

State Long-Term Services and Supports Scorecard What Distinguishes High- from Low-Ranking States? Case Study: Georgia

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Introduction

The *State Long-Term Services and Supports Scorecard* found wide variation in how states perform across the 25 indicators that comprise the key dimensions of a high-performing system. The *Scorecard* is designed to help states improve the performance of their long-term services and supports (LTSS) systems by targeting opportunities for improvement. Looking to other states that performed better in specific areas can inform potential paths for improvement. Leading states do well in many areas, but even states with a low ranking scored in the top quartile for at least one indicator. A series of case studies provides a deeper context for understanding how high-, medium-, and low-ranking states performed for the baseline *Scorecard*, and how they are already striving to improve LTSS for older people and adults with physical disabilities. This case study focuses on Georgia.

Highlights for Georgia

Like most southern states, Georgia ranked in the lowest quartile of state LTSS performance. As shown in table 1, Georgia had an overall rank of 42, meaning 41 states scored higher than Georgia on the overall ranking. Appendix A provides a complete summary of Georgia's overall ranking and the state's ranking on each of the 25 indicators that comprise the four dimensions.

- The biggest challenge Georgia faces is allowing consumers to exercise more *Choice of Setting and Provider*.
- The state's biggest achievement is providing legal and system *Support for Family Caregivers*.

¹ S. Reinhard, E. Kassner, A. Houser, and R. Mollica, *Raising Expectations: A State Scorecard on Long-Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers* (Washington, DC: AARP Public Policy Institute, September 2011).

- Although the state ranks in the first quartile for Affordability and Access of private-pay nursing home and home care costs, access to LTSS for low-income people in need of help is thwarted by a weak Medicaid safety net.
- Most *Quality of Life and Quality of Care* indicators signal a need for improvement, particularly in promoting employment opportunities for people with disabilities and reducing hospital admissions for long-stay nursing home residents.

Table 1: Georgia's Ranking on the Scorecard

| Georgia and the Scorecard Dimensions | Ranking where 1 = highest | Quartile Ranking where First Quartile is the highest |
|--------------------------------------|---------------------------|---|
| Overall Ranking | 42 | Fourth Quartile |
| Affordability and Access | 33 | Third Quartile |
| Choice of Setting and Provider | 44 | Fourth Quartile |
| Quality of Life and Quality of Care | 31 | Third Quartile |
| Support for Family Caregivers | 24 | Second Quartile |

Recent state policy changes offer promising progress. First, after 16 years of effort, the state promulgated assisted living regulations in January 2012. Second, state leaders convened multiple stakeholders to develop new "proxy caregiver" regulations that will permit direct care workers to provide more help with medication administration and other health maintenance tasks. New rules established in August 2011 should promote consumer direction and offer more relief to family caregivers.

To make further progress, policymakers need to commit to a progressive vision for promoting independence, dignity, and choice for older adults and people with disabilities. Strong leadership is needed to overcome departmental fragmentation at the state level and resistance to change from powerful provider groups and those who do not share other stakeholders' passionate demand for change.

Background

The *Scorecard* is the first attempt to use a multidimensional approach to comprehensively measure state LTSS system performance overall and across diverse areas of performance. It describes the goals to aim for when considering both public policies and private sector actions that affect how a state organizes, finances, and delivers service and supports for people who need ongoing help with activities of living (ADLs), instrumental activities of living (IADLs), health maintenance tasks, service coordination, and supports for their family caregivers. The *Scorecard* examines state performance across four key dimensions of LTSS system performance: (1)

Affordability and Access; (2) Choice of Setting and Provider; (3) Quality of Life and Quality of Care; and (4) Support for Family Caregivers.²

Georgia offers an important example of a state that had a low ranking score overall, a landmark Supreme Court decision that helped fuel a national movement toward more home- and community- based services (HCBS), and recent efforts to develop policies that might improve the state's future ranking.

A southern state of 9.7 million people, Georgia is a relatively "young state," with only 10.3 percent of its population age 65 years or older, compared with 12.9 percent nationally. The median household income of \$47,590 falls below the \$50,221 national median income but exceeds that of all its neighboring states, Alabama, Florida, Louisiana, Mississippi, North Carolina, South Carolina, and Tennessee. The state is slightly below the national average of people age 18–64 with an ADL disability (1.7 percent compared with 1.8 percent) and slightly above the national average for older people with an ADL disability (9.8 percent compared with 8.8 percent).

Administrative responsibility for LTSS is spread over multiple state departments, with no clear locus for aging and disability policy and program development, financing, and accountability. The Department of Community Health (DCH) administers the Medicaid program and is responsible for the licensing health care facilities, nursing home policy, and budgeting. The Division of Aging is under the Department of Human Services (DHS) and administers the Aging waiver, although waiver policy and the budget are with Medicaid in DCH. The Division of Aging also administers the Long-Term Care Ombudsman Program, which acts as an advocate for residents of nursing homes, personal care homes, and community living arrangements. Financial eligibility is determined at county level by the Department of Human Services Division of Family and Children Services.

