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

Interim Outcomes Report

Executive Summary

Prepared for:

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EXECUTIVE SUMMARY

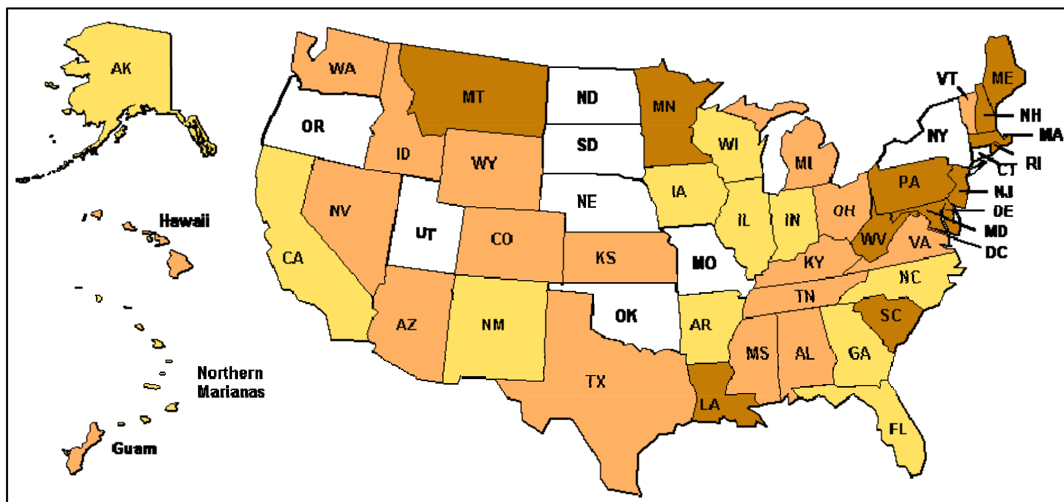
Background

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.

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

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.

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

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

- 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.

- 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.
- 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).

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%

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%)***	
• 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	• 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%)***	
• 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	• 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%)***	
• Partnerships between aging and disability agencies • Partnerships with state and county Medicaid agencies	• Involving partners early in the planning process. • Identifying champions in partnering organizations.

Challenges	Facilitators/ Lessons Learned
• Partnerships with other agencies	• 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%)	
• Integrating ADRC with other Medicaid system reform efforts/initiatives • Fragmentation of eligibility determination processes • Privacy concerns related to data sharing between agencies	• 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%)*	
• Recruiting consumers from target populations to participate • Maintaining active involvement of consumer participants	• 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.