
Other	3	13%
Staffing and leadership challenges	15	63%
Administration and leadership changes	9	38%
Delays in hiring key staff due to hiring freezes, budget delays	8	33%
Turnover of key staff during grant period	5	21%
Insufficient staff capacity	2	8%
Difficulty forming and maintaining partnerships with other agencies	13	54%
Partnerships between aging and disability agencies	8	33%
Partnerships with state and county Medicaid agencies	7	29%
Partnerships with other agencies	4	17%
Streamlining access challenges	11	46%
Integrating ADRC with other Medicaid system reform efforts/initiatives	8	33%
Fragmentation of eligibility determination processes across agencies	4	17%
Privacy concerns related to data sharing between agencies	4	17%
Difficulty maintaining consumer involvement	9	38%
Total Grantees Reporting Any Significant Challenge	24	100%

IT/MIS Issues

Many of the grantees have plans to improve current IT/MIS technologies or adopt new technologies to facilitate better sharing of information across agencies and reduce duplication of effort in collecting and entering consumer information. However, this often requires collaboration across several agencies that have different information needs and different systems. Sixteen (67percent) grantees reported challenges to updating and integrating IT/MIS technologies. Of these, seven (29 percent) of the grantees reported that they had not allocated sufficient staff time or resources to coordinating a process to identify the information needs of all stakeholders and determining the specifications for the IT/MIS system, researching software options, and either developing a solution or procuring a software vendor.

Another seven (29 percent) grantees reported running into technical problems integrating IT/MIS systems across agencies. In several cases, data fields had to be restructured, functions reprogrammed, and/or information “re-keyed” before two systems could be successfully linked. Three (13 percent) of the grantees reported that their efforts to procure an IT/MIS vendor resulted in significant delays in implementing their IT/MIS plans. Also at the state level, three (13 percent) of the grantees reported that they needed to delay ADRC-related IT/MIS decisions and improvements in order to coordinate with other efforts in their states to streamline IT/MIS systems. Three grantees (13 percent) reported other IT/MIS challenges, including identifying appropriate IT/MIS software packages, functionality of selected software and other delays in selecting an IT/MIS vendor.

Staffing and Leadership

Over the course of the ADRC grant, several grantees experienced changes in administration at the state level and leadership changes at the state and local levels. In a few cases, the grants spanned a change in governor, which required grantees to re-establish relationships with and support from their administrations. In other cases, key leaders within the administration have retired or moved onto other positions. In total, eight (33 percent) of the 2003 and 2004 grantees reported changes in administration or leadership that presented substantial challenges to planning and implementation of the ADRC grant. When the commissioner of aging in one state left her position, the grantee reported that they had “lost their champion at the state level” and that they would have to find a new state champion to build support for the ADRC within the administration and with external stakeholders. In the case of another 2003 grantee, the retirement of the state’s Independent Living Center (ILC) director was a challenge because the grantee had invested significant time establishing a relationship with the director and they were in the process of developing an MOU. One of the 2004 grantees encountered a setback when the state’s Medicaid director resigned because the director had been a great supporter of the ADRC. With the departure of the director, the ADRC lost both a powerful advocate for the grant and someone who could help secure the Medicaid agency’s collaboration with streamlining efforts.

One half (12) of the 2003 and 2004 grantees have experienced barriers and challenges related to staffing issues. Most commonly, grantees reported that at the state level,

hiring freezes or budget delays resulted in significant delays in hiring key staff, especially project managers and coordinators. According to these grantees, this resulted in delays in planning and implementation of the grant, including delays in selecting sites, transferring funds to sites, establishing coalitions and partnerships, developing interagency MOUs, and selecting and hiring independent contractors for marketing and evaluation of the ADRC. Unsuccessful attempts to hire a full-time project coordinator prompted one 2003 grantee to subcontract project management to a local university.

Turnover in key staff posed another staffing issue for grantees. Five (21 percent) of the grantees reported that during the first one or two years of the grant, they lost key staff, including project managers and directors, due to retirements and agency reorganizations. Grantees reported that this resulted in some loss of institutional memory, delays in project planning and implementation, and setbacks in the areas of partnership and coalition building because relationships needed to be reestablished with new staff. Additionally, at the state level, two (8 percent) grantees reported that they had allocated insufficient staff to plan and implement the ADRC grant and that the workloads of their grant staff were too high. Specifically, they reported that they had not anticipated how much work would be required to build coalitions and to coordinate across agencies around streamlining access and IT/MIS issues.

Difficulty Forming and Maintaining Partnerships with Other Agencies

Successful implementation of the ADRC grants requires collaboration among multiple agencies at the state and local levels. Thirteen (54 percent) of the 2003 and 2004 grantees have reported substantial challenges in forming and maintaining partnerships with key agencies. Most commonly, grantees reported challenges establishing relationships between aging and disability agencies. At either the state or the local level, eight (33 percent) grantees have experienced resistance to partnership between aging and disability agencies. Many of the grantees attributed this to a history of mistrust between the agencies. Another source of tension between the agencies at the state level cited by one 2003 grantee is the substantial difference between the aging and disability agencies in terms of budget and staff.

Seven (29 percent) of the grantees reported significant challenges partnering with their Medicaid agencies at the state or local levels. In the case of several grantees, they have found it difficult to engage the Medicaid agencies, reporting that they do not attend meetings on the ADRC or do not support or prioritize ADRC activities. This has been most difficult to grantees around the issues of streamlining access to Medicaid, specifically with reducing duplication of effort to collect data from consumers and reducing steps in the Medicaid eligibility processes. In addition, four (17 percent) of the 2003 and 2004 grantees reported challenges establishing partnerships with other key partners, including a state 2-1-1 agency, which delayed linking ADRC and 2-1-1 databases, and with a state office on long-term care, which was resistant to streamlining access activities.