No clear state LTSS philosophy, vision, or commitment to consumer choice is found in statute or regulations. Stakeholders indicate that an LTSS vision has been articulated by both the Division of Aging and the Georgia Council on Aging, but these points of view do not appear to be shared by all state departments or a majority of legislators. Stakeholders see this as a major impediment to progress in achieving a high-performing LTSS system. In addition, the nursing home industry has successfully resisted policies and financing tools that promote HCBS. With growing focus on serving more Medicare-financed rehabilitation clients, some of that resistance appears to be abating. In addition, more providers see opportunities in providing HCBS services to a growing population of aging baby boomers who seek alternatives to institutional care.

Methodology

To better understand the context for Georgia's current *Scorecard* ranking and the state's plans for improvement, the authors conducted a site visit in January 2012. In addition to document reviews, data collection included participant observations and interviews.

² Adequate state-level data were not available to assess states' performance on a fifth dimension, *Effective Transitions and Organization of Care*.

³ All data are found in the *Scorecard* Exhibits 15–17. See http://www.longtermscorecard.org.

Participant observations took place at four meetings:

- Georgia Council on Aging leadership, with discussions of their LTSS vision and future goals
- The Coalition of Advocates for Georgia's Elderly (CO-AGE) quarterly meeting, including presentations on budget and legislative priorities
- Long-Term Care Vision Summit, including presentations from the vice-chair of the Senate Appropriations Human Development Committee and the executive director of the Georgia Budget and Policy Institute
- Olmstead Planning meeting

The following stakeholders were interviewed:

- State officials in the Division on Aging, Department of Community Health/Medicaid and Health Care Facility Regulation, and Board of Nursing
- Local/regional leaders in Area Agencies on Aging
- Health care professionals
- LTSS providers
- Consumer advocates, including AARP Georgia staff and volunteers, Alzheimer's Association staff, and developmental disability advocates

We focused on factors that affect Georgia's performance in each of the *Scorecard*'s four dimensions, with priority attention to selected indicators in the top and bottom quartiles. We also explored current or planned activities that might lead to improvement.

Current Status and Future Potential for Progress

Affordability and Access

The dimension of *Affordability and Access* measures the extent to which individuals and their families can easily navigate their state's LTSS system, finding readily available, timely, and clear information to make decisions about LTSS. In a high-performing system, services are affordable for those with moderate and higher incomes, and a safety net is available for those who cannot afford services. Eligibility is determined easily and quickly, and the costs of LTSS do not impoverish the spouse of the person needing LTSS.

Georgia ranks 8th in median annual nursing home private-pay cost as a percentage of median household income for people age 65 or older. Despite this high ranking, the annual nursing home cost averaged 188 percent of older people's annual income in Georgia. That means that nursing homes in Georgia are more affordable than in most other states but still too costly for middle-income people. Georgia ranks 17th in private-pay home care cost, but this care costs 86 percent of an older person's average income. Clearly, the cost of LTSS is more than most people can manage, and few people in Georgia have purchased long-term care insurance to help. Georgia ranked 41st in the percentage of people who have long-term care insurance, meaning 40 other states had higher percentages. In addition, the percentage of adults with an ADL disability and

limited income who receive Medicaid LTSS is low because the financial eligibility criteria for Medicaid are restrictive compared to other states.

Georgia does have a statewide system for helping older people and adults with disabilities access information about a range of services and supports. Twelve Area Agencies on Aging (AAAs) have contracts with the Division of Aging to create and administer a Gateway/Aging and Disability Resource Connection (ADRC) system of information and referral. In state fiscal year 2011, some 62,344 people contacted one of the 12 ADRCs.⁴

ADRCs perform four functions:

- Provide information and assistance to older adults and individuals with developmental and physical disabilities;
- Use the Enhanced Services Program database, with its 24,000 listings, to search for statewide and local resources based on an individual's needs;
- Screen individuals using the Determination of Need-Revised assessment to determine the need for services and maintain the waiting lists for state services; and
- Maintain a toll-free line for callers.

One critical function that the Georgia ADRCs do not perform is nursing facility preadmission screening. Nursing homes perform this function, which means consumers do not have access to an unbiased expert who can review all of their service options.

Choice of Setting and Provider

Georgia's greatest challenge is its 44th ranking in offering consumers more noninstitutional choices for LTSS and more control over how services are provided. The state's policy and funding decisions over the past decade appear to show a priority for institutional settings rather than access to HCBS.⁵ And the state has far to go in offering consumers more options to direct their services.

Choices

Between 2002 and 2007, Georgia increased Medicaid HCBS spending for older people and adults with physical disabilities, as a percentage of total LTSS spending, by only 7 percent. In 2007, \$821 million was spent on nursing home care versus \$183 million on HCBS for these populations. Georgia ranked 44th on HCBS expenditures per person.⁶

⁴ Unless otherwise stated, information reported on the Community Care Services Program (CCSP) is taken from its 2011 Annual Report, http://aging.dhr.georgia.gov/DHR-DAS/DHR-DAS Publications/CCSP%20STATEWIDE%20SFY%202011%20ANNUAL%20REPORT%20%20%2012.7.2011.pdf.

