By *Carol V. O'Shaughnessy*

Aging and Disability **Resource Centers** Can **Help** Consumers **Navigate the Maze** of Long-Term Services and Supports

Some might consider taming the LTSS access system to be a sisyphean challenge. Between the amended Older Americans Act and the ACA appropriations through fiscal year 2014, is there help on the horizon for the ADRC initiative?

Researchers and bloggers have described the process of gaining access to long-term services and supports (LTSS) as similar to wandering through a maze (Kane and Kane, 1981). Even to people knowledgeable about caring for elders and younger people with disabilities, the LTSS "system" seems to be a tangle of complicated services, programs, funding streams, and eligibility requirements. Most individuals, including those who have financial resources to pay for their care, do not know where to get help or how to access preferred services. They often find the LTSS system confusing, difficult, and frustrating.

Given the enormous federal and state costs (in 2009, LTSS spending was more than $203 billion, almost 10 percent of all personal healthcare spending in the United States), policy makers have sought ways to improve LTSS access and provide better outcomes for consumers, providers, and payers. The Patient Protection and Affordable Care Act (ACA) offers states expanded opportunities to improve LTSS access for consumers and their families.

Helping Consumers Through the Maze

Beginning in the 1980s, a few state aging and Medicaid agencies implemented ways to streamline access for public LTSS programs through "single point of entry" and "no wrong door" approaches. Single points of entry provide

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consumers access to LTSS through one agency that sorts out care alternatives and helps people make decisions about the best and most feasible

Chronology of ADRC Development

1999—The *Olmstead vs. L.C.* Supreme Court decision requires states to administer services, programs, and activities to appropriately meet the needs of people with disabilities in the most integrated setting.

2001—President Bush announces the New Freedom Initiative as part of a nationwide effort to remove barriers to community living for people with disabilities.

FY 2001— Department of Health and Human Services (HHS) initiates Real Choice Systems Change (RCSC) Grants for Community Living to help states modify their LTSS systems to promote home and community-based services.

FY 2003—First federal grants made to twelve states for ADRC development under the RCSC initiative; funding continues through fiscal year 2010.

2003—ADRC Resource Center Technical Assistance Exchange established (*www. adrc-tae.org*).

2006—Older Americans Act legislation adds requirement that the Administration on Aging establish ADRCs in all states.

2009—President Obama announced the Year of Community Living, and HHS announced the Community Living Initiative that includes ADRCs.

2010—P.L. 111–149, the Patient Protection and Affordable Care Act, appropriated $10 million for ADRCs for each of fiscal years 2010 through 2014.

options (Mollica and Gillespie, 2003). In the second approach, multiple agencies cooperate to assist consumers in need, regardless of which agency is the first consumer contact point, so they may enter through no wrong door.

The Administration on Aging (AOA) and the Centers for Medicare and Medicaid Services

(CMS) have expanded both approaches into a national initiative to create Aging and Disability Resource Centers (ADRC). The purpose of these centers is to help people of all ages, disabilities, and income levels to more easily access LTSS and transition among various sites of care, make more efficient use of care options, and maximize available services. The AOA and the CMS envision ADRCs as highly visible and trusted places, available in every community across the country, where individuals can get information on the full range of LTSS options.

Initial federal grants were made to twelve states in fiscal year 2003, and additional states received grants in succeeding years. In 2006, Congress amended the Older Americans Act to require the AOA to establish ADRCs in all states. The ACA continued this initiative by appropriating $10 million for each of fiscal years 2010–2014.

As of February 2011, more than 340 ADRC sites were in operation across fifty-three states and territories (see Table 1, page 66), about one-third of which have statewide systems (Administration on Aging, 2011). Based in part on the experience gained from state initiatives for the "single point of entry" and "no wrong door" approaches, the AOA and the CMS have defined five key functions to be carried out by ADRCs: consumer information and referral-awareness services; options counseling; stream-lined eligibility determination for public programs and access to services; person-centered transition support; and quality assurance and continuous improvement (Administration on Aging, 2010). Information specialists, nurses, social workers, a multidisciplinary team, or other trained staff perform ADRC functions and work in collaboration and at the direction of consumers. Agencies that serve both the aging and disability communities are built into the ADRC design.

States have developed two types of ADRC models, based on the "single point of entry" and "no wrong door" approaches described. In addition, some ADRCs may use hybrids of the

integrated-centralized and coordinated-decentralized model; for example, they might use one approach for aging services and another approach for services to younger people with disabilities (Blakeway, 2007). Organizationally, most states have designated area agencies on aging as lead agencies, which cooperate with other partners to carry out ADRC functions. Some have designated centers for independent living to serve as lead agencies.