Streamlining Access Activities

One of the most challenging aspects of the ADRC program involves streamlining consumer access to services and supports. Grantees cannot accomplish this goal without

considerable support and participation of state and local Medicaid partners. In addition to the partnership challenges outlined above, 11 (46 percent) of grantees faced other barriers to the process of streamlining access. Eight (33 percent) grantees reported challenges related to coordinating their ADRC activities with other systems change efforts and grant programs. In some cases, ADRCs had to put their activities on hold while other systems change initiatives were implemented. In other cases, grantees found that their streamlining plans conflicted with or duplicated the effort of other programs or initiatives and needed to be redesigned. Four (17 percent) grantees reported that the fragmentation of eligibility requirements and determination processes across various state departments and programs for ADRC populations has posed challenges to their streamlining activities. Overcoming this fragmentation is an inherent challenge of the ADRC initiative; it often involves mapping the system, identifying all the entities involved, coming to a consensus, and then coordinating change with all the entities. In addition, four (13 percent) grantees reported challenges around protecting consumer privacy while sharing consumer data across agencies.

Difficulty Engaging Consumers

ADRCs are required to involve consumers in their activities and many ADRCs have consumer representatives on their advisory committees. Consumer board members help the ADRC staff review outreach materials, identify service providers and help the ADRC in collaborating with other advocacy groups. However, nine (38 percent) of the 2003 and 2004 grantees reported that they experienced substantial challenges with involving consumers in the development of their ADRC programs. Two of the 2003 grantees reported that at the state level, they had a core group of active consumers on their advisory boards, but that the remainder of the boards appeared to be “drifting by.” At the state and the local levels, other grantees have had difficulty recruiting and maintaining certain types of consumer populations, particularly individuals with disabilities, to participate in their advisory boards.

Facilitators and Lessons Learned

While grantees encountered a number of barriers to successful implementation of their ADRC programs, they also established a variety of practices to facilitate their efforts to provide streamlined access to long-term care services. These include investing time in building partnerships and effectively managing changes in the political environment, such as changes in administration. The most frequently reported facilitators are listed in *Exhibit 57* below.

Exhibit 57: Facilitators and Lessons Learned About Planning and Implementing ADRC Grants

Barriers	Facilitators/Lessons Learned
IT/MIS	Allowing adequate time and resources for determining IT/MIS needs and procuring a vendor
	Establishing systematic process for determining user specifications
	Involving end users early in selection/development process
Staffing and Leadership	Establishing relationships with new leaders early and educating them about the ADRC
	Appointing a dedicated project manager
	Cross-training staff from partnering organizations
	Monitoring impact of ADRC on case loads
Partnerships with Other Agencies	Co-locating staff from partnering agencies
	Involving partners early in the planning process
	Identifying champions in partnering organizations
	Setting clear and realistic expectations for partners
	Remaining flexible in determining partner roles
Streamlining Access	Selecting pilot sites that already have strong partnerships with key agencies
	Coordinating closely with other system reform initiatives and grant programs
	Taking incremental steps toward streamlining
Consumer Involvement	Implementing policies to protect consumer privacy and facilitate data sharing
	Involving consumers in meaningful ways
	Establishing links with existing advisory committees
	Creating a separate board for consumers

IT/MIS

- **Allowing adequate time and resources for determining IT/MIS needs and developing systems.** One of the primary lessons learned about implementing the ADRC grant for many of the 2003 and 2004 grantees has been planning for significant time and resources to be spent on determining IT/MIS needs and developing systems or procuring vendors. One 2003 grantee advised other grantees to “estimate the time that you think it will take for IT and multiply that by three.”
- **Establishing systematic process for determining IT/MIS needs.** One 2003 grantee engaged a diverse group of stakeholders to assist with the process of determining IT/MIS needs and designing a system, which reduced the burden on the core ADRC project staff responsible for overseeing all grant activities. The group developed a form for soliciting the IT/MIS needs of all users and used the results to develop the specifications for its system.

- **Involving end users early in selection/development process.** One strategy to ensure that the final product purchased or developed will be accepted, accessible, and used by those who are intended to use it is to involve users in the planning, development and selection of the software. At least three grantees conducted focus groups with professional and consumers prior to selecting an IT/MIS vendor and used this feedback to help guide their IT/MIS decisions.

Staffing and Leadership

- **Establishing relationships with new leaders early and educating them about the purpose of the ADRC.** Over the course of the grant, many of the ADRCs have experienced changes in administration at the state level and/or changes in the leadership of their agency. Because the purpose of the ADRC program is to streamline and improve existing systems, leadership commitment to the ADRC goals is critical to the success of the grants and a change in leadership is a potential barrier. One of the lessons learned from the 2003 and 2004 grantees is that when there is a change in leadership or administration, it is important for the grant staff to reach out to the new leadership early, establish a relationship with them and educate them about the goals of the ADRC program and how the ADRC initiative fits with other system reform efforts.
- **Appointing a dedicated project manager.** At the state level, it is very helpful to have a dedicated project manager to oversee planning and implementation of the ADRC grant. One of the critical roles at the state level is establishing partnerships between the lead agency and other agencies and stakeholders. Several of the grantees have reported that having a dedicated project manager in this role has been critical to the success of their programs. However, some grantees have also observed that this will be one of the most difficult components of the ADRC program to sustain beyond the grant period.
- **Cross-training staff from partnering organizations.** Several of the 2003 and 2004 grantees are helping the staff from their agencies and other agencies enhance their knowledge and skills in serving multiple populations by facilitating cross-training of staff from multiple agencies. Cross-training helps aging and disability staff better understand the needs and values of both populations and enables them to serve both populations more effectively. Typically, the grantees' cross-training practices are ongoing.
- **Monitoring impact of ADRC on case loads.** Another lesson learned from the 2003 and 2004 grantees is the importance of monitoring the impact of the ADRC on calls and case loads and adjusting staff configurations as needed. Many of the grantees have found that call and caseload volumes have increased over time and have had to adjust how they staff the ADRCs accordingly.
- **Co-locating staff from partnering agencies.** Grantees reported that co-location (physical or virtual) of staff responsible for determining eligibility for public assistance programs (e.g., Medicaid, Food Stamps, and Temporary Cash Assistance) within the ADRC, has been helpful in streamlining access to services and presenting a seamless process for consumers. Similar to financial eligibility determinations,

grantees reported that the physical and/or virtual co-location of the ADRC with organizations (e.g., Waiver Units) that determine functional eligibility for nursing home admission and home and community-based services has been helpful in streamlining access. Where physical co-location of staff is a new feature, one ADRC reports that it is important to intentionally and carefully cultivate new staff so that they feel like part of the overall team.