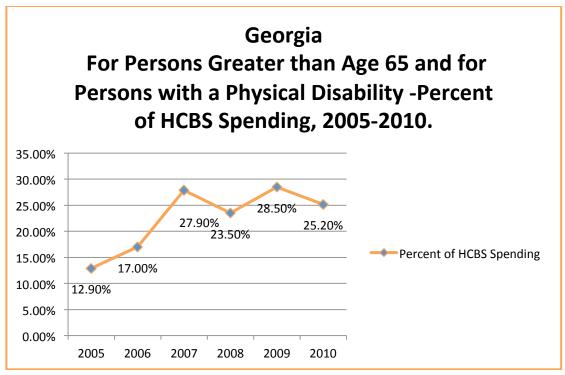
⁵ The original *Olmstead* decision that helped fuel the national push for better access to HCBS was based on a 1995 case that the state of Georgia fought for four years before losing in the Supreme Court in 1999. For a brief historical review of the *Olmstead* case, see

http://www.chhs.ca.gov/initiatives/Olmstead/Documents/OlmsteadBackgroundFinal.pdf.

⁶ AARP Public Policy Institute, *Across the States: Profiles of Long-term Care and Independent Living* (Washington, DC: AARP PPI, 2009).

However, data from 2005 through 2010 show that Georgia made progress toward a balanced LTSS from 2005 to 2007 and has been flat since then. The percentage of Medicaid spending on HCBS for older adults and adults with disabilities increased from 12.9 percent in fiscal year (FY) 2005 to 27.9 percent in FY 2007, and was at 25.2 percent in FY 2010. (See figure 1.)

Figure 1: Percentage of HCBS Spending in Georgia for People Greater than Age 65 and for People with a Physical Disability, 2005–2010.



Data source: Thomson Reuters.

The effectiveness of mechanisms to offer a choice of institutional care or HCBS can be measured in part by the services beneficiaries use when they first enter the LTSS system. In Georgia, two-thirds of new Medicaid LTSS users first receive services in institutions rather than in the community, which reflects a lack of systems to divert people from institutional care by offering them choices outside of nursing homes, and timely information and help them get those services. It is difficult to divert when there is an HCBS waiting list (see below). The highest-performing state on this indicator serves more than 83 percent of new Medicaid LTSS users in the community. If Georgia improved its performance to this level, 6,241 more people funded by Medicaid to receive LTSS would be served in less expensive HCBS settings.

Based on lessons from higher-ranking states, two policy changes might help Georgia better balance its LTSS system by offering consumers a better chance to avoid unnecessary institutional care. First, as discussed above, the state could permit its ADRCs, or Medicaid

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⁷ S. Eiken, K. Sredl, B. Burwell, and L. Gold, *Medicaid Expenditures for Long-term Service and Supports: 2011 Update* (Thomson Reuters, October 31, 2011), p. 49, http://www.hcbs.org/files/208/10395/2011LTSSExpenditures-final.pdf.

waiver case managers—rather than nursing homes—to conduct preadmission nursing home Medicaid eligibility screenings. As unbiased assessors, the ADRC staff could help people understand their options as they determine eligibility. Second, the state could institute a "presumptive eligibility" policy for HCBS. More than a dozen other states have implemented this practice, which allows Medicaid financial eligibility workers or waiver case managers to use basic information to quickly presume that a low-income person will be eligible for Medicaid before the full formal process is completed. That person can then be offered an HCBS option. The state bears the risk if the ultimate determination finds the person is not eligible for Medicaid—an extremely low risk, as documented by states that have had this practice for years. Without presumptive eligibility for HCBS, only the nursing home providers are willing to bear the risk that the person will eventually become eligible for Medicaid. However, this policy would help only if the state were to eliminate the HCBS waiting lists. 9

The ramp-up of the Money Follows the Person (MFP) program may help increase access to HCBS, since there is no waiting list for this target group. Through MFP, the Centers for Medicare & Medicaid Services (CMS) provides states with enhanced reimbursement for HCBS services provided to Medicaid beneficiaries who move from an eligible institution (hospital, nursing home, or intermediate care facility for people with mental retardation) to an eligible residence in the community. The enhanced reimbursement is available for 365 days following the transition. After day 365, HCBS services continue at the regular federal matching rate. Eligible residences include a home, an apartment with a lease, or a group home that serves four or fewer residents.

Eligible participants must have lived in an institution (nursing home or hospital) for at least 90 consecutive days, excluding rehabilitative days, and have been Medicaid beneficiaries for at least one day prior to transition. Georgia's MFP program is a joint initiative between the Department of Community Health, the Department of Behavioral Health and Developmental Disabilities, and the DHS Division of Aging Services. Awarded to DCH in 2007 by CMS, MFP was implemented in September 2008. The Division on Aging began administering the program for older adults and adults with disabilities in July 2011.

