

Virginia State Profile Tool: An Assessment of Virginia's Long-Term Care System

Submitted to the Virginia Department of Medical Assistance Services

by

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Any opinions expressed in this report are the authors' and do not reflect the views of the Virginia Department of Medical Assistance Services.

Executive Summary

Description of the State Profile Tool Grant

In federal fiscal year (FFY) 2007, the Centers for Medicare & Medicaid Services (CMS) awarded grants to ten states under the Real Choice Systems Change program to develop profiles of their long-term care (LTC) delivery systems and participate in the process of developing national balancing indicators. The goal of the State Profile Tool (SPT) is to establish a template for states to assess their LTC systems with a focus on progress made in “rebalancing” from heavy reliance on institutional services to increased use of community-based services. SPTs will inform the second phase of the grant: the development of a national set of indicators of a balanced, person-centered LTC system.

Virginia was one of the ten states awarded the SPT grant, and the Virginia Department of Medical Assistance Services (DMAS) contracted with Thomson Reuters to assist with development of the Virginia SPT. Virginia’s SPT examines the LTC delivery system for five target groups: older adults; adults with physical disabilities; people with intellectual and developmental disabilities; adults with mental illness; and children with disabilities.

Organization of the State Profile Tool Report and Methodology

Virginia’s SPT is organized into two parts: two background sections that provide context for understanding the Commonwealth’s LTC system; and five separate sections describing the system as it pertains to the target groups referenced above. Assessing a state’s LTC delivery system by target group is useful in that it provides a framework for understanding a large, complex system, and helps identify strengths, challenges, and gaps that may be unique to subpopulations. However, these distinctions are somewhat misleading in that each target group is heterogeneous, and there is significant overlap among them. For example, many people with intellectual disabilities (ID) have co-occurring mental illness (MI) and/or physical disabilities (PD). The authors drew upon numerous sources of information to develop Virginia’s SPT: background reports; national, state, and local-level data; stakeholder interviews; site visits; and consumer focus groups.

Key Components for System Rebalancing

This report also assesses Virginia’s LTC system by examining how the system performs on eight components which have been identified by other states that made significant progress in reducing institutionalization and increasing access to community-based services.¹ The eight components are:

1. Consolidated state agencies – a single agency for both institutional and community services which coordinates policies and budgets to promote community options;

¹ Steve Eiken, *Technical Assistance Guide to Assessing a State Long-Term Care System*, Thomson Medstat, 2006.

2. Single access points – a clearly identifiable organization managing access to a wide variety of community supports, ensuring people understand the full range of options before receiving more restrictive services;
3. Institution supply controls – mechanisms such as Certificate of Need requirements that enable states to limit or reduce institutional beds;
4. Transition from institutions – outreach to identify institutional residents who want to move and assistance with their transition to the community;
5. A continuum of residential options – availability of support services in a range of options from mainstream single family homes and apartments to integrated group settings for people who need 24-hour supervision;
6. Home and community-based (HCBS) infrastructure development – recruitment and training to develop a sufficient supply of providers with the necessary skills and training to encourage consumer independence;
7. Participant direction – people who receive HCBS have primary decision-making authority over their direct support workers and/or their budget for supports; and
8. Quality management – an effective system that a) measures whether the system achieves desired outcomes and meets program requirements and b) identifies strategies for improvement.

Evaluating Virginia's LTC system based on these components can assist the State in determining the extent to which it has the necessary elements to achieve a balanced and person-centered system.