Partnerships

- **Involving partners early in the planning process.** The ADRC grant program has provided an opportunity for aging and disability agencies and networks to overcome historic differences and work together to streamline access to long-term care services to both populations. Several of the grantees based in state aging agencies have found that involving their colleagues in the disability agencies early on in the planning process for the ADRC has helped them establish trust with the disability agencies. In fact, involving all the key stakeholders in developing a shared vision for the ADRC grant can help secure their buy-in and ongoing support for the program. One grantee organized a retreat for key stakeholders at the beginning of the grant and brought in external experts to facilitate the meeting. This put the lead agency on a more equal footing with other meeting participants and helped the group come to consensus on a no wrong door approach for the ADRC grant. Grantees also streamlined processes through restructuring and/or creating new state-level executive teams or state agency units such as Central Enrollment Units, or the Division on Aging (designated as the State Unit on Aging).
- **Identifying champions in partnering organizations.** Another strategy that grantees have found effective in building effective partnerships with other agencies is identifying and cultivating relationships with champions for the ADRC program within those agencies. For example, several agencies that have reported difficulty engaging state Medicaid agencies around streamlining access to Medicaid have found that identifying a champion in either a leadership or other key position in the agency facilitates securing the agency's commitment to the goals of the grant. Champions may be in key leadership or program staff positions. At the leadership level, champions can be effective in securing their agencies' commitment to the ADRC program and in influencing programmatic and policy changes in support of the ADRC goals. Champions at the staff level can also be very valuable because they are often the program experts and best able to facilitate their agencies' role in the ADRC.
- **Setting clear and realistic expectations for partners.** Several grantees found that a key to successful partnering is being realistic about expectations for ADRC partners and being flexible about the partners' roles in the ADRC initiative. Several of the 2003 and 2004 grantees that have established work groups or advisory boards in which partners play a role have provided very clear guidance for the partners about expectations at the outset of the process. One 2004 grantee, for example, created a job description for individuals serving on its advisory board. In that grantee's assessment, establishing clear expectations at the outset was critical to the success of the advisory board.

- **Remaining flexible in determining partner roles.** As several of the 2003 and 2004 grantees have discovered, potential partnering organizations operate under their own financial, staff, structural and political constraints; these constraints often change over time, which can impact the extent to which partners can assist with key ADRC activities. State Medicaid agencies, for example, are critical partners for key ADRC activities, particularly around streamlining access to care, and often operate with multiple competing priorities and in complex environments. Several grantees strengthened their partnerships with Medicaid by offering to assist understaffed Medicaid offices with some of the steps involved in determining eligibility, such as working with consumers to locate and submit complete financial documentation.
- **Selecting pilot sites that are already working to integrate disability, aging and Medicaid functions.** Several of the 2003 and 2004 grantees carefully selected pilot sites that were more ready to function as an ADRC than other potential sites. For instance, a number of the sites that were selected as ADRC pilot sites already integrated some disability, aging and Medicaid functions or demonstrated strong partnerships across the three groups prior to the grant.

Streamlining Access Activities

- **Coordinating closely with other system reform initiatives and grant programs.** In most states, the ADRC initiative is happening along side several other systems change and Medicaid reform efforts. Grantees have worked to make sure the ADRC is not duplicating another effort or designing processes that will conflict with other changes in the works, by coordinating closely with other grant initiatives. Several states strategically designed their ADRC projects to continue activities started with earlier Real Choice Systems Change grants, or have built their ADRC Advisory Boards using existing systems change advisory boards or task forces. Several grantees have reported that regular communication among the various grant partners is essential to stay informed about other initiatives and to keep ADRC partners informed, so that the ADRC is fully integrated into all the state's long-term care activities.
- **Taking incremental steps towards streamlining application process.** Making substantial changes to the eligibility determination process for public programs requires the time, attention and cooperation of several state and local agencies. Several grantees determined early on in their grants that their state Medicaid agencies might not be able to make major changes to the functional or financial eligibility processes during the grant period. However, ADRCs found that in the meantime, they could take other important steps toward streamlining the application process and making it simpler and less time-consuming for consumers. For example, grantees have worked to standardize the initial screening process. Some have standardized screening tools used for all their long-term care programs to improve consistency in how they are used across counties. Some ADRCs pre-populate and submit applications on the behalf of consumers to eliminate the need for consumers to go to multiple agencies to apply for benefits. Many ADRCs assist consumers in gathering all the required documentation needed for financial applications. Additionally, some grantees use portable equipment such as scanners

and printers to copy consumers' financial information. This limits the need for consumers to travel to the ADRC or eligibility determination office, reduces the number of trips the staff must make to gather all required application documentation.

- **Implementing policies to protect consumer privacy and facilitate data sharing.** Grantees used different strategies to implement data sharing between partner agencies to reduce duplication and the number of times consumers have to tell their story. At least two grantees established their ADRC pilot sites as Business Associates under the Health Insurance Portability and Accountability Act (HIPAA) to facilitate the electronic exchange of client information.²⁷ Several grantees purchased or developed software applications that offer multiple security levels to control access by staff in some agencies to certain data elements. Two grantees developed electronic referral processes that do not involve electronic transfer of personal data, but alert partnering agencies to log-in to a secure web-based system for client updates. One grantee worked with their Medicaid agency to add a question to the Medicaid application asking consumers to consent to having their data shared with the ADRC.