The Georgia MFP program plans to transition 2,293 people from institutions over nine years and to increase the percentage of spending for HCBS to 50 percent for all populations by the end of the program in December 2016. ¹⁰ By December 2011, 744 people had transitioned from institutions to the community. Twenty percent of those who moved to the community were older adults, 27 percent were adults with physical disabilities, and 53 percent had intellectual/developmental disabilities.

New transition services were added to support participants who move to the community. These services include one-time purchases of basic household items and furnishings, utility deposits,

⁸ R. Mollica, *Fast Track, Presumptive and Expedited Eligibility* (New Brunswick, NJ: Community Living Exchange at Rutgers Center for State Health Policy and National Academy for State Health Policy, 2005).

⁹ All waivers (except the SOURCE program until January 2012) have waiting lists: For example, on December 1, 2011, there were 1,536 people waiting for CCSP, 2,879 waiting for the New Options Waiver, and 3,208 waiting for services from the Comprehensive Supports Waiver.

¹⁰ http://dch.georgia.gov/vgn/images/portal/cit 1210/49/44/174440175MoneyFollowsThePerson FY12.pdf.

security deposits, transportation to assist in housing searches, and funding for home environmental modifications.

Georgia originally had a goal of transitioning 1,300 people by 2011. It fell short of this goal for the following reasons:

- The complexity of working across Georgia's organizational structure
- The complexity of working with multiple populations and kinds of disabilities
- Performance contracting problems
- Problems hiring transition coordinators¹¹

As directed by CMS, Georgia set lower goals and was one of just a few states that exceeded its revised benchmark goal for the number of transitions in 2011. The state planned to support 200 transitions during all of 2011 and transitioned 209 during the first six months of the year. Georgia shifted the transition coordination function from a private contractor to ADRCs. This shift represents a better coordination between ADRC programs and other state agencies. Each ADRC received funding for transition coordinator and Minimum Data Set Section Q Options Counselor staff.

Choice of Setting and Provider

Georgia ranks 41st in consumer direction, a policy and programmatic approach that permits individuals to hire and fire their personal care worker and determine the schedule of when they think they need help. For the indicator that measures the percentage of HCBS users in publicly funded programs who direct their own services, Georgia's score of 2.8 percent compares to a national average of 22.3 percent. In other words, the average Medicaid program offers almost 10 times more self-direction than Georgia. Although Georgia has seven programs that include participant self-direction, fewer than 3,000 people used self-direction in February 2011. Family caregivers may not serve as paid workers under Georgia's Medicaid HCBS programs. Stakeholders contend that the state lacks a firm commitment to advancing consumer direction, although some state officials say they would like to see more progress.

Consumer direction/control is not a strong component of either of the two Medicaid programs that cover HCBS for older adults and adults with physical disabilities—the Elderly and Disabled Waiver, known as the Community Care Services Program (CCSP), and the SOURCE (Service Options Using Resources in Community Environments) program. ¹⁴ Georgia also has a state-only funded HCBS program for older adults, but the current waiting list is 20,117. ¹⁵

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¹¹ Kaiser Commission on Medicaid and the Uninsured, *Case Study: Georgia's Money Follows the Person Demonstration* (December 2011), http://www.kff.org/medicaid/8262.cfm.

N. Denny-Brown, D. Lipson, M. Kehn, B. Orshan, and C. S. Valenzano, *Money Follows the Person Demonstration: Overview of State Grantee Progress, January to June 2011* (Mathematica Policy Research, December 2011), http://www.mathematica-mpr.com/publications/PDFs/health/mfp_jan-jun2011_progress.pdf.
 http://www.thescanfoundation.org/sites/scan.lmp03.lucidus.net/files/TSF_CLASS_TA_No_10_Financial_Management_Services_FINAL.pdf See appendix A of this report for state data.
 http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/Waivers.html.

¹⁵ CO-AGE, "Funding for home and community based services," Fact sheet provided at the CO-AGE Winter 2012 Quarterly Meeting, January 5, 2012, KSU Center, Georgia.

The CCSP is administered by Area Agencies on Aging under contract with the Division of Aging Services. ¹⁶ The income level for the CSSP program is 300 percent of Supplemental Security Income (SSI), or \$2,094 per month. ¹⁷ The number of people using waiver services has declined over the past decade, from 16,653 in 2002 to 12,421 in 2011. Table 2 shows the services covered, the number of participants, and the costs of the services for 2011. ¹⁸ There is very little consumer direction in this program.