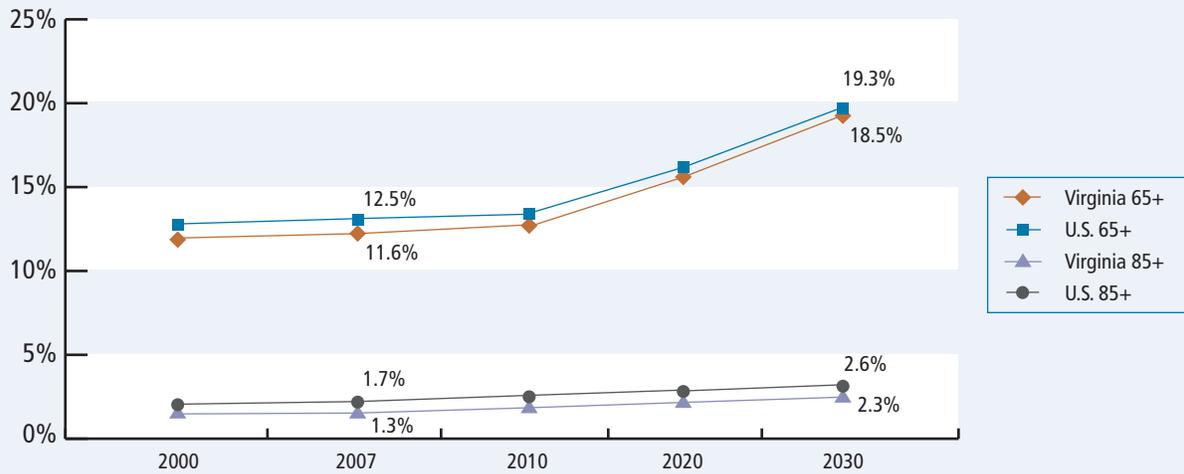
Background

Based on age, disability and health risk data, Virginians appear to have a slightly lower need for LTC compared to other Americans. Virginia has smaller shares of the population age 65 and older and age 85 and older compared to the U.S., as well as a lower share of people with disabilities. The percentage of the population in Virginia age 65 and older is 11.6 percent, compared to 12.5 percent in the United States as a whole.² And, Virginia's share of the population age 85 and older is 1.3 percent compared to 1.7 percent for the U.S.³ Population projections suggest that Virginia's shares of people age 65 and older and 85 and older are expected to remain lower than the national averages (see Figure ES.1).

² University of Virginia, Weldon Cooper Center for Public Service, for Virginia population estimates and U.S. Census, 2007 American Community Survey for U.S. population estimates.

³ Ibid.

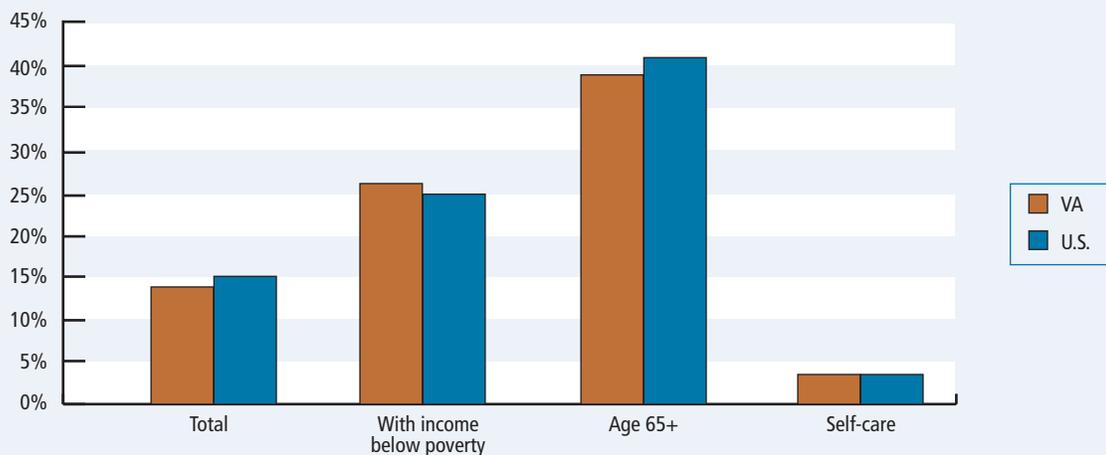
Figure ES.1. Share of Population Age 65+ and 85+: VA Compared to U.S., 2000 - 2030



Source: U.S. Census for all U.S. figures and Virginia 2000. U. of VA Weldon Cooper Center for Public Affairs for Virginia 2007. Virginia Workforce Connections population projections for Virginia 2010 - 2030.