Consumer Involvement

- **Involving consumers in meaningful ways.** ADRCs are required to involve consumers in the planning and implementation of their grant and many of the 2003 and 2004 grantees have identified strategies for engaging consumers in meaningful ways. Several of the 2003 grantees have invited consumers to participate in focus groups to review marketing messages, materials, and even the name of the ADRC. One 2003 grantee also conducted focus groups on two online resource directory systems that it was considering. Another 2003 grantee conducted consumer focus groups on a new online Medicaid application and another 2003 grantee tested its website with consumers. Inviting consumers to review and comment on materials and tools can provide grantees with valuable feedback on how they could be improved to better meet the needs of the target audience. Another way to engage consumers is through advisory boards. All grantees have consumer representation on their ADRC advisory boards, which provides consumers a voice in shaping the ADRC grants to best meet the needs of elders and people with disabilities. Consumers serving on advisory board can also be an effective sounding board for program staff. One ADRC actually created a separate Consumer Board, composed solely of consumers.
- **Establishing a link to existing advisory committees.** Some ADRCs have built upon advisory boards established under the Real Choice Systems Change Program to overcome the challenge that many of them face in identifying certain groups of consumers to serve on their committees. In some cases, they this existing advisory board serves as the ADRC Advisory Committee. Some ADRCs have also chosen to

²⁷ Health Insurance Portability and Accountability Act, 1996, Public Law 104-191. For more information see ADRC-TAE Issue Brief: ADRCs and HIPAA online at: <http://www.adrc-tae.org/tiki-index.php?page=TAEIssueBriefs#hipaa>

ask the Real Choice Systems Change board to advise the ADRC Committee, rather than to be involved in routine decision-making. Engaging the Real Choice board in conjunction with the ADRC Advisory Committee allows the grantees the opportunity to potentially streamline administrative support for several grants and helps ensure coordination among them.

- **Creating a separate Consumer Advisory Board.** One 2003 grantee established a separate board comprised entirely of consumers to advise them on ADRC planning and activities. The consumers are given orientation training as well as a stipend and reimbursement for expenses related to participation. The board has played a key role in reviewing project materials and getting the word out to the community about the ADRC.

V. CONCLUSION

Over the past three years, ADRCs have made significant progress in implementing the vision set forth by AoA and CMS to create integrated points of entry into long-term care systems; to empower individuals to make consumer-directed, informed choices about long-term care options; and to serve as highly visible and trusted places that people of all ages can rely on for a full range of information and supports regarding long-term care.

ADRCs are defined by their ability to provide integrated and seamless access to long-term care information, assistance and services. Whether it is called a “one stop” center, “no wrong door,” or a “single point of entry,” the ultimate goal of the ADRC initiative is to create consumer-driven, consumer-friendly systems that simplify access to needed services and support. ADRCs achieve this through enhancing or realigning existing intake, application and eligibility processes, and tracking procedures such that the process to access support is transparent to the consumer. Integrated service systems have the added benefit of streamlining data collection and reporting in order to improve quality of care and monitor costs.

Findings in this report clearly demonstrate that millions of U.S. citizens in communities across the country have access to and are benefiting from ADRC services, whether they are provided in physical locations or through web-based communications systems. ADRCs are unique in the services they provide and the target populations they serve. They provide comprehensive access to long-term care information, services and supports; they serve both publicly supported and privately paying individuals; their target populations include older adults as well as people of all ages with all types of disabilities; and their services are available for consumers, family members, care providers, agency staff, informal caregivers and individuals planning for future long-term care needs. ADRCs provide education, awareness and training for the public as well as for professionals involved in long-term care. They have informed public policy and raised the awareness of decision-makers at the local, state and national level about the diverse and complex needs of people who require long-term care services as well as the possibilities and opportunities for providing services that are comprehensive, efficient and effective.

ADRCs have accomplished these goals, underscored by the findings presented in this Interim Report, utilizing four overarching strategies: 1) Streamlining access to long-term care information, services and supports; 2) Building upon strategic partnerships and consumer empowerment to achieve project goals; 3) Establishing and operating replicable models of service delivery consistent with the ADRC philosophy and mission and program objectives; and 4) Creating programs that demonstrate the feasibility, effectiveness and value of rebalancing long-term care service systems.

ADRCs Have Effectively Utilized IT/MIS as a Vehicle for Establishing Streamlined Access to Services and Supports

A major goal of the ADRC project is to develop IT/MIS infrastructure that allows for integrated points of entry into the long-term care system. Consistent with the AoA/CMS

vision, ADRCs developed or plan to develop IT/MIS systems that enhance streamlined access to information and programs, allow for client tracking and a more unified case management system, support program monitoring and evaluation, and provide information for continuous improvement in program services and functions.

ADRCs used different strategies to build IT/MIS systems that serve multiple target populations. Progress has been made in developing IT/MIS systems that support client intake, assessment, eligibility determination, client tracking, case management, as well as tracking of service utilization levels and costs. In many cases, grantees did not build these systems “from scratch” but improved on, realigned or integrated existing systems. These strategies facilitate access to a comprehensive array of information and supportive services that represent a different and more effective way to serve consumers, both now and in the future. Moreover, the IT/MIS systems developed under the ADRC program have allowed grantees to better partner with related systems of care such as family services, health care, housing, employment, APS, and others.

ADRCs used web-based strategies to make information and services more accessible to more users. Seventy-five percent of the 2003 and 2004 grantees are moving toward developing and implementing web-based, centralized data management systems to provide access to information, expedite application and eligibility determinations and facilitate updating, sharing and tracking of consumer information. The web and internet-based information and assistance resources that ADRCs created promote information sharing and serve consumers, family members, professional care providers and decision makers at the national, state and individual community levels. Nearly all of the 2003 and 2004 grantees are using the Internet to raise public awareness of long-term care services and to provide web-based access to a comprehensive range of long-term care information via interactive sites and searchable databases. Some ADRCs have physically located their technology-based information systems in the community -- at user-friendly ADRC access points such as libraries, community centers or faith-based organizations, or in kiosks -- to expedite consumer access to long-term care information, services and care and future planning tools.

Challenges and Future Direction

Obtaining funding for ongoing investments in IT/MIS. IT/MIS investments are costly and new sources are continually needed to fund and support IT/MIS functions.

IT/MIS activities taking longer than expected. It is often a challenge to coordinate the work schedules of multiple partners when deadlines change due to delays or when unexpected barriers occur.