Table 2: CCSP Services Provided, Number of People Using Them, and Costs, 2011

| Community Care Services Program | Number of People Using Service | Funds Expended |
|--|-----------------------------------|-------------------|
| Adult Day Health (ADH) | 805 | \$ 5,399,370 |
| Alternative Living Services (ALS) | | |
| - Group Model | 1,622 | \$ 9,011,589 |
| - Family Model | 726 | \$ 3,914,012 |
| Consumer-Directed PSS option (CDPSS) | 370 | \$ 210,852 |
| Emergency Response Services (ERS) | 5,707 | \$ 1,261,754 |
| Home-Delivered Meals | 5,524 | \$ 9,028,480 |
| Home-Delivered Services (HDS) | 38 | \$ 69,464 |
| Skilled Nursing Services | 74 | \$ 145,527 |
| Out-of-Home Respite Care | 88 | \$ 79,978 |
| Personal Support Services (PSS, PSSX) | 9,101 | \$ 77,464,455 |
| Total | 12,421 | \$ 106,585,481 |
| Note: People can use more than one service | | |

Data source: Georgia Department of Community Health.

Georgia has a second program for older adults or adults with a physical disability called SOURCE. ¹⁹There is no consumer direction in SOURCE.

SOURCE is a statewide enhanced primary care case management service that links primary medical care with long-term services and supports in a person's home or community setting to

¹⁶ http://ois.dhr.georgia.gov/DHR-DAS/DHR-DAS Publications/client%20brochure%20Jan%2006.pdf.

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¹⁷ SSI payment amounts are shown at http://www.ssa.gov/OACT/COLA/SSIamts.html.

¹⁸ See the CCSP Annual Report for 2011, p. 16, http://aging.dhr.georgia.gov/DHR-DAS/DHR-DA

¹⁹ Interviewees report that there has been discussion between Georgia Medicaid staff and federal Medicaid staff about converting the SOURCE program from a Medicaid state plan program to a Medicaid program waiver. As of March 5, 2012, the Department of Community Health's website still refers to it as a Medicaid state plan program.

prevent unnecessary emergency room visits and hospital stays and avoid institutionalization.²⁰ Until January 1, 2012, there was no waiting list for SOURCE services. SOURCE has approximately a dozen agencies that provide case management services throughout the state.²¹ Many nursing homes are operating SOURCE programs. In 2010, approximately 21,381 people received a SOURCE service. The program has grown rapidly in recent years. In 2005 it had only eight providers and served 4,100 people.²² The income eligibility limits for the service are 100 percent of the SSI level. In 2012, 100 percent of SSI equaled \$698 a month for a single individual.

These data indicate that Georgia is downsizing CCSP, which provides HCBS services to people under 300 percent of SSI, and expanding SOURCE, which provides primary care case management to people under 100 percent of SSI. Moreover, CCSP has a waiting list; SOURCE has operated without a waiting list. As of January 2012, there were 2,086 people on the CCSP waiting list.²³ People interviewed indicate the state is struggling to combine the CCSP and SOURCE programs in the next waiver renewal.

One potential new policy that may help Georgia move to a higher ranking in the *Choice of Setting and Provider* dimension is new assisted living legislation, SB 178, and its implementing regulations promulgated in January 2012.²⁴ Interpretive guidelines will be published in the coming months. The Department of Community Health was charged to create a "meaningful distinction" in the level of care provided in LTSS. "Assisted living care" is to be an intermediate level of care between nursing homes and personal care homes. An assisted living community may not have fewer than 25 beds. And while in the past it was assumed that residents would self-administer medications, medication administration will be more regulated in assisted living. Assisted living communities must employ medication aides certified by DCH. The rules require random quarterly observations by registered nurses of how the medication aides administer medications to residents, and quarterly reviews of medications by a pharmacist.

The state intends to enable consumers to make better choices by "shopping around" for the level of care and other features they need and prefer. Nursing homes, assisted living communities, and personal care homes will all need to provide "profiles" that will become part of a searchable website so consumers can find the services they need (e.g., specialized care, presence of a nurse, pictures of rooms and lobby). The state will check the provider's profile for accuracy when inspecting the facility. The goal is to help consumers make more informed choices about where they purchase long-term care services.

An indicator on which Georgia scored low was "The number of home care aides per the population age 65 or older." Georgia's score of 20 was approximately half the national average. A shortage of health care workers in Georgia is hardly news. Efforts to address this situation go

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²⁰ See http://dch.georgia.gov/vgn/images/portal/cit_1210/28/23/31945394homencommbooklet27-12-2010.pdf, p. 8. ²¹ For a list of SOURCE case management agencies, see http://dch.georgia.gov/vgn/images/portal/cit_1210/28/23/31945394homencommbooklet27-12-2010.pdf, p. 8.

¹²⁷⁹¹¹⁹²⁷SOURCE Case Management Providers0jan2012.pdf.

²² J. Gillespie et al., *Coordinating Care in the Fee-for-Service System for Medicaid Beneficiaries with Chronic Conditions*, Report prepared for the U.S. Department of Health and Human Services, Office of Disability, Aging and Long-Term Care Policy (Washington, DC, May 2005), http://aspe.hhs.gov/daltcp/reports/ccMedben.htm.

²³ CO-AGE, Funding for home and community based services.