Virginia also generally has lower rates of disability compared to the U.S., with the exception of people with income below the poverty level. Figure ES.2 below compares Virginia's prevalence of disability to that of the U.S. for various subpopulations and specific to self-care disability (which is associated with functional impairment in activities of daily living).⁴ Virginians have lower prevalence of many health risks compared to the U.S., such as: obesity, smoking, diabetes, asthma, hypertension, and people reporting fair or poor health status.⁵

Figure ES.2. Prevalence of Disability by Subpopulation and Self-Care Disability: VA Compared to the U.S. (Age 5 and Older), 2007



Source: Thomson Reuters analysis of U.S. Census, 2007 American Community Survey.

Note: Self-care disability is based on functional impairment and is the Census disability measure most closely associated with the need for LTC.

⁴ U.S. Census, 2007 American Community Survey. The U.S. Census defines self-care disability as a physical, mental, or emotional condition lasting six months or more that makes it difficult dressing, bathing, or getting around inside the house.

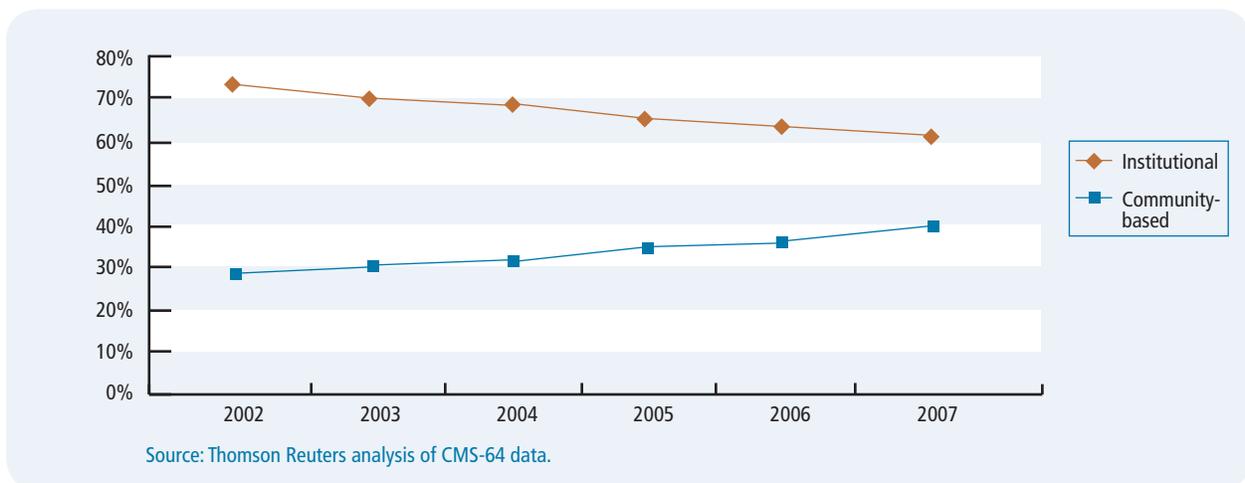
⁵ Centers for Disease Control and Prevention, 2007 Behavioral Risk Factor Surveillance Survey.