Maintaining IT/MIS partnerships as ADRCs expand. ADRCs will need to sustain the momentum of the partnerships that were formed in the initial phases of program development and implementation as the projects expand and new applications for the technology are developed.

Using IT/MIS applications effectively requires ongoing investments in staff training and learning to use new systems of information management is highly staff intensive. ADRCs have developed ongoing training programs for project staff as well as for staff of partnering organizations but are often challenged by the need to resources, both in

terms of money, hardware and people to maintain adequate levels of continuing education.

ADRCs Have Developed Strategic Partnerships and Strengthened Consumer Empowerment to Make Informed Decisions

Strategic partnerships are a key ingredient contributing to the success of ADRCs.

Strategic partnerships, whether formal or informal, provide the supporting framework for all other aspects of ADRC projects. The need to develop strong strategic partnerships among these groups was recognized early on as an important factor in ADRC success. Local sites that were selected by the state lead agency to pilot the ADRC initiative tended to be those sites that exhibited some existing capacity either in the area of strong local partnerships and/or solid IT/MIS.

An impressive feature of a number of ADRC programs is the presence of an extensive network of partners. It is likely that a great deal of the capacity that pilot sites have to leverage resources for ADRC activities is due to their close community connections and partners in the community. Through these partners, ADRCs broadened their scope of services and outreach activities to include multiple populations, including individuals with the ability to privately pay for services, people with disabilities, including those with mental illness and to individuals of all ages.

Developing partnerships greatly expands ADRC resources. Data in this report indicate that 75 percent of the annual budget of pilot sites was from sources other than the ADRC grant and included primarily OAA, Medicaid and state funds, local revenues and other grants such as from consumer and charitable grants. These partnerships provide new opportunities to leverage resources of diverse resources and they underscore the role of ADRCs as significant contributors to the health, well-being and strength of local communities.

Grantees are in the early stages of establishing processes for empowering consumers and their families to make informed, consumer-directed decisions about long-term support options. A significant goal of the ADRC is to extend beyond providing traditional assistance to support individuals and family members with informed decision-making about long-term care options. This is being provided through options counseling services that are unique to ADRCs. In addition, ADRCs report being involved in providing information and assistance to individuals who are beginning to plan for long-term care and for families needing advice for helping with futures planning for loved ones.

Challenges and Future Direction

While building strategic partnerships is one of the most critical components of ADRC success, it appeared to be one of the most challenging aspects of program development. This is not surprising since many of the elements that comprise long-term care services are located in diverse agencies and organizations and affect individuals in groups based on age or a medical diagnosis rather than on needs or shared values. The ADRC target populations and their natural strategic partners historically have not interacted with each other, shared information or leveraged

resources in collaborative partnerships.

ADRC projects must strengthen and maintain their partnerships with Medicaid at the state and local levels. While AoA and CMS have a formal partnership at the federal level and co-funded the grants, fostering strong partnerships with Medicaid at the state and local levels was challenging for some grantees. Several grantees reported difficulties getting Medicaid to take an active role in the project, although the input and involvement of Medicaid is necessary to move forward with plans to streamline access, integrate IT/MIS systems, and implement systems for sharing data.

Several grantees reported that developing partnerships with Medicaid entities at the local levels, in addition to the state level, was critical to successful streamlining. States can play a role in promoting strong local partnerships, by providing templates for local level MOUs, initiating policy changes that will facilitate access at the local level, supporting the development of IT/MIS infrastructure to facilitate data sharing between partners at the local level, and setting an example with state level partnerships.

The aging and disability communities need to strengthen their working relationships. Over the past three years, ADRCs have reported challenges in developing partnerships between the aging and disability communities. For example, it was particularly difficult for some pilots to develop aging and disability partnerships when no state-level partnership existed. In addition, states in which Independent Living Centers (ILC) and Area Agencies on Aging (AAA) cover different planning and service areas will need to determine how best to coordinate with one another and define potential benefits gained from partnering, such as enhanced service access.

Furthermore, since many of the ADRCs are operated by AAAs, and these organizations generally seek personnel who have experience working predominantly with older adults, there tends to be less in-house in-depth experience with the disability community, particularly as it relates to accessibility. Disability agencies, in contrast, tend to have greater expertise in issues related to accessibility, family-centered care planning and employment. For an ADRC to be successful, it is important that partners from both networks be actively involved and share their expertise with each other. Individual champions can have a significant impact on progress in creating bridges between the two communities.

To ensure that ADRCs are successful in serving consumers of all types of disabilities, stronger partnerships are needed at the federal level with the Administration for Children and Families' Administration on Developmental Disabilities, the National Council on Disability, and the DHHS Office on Disabilities, as well as their respective associations.

ADRCs Have Established Replicable Models for More Efficient and Effective Delivery of Long-Term Care Services

ADRCs have evolved into an array of program models based on three key characteristics: management, structure and mode of consumer access. ADRCs differ by management (those that are state-driven to those that are locally-driven); structure (those with highly centralized management to those that are managed predominantly by local organizations and partnerships); and mode of consumer access (those with a high

level of virtual access to those where services are accessed primarily at physical locations through face-to-face interactions with staff). Elements contributing to the evolution of these various ADRC typologies include political climate, available resources, historical partnerships, community infrastructure and state organization. These factors are highly variable and posed considerable challenges in implementing and expanding the ADRC program nationwide. Experiences over the past three years have shown that ADRCs have the capacity to adapt to differing environments and to effectively utilize environmental differences to maximize and leverage project outcomes and achieve overall success.

As ADRCs expand, it is likely that they will retain fidelity to the original philosophy, goals and activities envisioned by AoA and CMS for the ADRC program. The past three years of experience with ADRCs have demonstrated that embedding clear goals into project expectations at the outset, of monitoring the projects and providing feedback at all stages of implementation are major contributors to ADRC success and long-term sustainability. The identification of clear ADRC typologies will help new ADRCs achieve fidelity to the program model, even in diverse state and local environments. Typologies will assist ADRC program managers to more effectively deal with future challenges that may arise and apply “lessons learned” to new challenges they encounter, without having to reinvent new implementation strategies from the ground up.