²⁴ http://www.legis.ga.gov/legislation/en-US/Display/20112012/SB/178.

back more than a decade. For example, in 2002 Georgia received a \$5 million grant from the Department of Labor to recruit and train employed people to be nurses and health care workers. Another example is the state's 2003 reporting on the results of its Real Choice System Change grants, which identified workforce shortages. At a macroeconomic level, a shortage of personal and home care aides is understandable, given the wages paid them. When inflation is taken into account, wages for personal and home care aides in Georgia have gone down over 2000–2009. In 2000 wages for personal and home care aides were \$7.37 per hour, and in 2009 the average wage was \$7.13.²⁷

Quality of Life and Quality of Care

Most *Quality of Life and Quality of Care* indicators signal a need for improvement, particularly in promoting employment opportunities for people with disabilities and reducing hospital admissions for long-stay nursing home residents. Whereas the highest-performing state had only 8.3 percent of its nursing home residents admitted to hospitals, Georgia's nursing homes admit 20.8 percent of their long-stay residents to hospitals. If Georgia could meet the performance of the top state in this area, 3,112 people would avoid unnecessary hospitalizations, with a savings to the Medicare and Medicaid programs of more than \$25 million.²⁸

Support for Family Caregivers

Although Georgia ranked 47th in the percentage of caregivers usually or always getting needed support, the state is a national leader (7th) in providing legal and system supports for caregivers. The composite indicator measuring this support includes five components. Like most states, Georgia does not exceed the federal requirements in the Family Medical Leave Act, have mandatory paid family and sick leave, or protect caregivers from discrimination. These are three areas that the state could consider for further leadership. However, Georgia does have strong spousal impoverishment provisions in its HCBS regulations, in part because it was one of the last states to enforce Medicaid estate recovery, and state policies apparently placed a high value on allowing beneficiaries to keep their homes, according to one experienced stakeholder.

The state also offers caregivers an assessment of their own needs for support and refers them to helpful resources. Stakeholders credit the strong advocacy of the Roselyn Carter Institute for Caregiving in Georgia as a factor in the state's success in this area. The state uses the Tailored Caregiver Assessment and Referral model to guide family caregiver assessments by the ADRCs.²⁹

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²⁵ http://www.careerinfonet.org/crl/CRL_RRSearch.aspx?docn=9517.

²⁶ J. O'Keeffe et al., *Real Choice Systems Change Grant Program, FY 2003 Grantees: Final Report*, prepared for the Centers for Medicare & Medicaid Services (Washington, DC, July 2009), pp. 3–33 ff, http://www.hcbs.org/search.php?glbSearchBox=georgia&ofs=10&sby=Date&lim=ALL.

²⁷ PHI, State Chart Book on Wages for Personal and Home Care Aides, 1999-2009 (Bronx, NY, June 2010), http://www.hcbs.org/files/194/9662/ChartBook 1999 2009.pdf.

²⁸ Calculated by Vincent Mor of Brown University. Work performed as part of *Rising Expectations* report. See footnote 1.

²⁹ Georgia Department of Human Services, Division of Aging Services, *State Plan on Aging, Federal Fiscal Year October 1, 2011 through September 30, 2015* (Atlanta: DHS, 2011).

Although Georgia did not provide data on nurse delegation for the *Scorecard*, the site visit revealed that new regulations will make it possible for more people to get help with their health maintenance tasks, such as medication administration and tube feedings. 30 Disability advocates led the way, testifying that not having this public policy created real hardship for individuals with disabilities, especially those who wanted to self-direct. Advocates for family caregivers were vocal as well.

In August 2011, Georgia promulgated rules and regulations for "proxy caregivers" (PCs) at Chapter 111-8-100.³¹ A rule-making process convened by the Georgia Department of Community Health's Health Care Facility Regulation Division garnered support among disability and family caregiver advocates, the Georgia Council on Developmental Disabilities, the state's Ombudsman, AARP, the Georgia Board of Nursing, the Georgia Nurses Association, provider organizations, and others for these new rules for unlicensed caregivers.

PCs can assist individuals with their "health maintenance activities." The rules at 111-8-100-.03(f) define health maintenance activities as—

... those limited activities that, but for a disability, a person could reasonably be expected to do for himself or herself. Such activities are typically taught by a registered professional nurse, but may be taught by an attending physician, advanced practice registered nurse, physician assistant, or directly to a patient and are part of ongoing care. Health maintenance activities are those activities that do not include complex care such as administration of intravenous medications, central line maintenance, and complex wound care; do not require complex observations or critical decisions; can be safely performed and have reasonably precise, unchanging directions; and have outcomes or results that are reasonably predictable. Health maintenance activities conducted pursuant to this paragraph shall not be considered the practice of nursing.³²

Essentially, these rules provide for an "exemption" from the Nurse Practice Act for unlicensed workers who have been properly trained to perform specific tasks where the disabled individual gives informed consent for the particular worker. That is, nurses do not need to delegate these tasks to a direct care worker. Rather, PCs can perform these tasks according to the rules promulgated by the Department of Community Health.