Long-Term Care Expenditures and Utilization

Expenditures

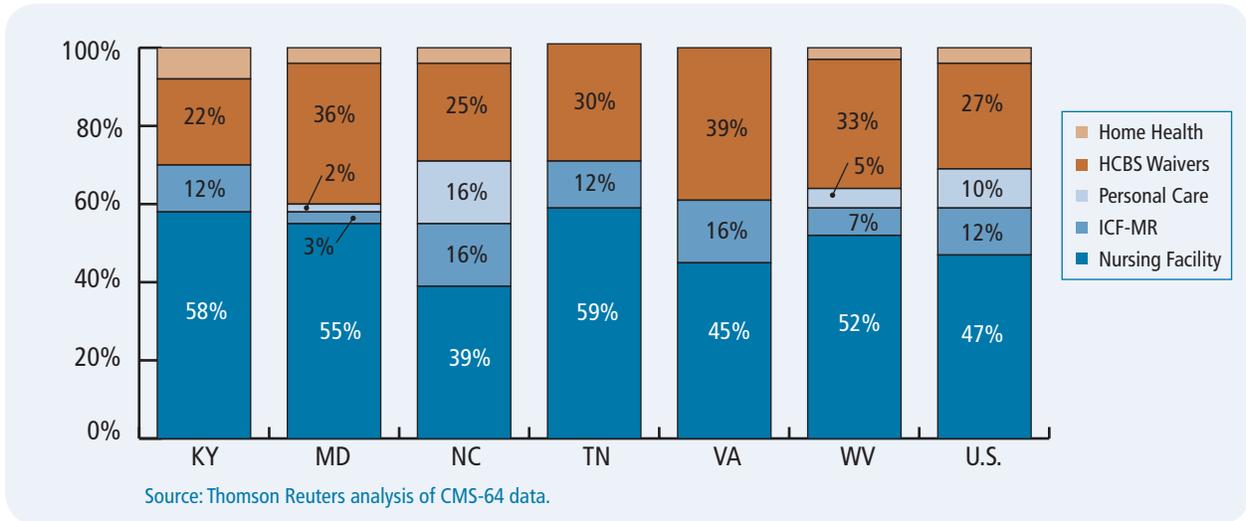
Medicaid LTC expenditures represented 32 percent of total FFY 2007 Medicaid expenditures in Virginia, nearly identical to the national average. Virginia's Medicaid LTC expenditures have been increasing by an annual average of over seven percent over the past five years, a rate that exceeds the average annual increase for the U.S. of roughly four percent. Institutional LTC service expenditures represented 60 percent of Virginia's total Medicaid LTC service expenditures in FFY 2007, exceeding the national average of 58 percent. The share of Medicaid LTC expenditures going toward institutional services has decreased in Virginia by over 17 percent in the past five years, from 73 percent in FFY 2002. Figure ES.3 below shows trends in the balance between institutional and community-based LTC in Virginia over the past five years.

Figure ES.3. Distribution of Medicaid LTC Expenditures in VA: Institutional vs. Community-based, 2002 - 2007



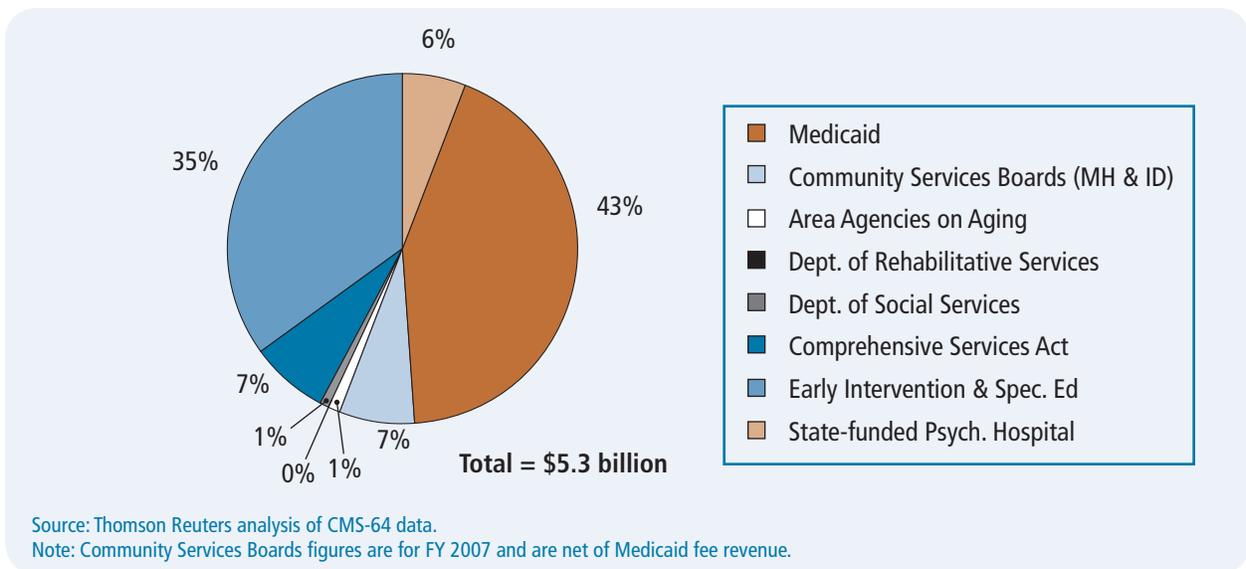
Virginia's spending on HCBS waivers as share of total Medicaid LTC spending has increased dramatically since 2002, from about a quarter of total Medicaid LTC expenditures to nearly 40 percent. Compared to most neighboring states and the U.S., Virginia's share of Medicaid LTC spending on HCBS Waivers is higher and its share of spending on NF services is lower (Figure ES.4). However, its share of spending on ICF-MR services is also higher.