ADRCs Have Contributed Significantly to Rebalancing Long-Term Care Systems

Several characteristics differentiate ADRCs from other long-term care organizations and establish them as leaders in rebalancing systems of care historically oriented toward institutional care. These include:

- Delivery of efficient, simplified access to a wide range of information and supports about community-based options for an array of consumer groups seeking information or access into the long-term care system through diverse entry points;
- Commitment to providing resources based on the values of consumer direction, person-centered planning, and individual choice and autonomy, particularly through options counseling;
- Capacity to facilitate effective linkages at multiple junctures involving diverse stakeholders along the long-term care continuum; and
- Ability to prevent institutional placement by maximizing access to comprehensive, updated and credible information about alternate resources in the community including access to HCBS waiver services.

The ADRC program is a collaborative effort mobilizing both public and private sector resources. The program’s initiatives provides states with creative opportunities to effectively maximize and use their long-term support resources for providers and consumers in a single coordinated serviced delivery system consistent with the goals of long-term care rebalancing initiatives taking place at all levels.

ADRCs demonstrated their value in helping to shape long-term systems reform through various leadership initiatives. Many ADRCs facilitated the roll-out of Medicare Part D by working with AAAs, CMS, SHIPS, ILCs and other organizations to provide services

to thousands of individuals the provision of information and, in some instances, Part D enrollment. Many ADRCs have served as catalysts at the state and local levels for other long-term reform efforts through their partnerships with Systems Transformation Grants, Family 360 Grants, the Own Your Own Future campaigns and other initiatives. As the work of the ADRCs continue, ongoing beneficial outcomes are expected as these programs begin to proactively address the information and service needs of consumers seeking to improve their health status and opportunities for independence by maximizing community living opportunities and delaying or preventing dependence on institutional care.

Challenges and Emerging Roles for ADRCs

The Administration on Aging (AoA) and the Centers for Medicare and Medicaid Services (CMS) encourage ADRC grantees to further incorporate health promotion and disease prevention into their programs. Health promotion and disease prevention will continue to be a priority at the federal level as evidenced by the AoA Choices for Independence proposal which includes an evidence-based health promotion/disease prevention component that specifically builds on the lessons learned from AoA funded initiatives that enable older people to make behavioral changes that will reduce their risk of disease, disability, and injury.

ADRCs should consider disease prevention and health promotion as one of the functions of an ADRC. The prevention of acute and long-term care crises and chronic disease and disability enables individuals to sustain a high quality of life. Healthy individuals incur less medical expenditures. ADRCs can promote health by offering information, assistance and resources to individuals and families to enable informed decision-making before crises ensue. ADRCs offer other opportunities to educate individuals about health and wellness, begin special evidence-based programs, and collaborate with key health agencies in the community.

The outcomes that ADRCs have achieved over the past three years have had significant impact at the individual, program, community and state levels. The benefits, successes and lessons learned through ADRC experiences have energized and informed policymaking and program development at all levels in the long-term care arena. ADRCs have shown, as demonstrated in the findings in this report, that it is possible to develop more efficient and effective access to information and supports and that these initiatives are widely endorsed by diverse stakeholders involved in the rebalancing enterprise. They have demonstrated that it is possible to achieve economies of scale through decreasing duplication of effort, maximizing existing resources and building new, more effective partnerships.

**APPENDIX A:
ACRONYMS & GLOSSARY**

GUIDE TO ACRONYMS

AAA	Area Agency on Aging
ADRC	Aging and Disability Resource Center
AOA	Administration on Aging
APS	Adult Protective Services
CMS	Centers for Medicare & Medicaid Services
DHHS	U.S. Department of Health and Human Services
DHS	Department of Human Services
DSS	Department of Social Services
FTE	Full Time Equivalent
FY	Federal Fiscal Year
FFP	Federal Financial Participation
FPL	Federal Poverty Level
HCBS	Home and Community Based Services
I&R/A	Information and Referral/ Assistance
ILC	Independent Living Center
IT/MIS	Information Technology/ Management Information Systems
LIHEAP	Low Income Home Energy Assistance Program
MOU/A	Memorandum of Understanding/ Agreement
NFI	New Freedom Initiative
OAA	Older Americans Act
PAS	Pre-Admission Screening
SART	Semi-annual Reporting Tool
SHIP	State Health Insurance Assistance Program
SILC	State Independent Living Council
SSA	Social Security Administration
SSBG	Social Services Block Grant
SSI/SSDI	Supplemental Security Income/Social Security Disability Insurance
SUA	State Unit on Aging
TAE	Technical Assistance Exchange

GLOSSARY OF TERMS

2-1-1:

2-1-1 provides callers with information about and referrals to human services for every day needs and in times of crisis. Services that are offered through 2-1-1 vary from community to community. There are currently 209 2-1-1s operating in all or part of 41 states.

Adult Protective Services (APS):

A program that is typically state-administered and which involves the investigation of allegations of abuse, neglect, and exploitation of anyone over age 18 and provides protective services to those who are found to be maltreated.

Aging Network:

A highly complex and differentiated system of federal, state and local agencies, organizations, institutions, and advocates, which serve and/or represent the needs of older people.

Area Agencies on Aging (AAAs):

Public or private non-profit organizations designated by the state to develop and administer the area plan on aging within sub-state geographic planning and service areas.

Caregiver:

A generic term referring to a person either paid or voluntary, sometimes a family member or friend, who provides long-term care and support to a person in need of assistance.

Consumer:

A generic term for an individual who might be served by an ADRC.

Cost-sharing:

The practice of requesting that service recipients contribute a portion of the cost of a service provided.

Independent Living Center (ILC):

A consumer-controlled, community-based, cross-disability, non-residential non-profit agency that (1) is designed and operated within a local community by individuals with disabilities; and (2) provides an array of independent living services.

Disability network:

A highly complex and differentiated system of federal, state and local agencies, organizations, institutions, and advocates, which serve and/or represent the needs of people with disabilities.

Eligibility:

Financial eligibility: Financial eligibility requirements for Medicaid and other public long-term care programs vary from state to state, but generally include limits on the amount of income and the amount of assets an individual is allowed to have in order to qualify for publicly-funded services.