The AOA and the CMS have been fairly specific about ADRC functions, and have articulated the vision in many venues. They have supported multiple technical assistance conferences and an extensive Technical Assistance

Exchange effort (*www.adrc-tae.org*) to help states implement their vision. Even with these efforts, ADRC operations and capacity vary widely. Variation is expected, and implementation is affected by state and local commitment, resources, and infrastructure differences. Recently, the AOA has directed states to use federal grant funds to standardize functions and use evidence-based models in ADRC implementation (AOA, 2010).

Evaluation Efforts

State and federal evaluation efforts will affect future ADRC development. Some states have already evaluated their programs. High levels of consumer satisfaction were found in state

Table 1. Federal Funding for ADRC State Grants, Fiscal Years 2003–2010 (in Millions of Dollars)

Fiscal Year	No. of States Funded	AOA[a]	CMS[b]	Total	Funding Source/Authorizing Legislation
2003	12	$9,688	$4,911	$14,599	AOA Title IV funding and CMS Real Choice System Change grants
2004	12[c]	$7,936	$4,485	$12,421	AOA Title IV funding and CMS Real Choice System Change grants
2005	19[d]	$8,922	$6,164	$15,086	AOA Title IV funding and CMS Real Choice System Change grants
2006 & 2007	None	0	0	0	
2008	11	0	$12,976	$12,976	CMS Person-Centered Hospital Discharge Planning grants and CMS Real Choice System Change grants
2009	49[†]	$22,367	0	$22,367	AOA Title II and Title IV funding
2010	43[d]	$23,132	$9,986	$33,118	Patient Protection and Affordable Care Act, Money Follows the Person Rebalancing Demonstration; and AOA Title II and Title IV funding
Total Funding All Years		$72,045	$38,522	$110, 567	

a Administration on Aging; b Centers for Medicare and Medicaid Services; c Includes Northern Marianas; d Includes District of Columbia; † Includes District of Columbia, Puerto Rico, and Guam

Source: Administration on Aging, e-mail communication with author, October 8, 2010.

Note: The Administration on Aging did not fund ADRC grants in 2008. The CMS reported funding for 2008 and 2009 combined.

evaluations in Wisconsin, Michigan, New Hampshire, Vermont, and Georgia. Satisfaction measures included services received, ease of access, staff responsiveness to unique individual needs and preferences, and other areas (Wisconsin Department of Health Services, 2009; Aging and Disability Resource Centers, Technical

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Assistance Exchange, 2010). Supporters of ADRCs indicate that they offer opportunities for greater cost efficiencies in delivering LTSS, such as streamlining consumer assessment and eligibility determinations and helping consumers access home- and community-based alternatives to institutional services. To date, little attention has been given to the impact of ADRCs on cost effectiveness, with the exception of limited state evaluation efforts.

The AOA has initiated a national evaluation of ADRCs in order to understand the broad experiences of people who access LTSS as well as the community and program characteristics that facilitate access. The federal evaluation faces numerous challenges. Because of the wide variation among ADRCs nationwide and because ADRC functions are multilayered and complex, outcomes may have to be assessed within the context of broader state policies, programs, and funding streams.

Policy Challenges, Questions to Consider

As the national ADRC initiative continues to unfold in coming years, policy makers may want to consider the following questions:

- What level of federal, state, and local resources and staffing will it take to fully implement the ADRC vision and the objective to have statewide ADRCs in all states?
- How will outcomes be assessed? Can ADRCs improve consumer access to and coordination of LTSS systems? Will these efforts be sufficient to achieve high consumer satisfaction and outcomes, even if cost effectiveness is difficult to demonstrate? What factors external to ADRC implementation will affect cost effectiveness?
- ADRCs are tasked with helping people plan ahead for LTSS needs before they need care. What impact will ADRCs have on this objective?
- ADRCs are intended to improve consumer access but are not funded to provide home- and community-based services. Can the information ADRCs provide about unmet service needs in their communities be used to better target new investments in the home- and community-based services system?

Some might consider the taming of the LTSS access system to be a sisyphean challenge. Moving from the original conceptualization of ADRCs, to pilot projects in a small number of states, to fully functional ADRCs in all states will take time and an undefined level of investment. The ADRCs are charged with implementing a multifaceted agenda with limited resources. Thus far, federal AOA and CMS resources devoted to the effort ($111 million through fiscal year 2010) are extremely modest. The ADRC fiscal year 2010 appropriations of $10 million represent less than $1 for each person receiving LTSS and less than one-third of 1 percent of total Medicaid home- and community-based services spending for fiscal year 2009.

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Note from the Author

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For Further Reading

Please refer to March 15, 2011, paper, "National Spending for Long-Term Services and Supports (LTSS)" by Carol V. O'Shaughnessy, National Health Policy Forum. www.nhpf.org/library/the-basics/Basics_LongTermServicesSupports_03-15-11.pdf.

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