These rules apply to all programs where the PCs can operate, including private homes, personal care homes, community living arrangements, assisted living, drug abuse treatment education programs, and traumatic brain injury facilities. PCs are not authorized to function in hospitals, hospices, home health agencies, or nursing homes.

³⁰ The National Council of State Boards of Nursing conducted a national survey on delegation of health maintenance tasks in January 2011. The Georgia Board of Nursing says that it did not respond to that survey because it was in the process of working with the state to develop the proxy caregiver regulations that were subsequently adopted in August 2011.

³¹ See final rules at http://www.georgia.gov/vgn/images/portal/cit 1210/22/28/177543229Proxy Caregiver Rules <u>Interpretive Guidelines October 17 2011.pdf.</u>

The regulations are silent on injections, such as insulin injections.

Since these are such new regulations, interviewees had questions about how they will play out in the real world, particularly in relation to the new assisted living regulations. While assisted living communities must have certified medication aides, personal care homes may hire PCs to administer medications, although the resident has to give written informed consent by name for use of a specific PC. Individuals in personal care homes can also hire their own PC if the personal care home allows it. The personal care home would be responsible for making certain that the resident has given informed consent, that the PC has been trained, and that there is a written plan of care prepared by a licensed person (physician, physician assistant, advanced practice nurse, or physical therapist, for example).

If the PC is hired directly by the consumer, that consumer may train the PC, including in medication administration, with no special training required, provided there is a written plan of care. The plan of care must implement the written orders of the attending physician, advanced practice registered nurse, or physician assistant and specify the frequency of training and evaluation requirements, including additional training when changes in the written plan of care require a change in duties for the PC. If the PC works for a facility, then the PC has to have a skills competency test and a test of functional health literacy.

The PC rules are important because they define and regulate the type of care that a direct care worker hired by the consumer May provide. Setting clear ground rules should lead to the increasing use of self-directed caregivers.

Summary and Conclusions

There are signs that Georgia is working to promote more consumer direction and support for family caregivers, especially through the very recent adoption of proxy caregiver regulations. It also appears that the state is gearing up to promote more residential LTSS choices for consumers, and better ways to find them in searchable databases. The relationships among ADRCs and the major departments have been strengthened through the MFP program.

But Georgia's progress in developing a high-performing LTSS system for those who need a public safety net will depend on the extent to which it can overcome its institutional bias. Georgia needs a clear policy decision that HCBS services should have priority over institutional services. Such a priority does not now exist. For example, the Governor's budget for FY 2012 and FY 2013 contains \$4.7 million to restore a 1/2 percent cut to nursing homes, while appearing to leave CCSP waiting lists intact. Over the past 10 years, successful lawsuits have been more of a factor than proactive leadership in promoting the use of HCBS. With long HCBS waiting lists and reliance on nursing homes to conduct Medicaid preadmission screening of people already in their facilities, it is a struggle for consumers to find alternatives.

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http://www.dch.georgia.gov/vgn/images/portal/cit_1210/8/33/180741920January_19_DCH%20Pres_to_Joint_Approp.pdf.
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agreement, which is an increase of \$29.8 million above the FY 2012 budget. Additional increases in state funding will be needed to continue compliance with the settlement in the coming fiscal years." T. Sweeny, FY 2013 Budget Analysis: Behavioral Health and Developmental Disabilities (Atlanta: Georgia Budget and Policy Institute, January 2012), http://gbpi.org/wp-content/uploads/2012/01/fy2013 Budget-Analysis BHDD FINALD 01272012.pdf.

The coming of a more managed care environment for Medicaid people who are over the age of 65 or have physical disabilities may provide opportunities for increasing the use of HCBS. The January 2012 Navigant report on Medicaid redesign provided advice to the state:

".... nursing home admissions are subject to limited checks and balances, and, as a result, examination of the nursing home admissions in Georgia might reveal opportunities to further enhance reliance on HCBS. Likewise, nursing home reimbursement policies warrant careful examination to consider incentives they might or might not introduce for encouraging use of HCBS. Overall, for both its HCBS and nursing home settings, Georgia would benefit from the collection, analysis and use of independently generated outcomes and performance data. Doing so will better enable DCH to understand where opportunities lie to improve quality and cost-effectiveness and, eventually, to link performance to payment and to inform future program design changes and interventions."³⁵

The Navigant report recommends multiple ways for people who are interested in promoting HCBS to work within a managed care context.

Whether HCBS services occur in a managed care environment, as Navigant suggests, or outside of managed care, there are sound ideas that can be adopted. What is less clear, and what is the major challenge for Georgians, is how to build the coalition of legislators, state staff, and advocates to create a durable, sustaining vision that stresses HCBS as the preference in long-term care services and supports.





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³⁵ Navigant Consulting, Appendix M, Long-Term Care Services (January 2012), http://dch.georgia.gov/vgn/images/portal/cit 1210/29/3/180740570Navigant Final Report to GA Appendices L to R.pdf.