Functional or programmatic eligibility: Medical, functional and/or programmatic eligibility requirements for Medicaid and other public long-term care programs vary from state to state and by type of program (e.g. Medicaid state plan personal care services, home and community based services waiver), but generally include a requirement that an individual undergo a Level of Care or needs assessment and be determined to meet a certain threshold of need for assistance.

Federal Financial Participation (FFP):

Federal reimbursement to the state for a percentage of their allowable expenditures for Medicaid services or administrative costs

Home and Community-Based Services (HCBS):

A variety of supportive services delivered in community or home settings designed to help individuals in need of long term support remain living at home and avoid institutionalization.

Information & Referral/Assistance (I&R/A):

Information Specialists provide assistance and linkage to available services and resources. Information and assistance/referral may be provided via Internet, in person, or over the phone.

Long-term care (LTC) supports and services:

A set of health, personal care, and social services delivered over a sustained period of time to persons who have lost or never acquired some degree of functional capacity – either mental or physical. Services can be provided in an institution, the home, or the community, and include informal services provided by family or friends as well as formal services provided by professionals or agencies.

Low-income individuals:

Individuals with an annual household income that falls below the official poverty measure as established in the federal register by the U.S. Department of Health and Human Services.

Medicaid Agency:

The state agency that administers the federal and state-funded Medicaid program, which provides a broad array of medical and long-term care services to eligible individuals.

Medicaid HCBS waiver:

Funding for home and community-based services provided under the Medicaid program. States can receive waivers from certain Medicaid requirements in order to provide targeted assistance to different populations in non-institutional settings.

Mental Illness (MI):

MI includes such disorders as schizophrenia, schizoaffective disorder, bipolar disorder, major depressive disorder, obsessive-compulsive disorder, panic and other severe anxiety disorders, autism and pervasive developmental disorders, attention deficit/hyperactivity disorder, borderline personality disorder, and other severe and persistent mental illnesses that affect the brain.

Mental Retardation/Developmental Disability:

Diagnostic criteria for mental retardation usually include significantly sub-average intellectual functioning, concurrent deficits or impairments in present adaptive functioning in areas of major life activity, and onset before age 18. The Federal Developmental Disabilities Act defines Developmental Disability as a severe, chronic disability that is attributable to mental or physical impairment or a combination of impairments, is manifested before the person attains age 22, is likely to continue indefinitely, results in substantial functional limitation in three or more areas of major life activity usually arising before adulthood as a result of congenital causes, but sometimes due to brain injury, and characterized by any of various cognitive deficiencies, including impaired learning, social, and vocational ability.

National Family Caregiver Support Program (NFCSP):

Established by the Older Americans Act Amendments of 2000 to assist the aging network to develop a multi-faceted system of supports for caregivers.

Older Americans Act (OAA):

Federal law enacted in 1965 to provide money for programs and direction for a multitude of services designed to improve and enrich the lives of senior citizens.

Older adults:

Most ADRC grantees serve adults aged 60 and over, but in some cases the term older adults may include individuals aged 55 and over.

Options counseling:

Options counseling is a required function of an ADRC and refers to assisting consumers with making informed decisions about their long term support options. Options counseling is defined differently by different grantees. It may include some combination over time of the following activities: provision of information, making referrals, counseling, deliberating, assisting with applications, advocating, home visits, short-term case management, and conducting needs assessments and reassessments.

Personal care:

Assistance with activities of daily living, such as bathing, as well as with self-administration of medications and preparing special diets.

Physical Disability (PD):

A physical condition, including an anatomical loss or musculoskeletal, neurological, respiratory or cardiovascular impairment that results from injury, disease or congenital disorder and that significantly interferes with or significantly limits at least one major life activity of a person.

Single Point of Entry (SPE):

A system that enables consumers to access long term supports and services through one agency or organization.

State Health Insurance Assistance Program (SHIP):

A national program that offers one-on-one counseling and assistance about Medicare to recipients and their families. Through grants directed to states, SHIPs provide free counseling and assistance via telephone and face-to-face interactive sessions.

State Units on Aging (SUA):

SUAs are located in every state and U.S. territory. In addition to funding critical nutrition and supportive services, AoA funds are awarded to the SUA for elder rights programs, including the long-term care ombudsman program, legal services, outreach, and elder abuse prevention efforts.

Short-term case management (STCM):

STCM is used to stabilize individuals and their families in times of immediate need before they have been connected to ongoing support and services. It often involves more than one follow up contact.

Waiver: see Medicaid HCBS waiver

**APPENDIX B:
LIST OF EXHIBITS**

LIST OF EXHIBITS

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APPENDIX C: EXAMPLES OF PROGRAM RESOURCES

Exhibit C-1: Wisconsin ADRC Prevention Projects

Five Wisconsin ADRCs received funding from the Wisconsin Department of Health and Family Services to implement prevention projects. The projects are summarized in the chart below. Many partnered with the local university to add a research component.

County and Topic	Funding Source/ Amount/ Timeframe	Evidence-based Model	Activity in Grant Period	Evaluation Design/ Results	Descriptive Information/ Partnerships
Jackson Falls Prevention	2000/2001	NA	<ol style="list-style-type: none"> 1. Evaluated 59 adults ages 75 and over for balance, muscle strength, and walking speed. Western Dairyland EOC did home assessments for all and 40 homes had safety modifications. High school students trained to help older adults complete in-home daily exercise to increase leg strength and overall stability. 2. Started community-based weekly exercise and safety education program (92 active adults 55 and older). 	Pre- and post-tests for fall risk for 20 participants	Intergenerational effort – Collaboration with high-school, hospital rehab, Western Dairyland Economic Opportunity Council (EOC), Inc., and the physical therapy department at UW La Crosse.
Kenosha Falls Prevention	\$243,191 (2000/2001) \$265,782 (2001/2002)	Multifactor causes for falls. American Geriatric Society (2001) ²⁸	<ol style="list-style-type: none"> 1. Enrolled 346 participants in control or intervention group. 2. Offered intervention plans to intervention group including in home assessment by RN or PT and monthly follow-up. Plans included referrals to PT and recommendations to participant's physicians. 	Control and intervention groups. Participants reported falls on monthly basis.	Partnered with Dr. Gene Mahoney, UW Madison and Dr. Terry Shay, PT
Marathon In-Home Preventive Health Care	\$356,612 (2000/2001) \$381,928 (2001/2002)	Replicated a model which reduced disability rates and nursing facility use Stuck (2000) ²⁹	<ol style="list-style-type: none"> 1. In-home assessments by geriatric nurse practitioner for individuals <ul style="list-style-type: none"> -75 and older living at home; -no significant physical/ cognitive impairment; and -not terminally ill. 2. Telephone monitoring. 3. Linkage to RC services. Expect 430 participants over 3 years 	Control and intervention groups	North Central Health Care, Dr. Mark Sager, and UW Madison Medical School