Figure ES.4. Distribution of Medicaid LTC Expenditures by Type of Service: VA Compared to Border States & the U.S., 2007



Looking at total public LTC expenditures in Virginia, Medicaid pays the largest portion, followed by early intervention and special education services. Figure ES.5 below shows the distribution of current public LTC spending in Virginia on the five SPT target groups by program.⁶

Figure ES.5. Distribution of Public LTC Expenditures in VA by Program: FY 2008



⁶ The Medicaid expenditures shown here are 5.5 percent higher than those cited in the separate target group sections of this report because they include payments made outside of the Medicaid Management Information System (such as consumer-directed services provided under the HCBS waivers). This “offline” payment information is not available at the level of detail needed to allocate the expenditures among the SPT target groups.

Utilization

Virginia appears to rely less on institutional LTC settings compared to neighboring states and the U.S., with the exception of large ICFs-MR. As shown in Table ES.1 below, Virginia has the lowest number of people served per capita in nursing facilities (NFs) and state mental health hospitals among the comparison states and the U.S., but the second highest number served in large (16+ bed) ICFs-MR.⁷

Table ES.1 Use of Institutional LTC Services in Virginia

State/U.S.	Number Served in NFs per 1,000 People age 65+ (2007)	State/U.S.	Number Served in State Mental Health Hospitals per 100,000 Population (2006)	State/U.S.	Number Served in Large (16+ bed) ICFs-MR per 100,000 Population (2006)
KY	41.8	MD	21.3	NC	25
TN	41.4	U.S.	15.6	VA	19.2
MD	37.3	TN	13.3	U.S.	18.7
U.S.	36.9	NC	12.2	KY	14.5
WV	35	KY	11.7	TN	11.4
NC	34.3	VA	2.8	MD	6
VA	31.1	WV	N/A	WV	2.6

Source: See footnote 7.

Looking at community-based LTC services, in 2005 Virginia ranked third among its neighbors on the number of HCBS waiver participants per capita as measured both by state population and by the disabled population age five and older.⁸