Appendix A

Georgia's Ranking on Each of the 25 Indicators

| Dimension and Indicators | Data Year | State Rate | All States Median | Top 5 States | Best State Rate | Rank |
|--|--------------|---------------|-------------------------|-----------------|-----------------------|------|
| Affordability and Access | | | | | | 33 |
| Median annual cost for private-pay nursing home resident, as percentage of median household income, age 65 | 2010 | 188 | 224 | 171 | 166 | 8 |
| Median annual cost for private-pay home care, as percentage of median household income, age 65 | 2010 | 86 | 89 | 69 | 55 | 17 |
| Private long-term care insurance policies in effect per 1,000 population, age 40 | 2009 | 34 | 41 | 150 | 300 | 41 |
| Percentage of low-income adults at or below 250% of poverty level with ADL disability and enrolled in Medicaid or other public health insurance, age 21 | 2008- 09 | 48 | 49.9 | 62.2 | 63.6 | 38 |
| Medicaid LTSS participant years per 100 adults with ADL disability in nursing homes or living in the community at or below 250% of poverty level, age 21 | 2007 | 20.5 | 36.1 | 63.4 | 74.6 | 45 |
| Ability to access LTSS system through ADRC or other single entry point (composite indicator, rated on 0–12 scale) | 2010 | 8.1 | 7.7 | 10.5 | 11 | 24 |

| Dimension and Indicators | Data Year | State Rate | All States | Top 5 States | Best State Rate | Rank |
|--|--------------|---------------|---------------|--------------|-----------------------|------|
| Choice of Setting and Provider | Year | Kate | Median | Average | Kate | 44 |
| Percentage of Medicaid and state-funded LTSS spending going to home- and community-based services for older people and adults with physical disabilities | 2009 | 26.8 | 29.7 | 59.9 | 63.9 | 33 |
| Percentage of new Medicaid LTSS users first receiving services in the community | 2007 | 32.7 | 49.9 | 77.1 | 83.3 | 36 |
| Number of people with disabilities directing own services, per 1,000 adults age 18 | 2010 | 2.8 | 8 | 69.4 | 142.7 | 41 |
| Tools and programs to facilitate consumer choice (composite indicator, rated on 0–4 scale) | 2010 | 2.75 | 2.75 | 3.79 | 4 | 22 |
| Home health and personal care aides per 1,000 population age 65 | 2009 | 20 | 34 | 88 | 108 | 45 |
| Assisted living and residential care units per 1,000 population age 65 | 2010 | 30 | 29 | 64 | 80 | 22 |
| Percentage of nursing home residents with low care needs | 2007 | 12.7 | 11.9 | 5.4 | 1.3 | 26 |

| | Data | State | All States | Top 5 States | Best State | |
|---|---------------|-------|---------------|-----------------|---------------|------|
| Dimension and Indicators | Year | Rate | Median | Average | Rate | Rank |
| Quality of Life and Quality of Care | | | | | | 31 |
| Percentage of adults age 18 with disabilities living in the community who usually or always get needed support | 2009 | 66.7 | 68.5 | 75.5 | 78.2 | 39 |
| Percentage of adults age 18 with disabilities living in the community who are satisfied or very satisfied with life | 2009 | 87.4 | 85 | 90.9 | 92.4 | 9 |
| Rate of employment for adults with ADL disability relative to rate of employment for adults without ADL disability, ages 18–64 | 2008- 2009 | 22.3 | 24.2 | 42.4 | 56.6 | 38 |
| Percentage of high-risk nursing home residents with pressure sores | 2008 | 11.8 | 11.1 | 7.2 | 6.6 | 34 |
| Percentage of long-stay nursing home residents who were physically restrained | 2008 | 4.1 | 3.3 | 1.3 | 0.9 | 33 |
| Nursing home staffing turnover: ratio of employee terminations to average number of active employees | 2008 | 45.2 | 46.9 | 27.2 | 18.7 | 21 |
| Percentage of long-stay nursing home residents with hospital admission | 2008 | 20.8 | 18.9 | 10.4 | 8.3 | 33 |
| Percentage of home health episodes of care in which interventions to prevent pressure sores were included in care plan for at-risk patients | 2010 | 92 | 90 | 95 | 97 | 16 |
| Percentage of home health patients with hospital admission | 2008 | 28.8 | 29 | 23.2 | 21.8 | 25 |

| Dimension and Indicators | Data Year | State Rate | All States Median | Top 5 States Average | Best State Rate | Rank |
|---|--------------|---------------|-------------------------|----------------------------|-----------------------|------|
| Support for Family Caregivers | | | | | | 24 |
| Percentage of caregivers who usually or always get needed support | 2009 | 73.9 | 78.2 | 82.2 | 84 | 47 |
| Legal and system supports for caregivers (composite indicator, rated on 0–12 scale) | 2010 | 5.1 | 3.17 | 5.9 | 6.43 | 7 |
| Number of health maintenance tasks able to be delegated to LTSS workers | 2011 | * | 7.5 | 16 | 16 | * |

* Data not available.
See *Scorecard* website for Georgia at http://www.longtermscorecard.org/DataByState/State.aspx?state=GA.