County and Topic	Funding Source/ Amount/ Timeframe	Evidence-based Model	Activity in Grant Period	Evaluation Design/ Results	Descriptive Information/ Partnerships
Milwaukee Changing Health Related Behaviors	\$241,261 (2000/2001) \$237,790 (2001/2002)	NA	Targeted minorities (African American, Hispanic, Native American, Southeast Asian) over 60 and all seniors over 70. Three interventions: 1. Computer-based health risk assessment and internet-based health and fitness education. 2. Individual fitness assessments by exercise physiologist and assess to equipment and structured workout time. 3. Print information (pamphlets, booklets, and newsletters.)	Control and intervention groups Measured actual change in fitness and feeling about fitness (i.e. what motivates individuals to change health behaviors)	Collaboration with UW Milwaukee
Trempealeau Nutrition Risk Identification and Intervention	2000/2001	NA	Identified high or moderate nutritional risk individuals and provide: 1. Nutritional Counseling. 2. Personal health planning. 3. Volunteer assistance such as friendly visitor, transportation, and meal preparation. Also used funds to purchase strength training equipment for senior centers.	Measured nutritional health of participants and also benefits for volunteers	Collaboration with United Volunteer Caregivers, Inc.

Exhibit C-2: New and Enhanced Public Websites (Implemented and Planned)

State	Grant Yr.	Pilot Site	Website URL	Features	Planning or Implemented / New or Enhanced Site
AK	2004	All 5 Pilot Sites	www.alaskasilc.org	Information only.	Implemented Enhancements to Existing Site
AR	2004	Aging and Disability Resource Center Southwest Arkansas	http://www.sa-hello.org/	Interactive statewide resource directory, 156 local providers.	Implemented Enhancements to Existing Site
CA	2004	Aging and Independent Services of San Diego	http://sandiego.networkofcare.org/	Interactive resource directory, featuring "My Record" system where consumers to enter and update personal information.	Implemented Enhancements to Existing Site
		Del Norte InfoCenter	http://www.a1aa.org/dninfocenter	Interactive resource directory.	Implemented Enhancements to Existing Site
FL	2004		Statewide website is planned.		Planning New Site
GA	2004	Atlanta	Atlanta Regional Commission (ARC) http://www.agingatlanta.com/search.asp Atlanta Alliance for Developmental Disabilities: http://www.aadd.org/	Interactive resource directory through ARC's AgeLine	Implemented Enhancements to Existing Site
		Central Savannah River Area:	http://www.csrardc.org	Information only.	Implemented Enhancements to Existing Site
IL	2004	Rockford	www.nwilaaa.org	Information only.	Implemented Enhancements to Existing Site

State	Grant Yr.	Pilot Site	Website URL	Features	Planning or Implemented / New or Enhanced Site
		Decatur	http://www.maconcountyhealth.org		Implemented Enhancements to Existing Site
IN	2004	Both Pilot Sites	http://www.link-age.org	Interactive resource directory.	Implemented New Site
IA	2004	Statewide	http://www.LifeLongLinks.org	Links to several interactive resource directories.	Implemented New Site
LA	2003	All 5 Pilot Sites	http://www.LouisianaAnswers.com	Interactive resource directory.	Implemented New Site
ME	2003	Bangor	State planning ADRC website	Information only.	Planning New Site
MD	2003	Howard County and Worcester County	New statewide website is planned. MAP of Howard County currently uses: http://www.horizonhelp.org	Interactive resource directory. Benefits Check-up.	Planning New Site
MA	2004	Merrimack Valley and North Shore	Statewide "Virtual Gateway" website at pilot stage.	Interactive resource directory planned.	Planning New Site
MN	2003	Hennepin County	http://www.minnesotahelp.info	Interactive resource directory.	Implemented Enhancements to Existing Site
MT	2003	Yellowstone County	http://www.ycco.org	Information only.	Implemented Enhancements to Existing Site
NH	2003	All 5 Pilot Sites	http://www.servicelink.org	Information only.	Implemented Enhancements to Existing Site
NJ	2003	Atlantic County and Warren County	http://www.state.nj.us/adrcnj	Interactive resource directory.	Implemented New Site

State	Grant Yr.	Pilot Site	Website URL	Features	Planning or Implemented / New or Enhanced Site
NM	2004	Santa Fe and Statewide	Statewide Social Services Resource Directory website planned.	Information only.	Planning New Site
NC	2004	Forsyth County and Surrey County	Contract in place to create a statewide interactive resource database website, "NC Carelink."	Interactive resource directory.	Planning New Site
RI	2003	Statewide	www.ThePointRI.org	Information only. Interactive resource directory planned.	Implemented New Site
SC	2003	Aiken and Santee Lynches	www.scaccesshelp.org	Interactive resource directory. Online Medicaid application.	Implemented Enhancements to Existing Site
WV	2003	Ohio County	www.familyservice-uov.com	Information only.	Implemented Enhancements to Existing Site
		Marion County	www.marionseniors.org	Information only.	Implemented Enhancements to Existing Site
WI	2004	All 9 Established Sites and 9 New Pilot Sites	State planning virtual Resource Center.	Interactive resource directory.	Planning New Site