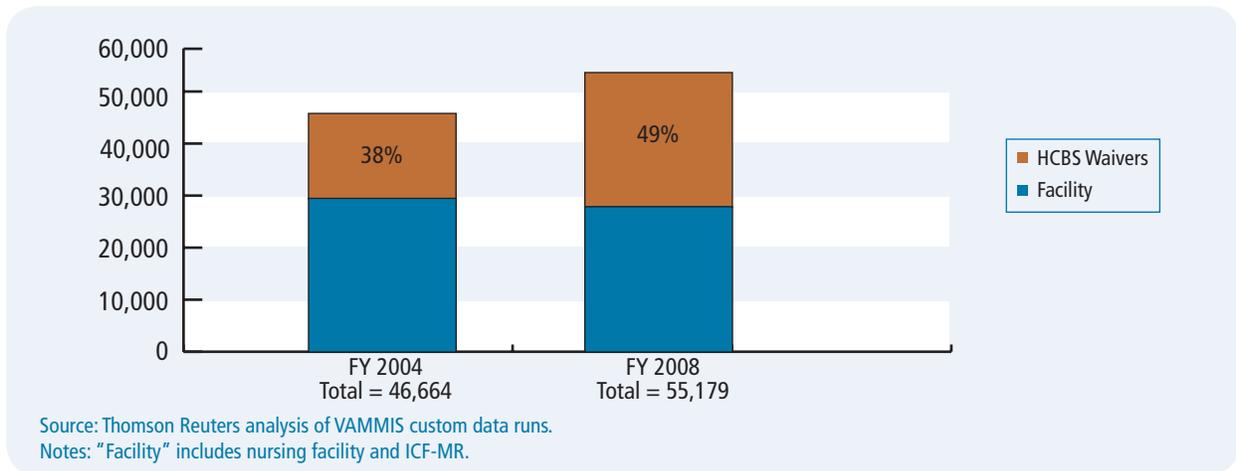
The number of people at an institutional level of care who are receiving Medicaid-funded LTC services has increased in the past five years, and Virginia is serving a higher share of these people in community-based settings. Figure ES.6 below shows the number of people receiving institutional and HCBS waiver services in FY 2004 as compared to FY 2008: the total number of people served has increased from 46,664 to 55,179 and the share served in HCBS waivers has increased from 38 percent to nearly one-half.⁹

⁷ For NFs: CMS Minimum Data Set Active Resident Report, 2nd Quarter 2007, Weldon Cooper Center for Public Affairs population estimate for Virginia, and U.S. Census 2007 American Community Survey population estimates for other states and the U.S. For state mental hospital: National Association for State Mental Health Program Directors Research Institute (West Virginia did not report data and the U.S. average is based on 43 states). And, for ICF-MR: Thomson Reuters analysis of Prouty et al (eds.) University of Minnesota, 2008.

⁸ Kaiser Family Foundation, statehealthfacts.org, *Medicaid 1915(c) Waiver Participants, by Type of Waiver, 2005*. These are the most recent comparative data available.

⁹ People at an institutional level of care receiving long-term mental health services were not included because of the difficulty in identifying people living in the community who require this level of service (other than children and adolescents at a Psychiatric Residential Treatment Facility level of care participating in the Children's Mental Health program).

Figure ES.6. Number of Virginians at an Institutional Level of Care Receiving Medicaid LTC Services by Type of Care: FY 2004 Compared to FY 2008



Historical and Political Factors Relevant to Long-Term Care in Virginia

The general consensus of stakeholders interviewed in early 2008 was that momentum was building to reform Virginia's LTC system and it appeared to be an opportune time to do so. (It is important to note that these interviews took place before there was a general awareness of the severity of the current recession.) Many felt that the previous and current Administrations were particularly committed to increasing community-based LTC resources (including transformation of the mental health system). Figure A.1 in Appendix A identifies key events related to the expansion of community-based LTC options in Virginia.

Stakeholders believed the combination of political will and demographic pressures were dovetailing to create a unique opportunity to make real change in Virginia's LTC system. However, it is unclear what impact the weak economy will have on this momentum. The declining economy played a role in putting an integrated acute and LTC initiative on hold. Stakeholders also noted that Virginia's requirement of a single-term Governor tends to inhibit progress because it's difficult to sustain focus from one administration to another. Overall, there was consensus that investment of state funds in person-centered community-based LTS will have to be incremental, in keeping with the Commonwealth's values of efficiency in government and fiscal restraint.

Current Long-Term Care Reform Efforts in Virginia

Virginia has undertaken numerous initiatives to enhance and reform the LTC system: some funded to a large extent by federal grants while others are funded primarily through state general funds. The Governor's Task Force on Health Reform, Money Follows the Person Demonstration and Real Choice Systems Change grants, *No Wrong Door*, Own Your Future, Long-Term Care Partnership, and other initiatives are moving the Commonwealth forward in creating a more balanced and sustainable system.

Long-Term Care Workforce in Virginia

Informal Caregivers

Informal caregiving refers to unpaid care provided to people needing LTC, usually by relatives, friends, or neighbors. Nationally, the majority of informal caregivers are women, a large share being age 65 and older.¹⁰ The average caregiver is age 46, female, married and working.¹¹ A number of trends are converging which are expected to diminish the pool of informal caregivers for the baby boomer generation: women's overall increased labor force participation; an increase in women working at older ages; and decreased number of children per family. AARP estimates of the number of informal caregivers in Virginia, neighboring states, and the U.S. and associated economic value are shown in Table ES.2 below.¹² The estimated economic value of informal care as share of total Medicaid LTC expenditures is higher in Virginia compared to neighboring states and the nation, reflecting Virginia's relatively low Medicaid LTC expenditures.

Table ES.2 Caregiving Statistics: Virginia Compared to Border States and the U.S., 2007

State	Number of Caregivers	Caregivers per Capita	Economic Value per Hour	Economic Value (billions)	Economic Value as Share of Medicaid LTC
KY	520,000	.124	\$9.48	\$5.4	4.2
MD	600,000	.107	\$9.79	\$6.3	3.8
NC	1,080,000	.122	\$9.14	\$10.7	4.0
TN	770,000	.127	\$8.71	\$7.2	3.8
VA	900,000	.118	\$10.18	\$9.9	5.7
WV	270,000	.149	\$8.30	\$2.5	3.0
U.S.	34,000,000	.114	\$9.63	\$350	3.7

Source: Houser and Gibson (2008), AARP Public Policy Institute.

Paid Long-Term Care Workforce

The LTC workforce is commonly thought of as direct care workers (DCWs) such as home health aides and personal care attendants. However, there are many other types of personnel who are critical to the provision of LTC services, such as social workers, behavioralists, and other mental health professionals; and physical, occupational, speech, and other therapists. It can be challenging to measure the supply of these other types of providers.

Virginia's supply of DCWs appears to be lower than the national average, as measured by the number of workers per 100,000 people age 65 and older. For example, the number of home health aides in Virginia per 100,000 people age 65 and older is 39 percent lower than the national average. Table A.2 in Appendix A shows the number of workers per capita in Virginia, neighboring states, and the U.S. in a number of occupations which are key to providing services to older adults and people with disabilities.

¹⁰ National Caregiver Alliance, *Women and Caregiving: Facts and Figures*, undated.

¹¹ Ibid.

¹² Ari Houser and Mary Jo Gibson, *Valuing the Invaluable: The Economic Value of Family Caregiving, 2008 Update*, AARP Public Policy Institute, November 2008.

Virginia's average hourly wages for DCWs are also low compared to the national average, and most other states. According to Bureau of Labor Statistics occupational data, Virginia ranks 33rd on wages for nursing aides, 38th on wages for home health aides, and 44th on wages for personal care workers.¹³

Stakeholders described challenges related to the Virginia direct care workforce. Some people with disabilities said it was very difficult to find reliable DCWs. However, they also noted that the bad economy was working in their favor as the pool of workers had expanded. Some rural community-based organizations described problems with finding adequate numbers of DCWs who pass criminal background checks.

Key State Agencies in the Long-Term Care System

The lead agencies with authority over the LTC system in Virginia are within the Secretariat of Health and Human Resources (HHR). The organization chart in Figure A.2 in Appendix A shows the lead agencies within HHR as well as the Office of Community Integration and other state agencies with a key role in the LTC system. In 2007, the Virginia General Assembly passed legislation designating the Secretary of HHR as the lead for coordinating and implementing LTC policy for the Commonwealth, although some note HHR had already assumed this role.

While having all of the lead agencies within one Secretariat enhances the potential for coordination of LTC services, stakeholders noted that there is considerable fragmentation in the system. This fragmentation has two forms. There are “silos” in that older adults and people with certain types of disabilities are served primarily by separate agencies and programs. And, at the same time, people using LTC services are typically served by multiple agencies, making navigation of the system confusing and difficult. As noted above, many state agencies have varying roles in the LTC system. These roles, as they pertain to the five SPT target groups, are described in greater detail in Table A.3 in Appendix A. On a positive note, many stakeholders commented that collaboration among the state agencies with key roles in the LTC system has improved significantly in recent years.

Services for Older Adults

Summary of Strengths and Gaps

Virginia's LTC system for older adults has many strengths. The Commonwealth has devoted considerable attention in recent years to LTC in general, and the impacts of the aging population on state and local programs. As noted previously, the Governor's task force on health reform established a workgroup to examine LTC issues and make recommendations. And, the General Assembly directed the Joint Legislative Audit and Review Commission (JLARC) to study the impact of the aging population on state agencies. In addition, some important public-private collaborations have developed in the past few years aimed at helping older adults navigate the services system, planning for the impact of the “age wave” and addressing the mental health needs of older adults. Further, Virginia has grown its PACE program

¹³ Bureau of Labor Statistics, *Occupational Employment Statistics*, May 2007.

significantly over the past few years from one program in 2007 to six programs as of February 2009.¹⁴ Enrollment in PACE has increased by 50 percent since SFY 2008 to 288 participants. Last, Virginia's reliance on NF care is lower than most of its neighbor states and the nation as measured by the number of nursing home beds and residents per 1,000 state residents age 65 and older, and the percentage of state residents age 65 and older with at least one nursing home stay.¹⁵

Despite a wide array of community-based LTC services for older adults, there is still significant unmet need for LTS and much variation in services available and the funding of services by locality. As of October 2008, AAAs reported nearly 24,000 people either unserved or underserved (most were underserved) for home-delivered meals and over 2,000 with unmet needs for homemaker services.¹⁶ Further, the lack of affordable, accessible supported housing and funding for home modifications and/or repairs, as well as gaps in public transit have been repeatedly identified as major barriers to aging in place. Thus, where an older adult lives in many ways determines the extent to which supports are available.¹⁷

DMAS was unable to implement its integrated care program due to declining economic conditions and changes in Medicare health plan requirements, which is unfortunate in that, outside of the PACE program, Virginia's Medicaid program does not generally have a strong care management component for the elderly to prevent or delay the need for institutional care. As noted, the EDCD waiver does not cover case management services, and only six of the 25 AAAs offer these services, billable as targeted case management under the Medicaid State Plan. Only two percent of EDCD waiver participants receive case management services.

Services for Adults with Physical Disabilities

Summary of Strengths and Gaps

Virginia has shown commitment to increasing community integration for adults with PD in a number of ways. As described earlier in this section, the share of people with PD requiring an NF level of care who are living in the community has shifted from a minority of people served to a majority. And, stakeholders give DMAS much credit for transparency in program design by including people with disabilities in the decision-making process. Clearly, Virginia's continued commitment to its OCI demonstrates a strong effort to improve access to community-based services for all people with disabilities.

However, stakeholders are concerned that the fragmented nature of Virginia's LTC delivery system causes some groups to "fall through the cracks." For example, many people report people with Traumatic Brain Injury (TBI) are underserved. While DRS has some funding devoted to this population, stakeholders believe people with TBI are not well-served by the HCBS waivers.¹⁸ As noted, plans to implement a Brain Injury waiver were put on hold due to a lack of funding. The adverse social and

¹⁴ DMAS.

¹⁵ Centers for Medicare & Medicaid Services, *2008 Nursing Home Data Compendium*.

¹⁶ VDA.

¹⁷ This refers mainly to older adults who are low- or middle-income, who are more apt to use publicly-funded LTS. The report does not attempt to assess whether there are sufficient supported residential settings and other LTS for high-income people.

¹⁸ A person who incurs a TBI before the age of 22 is potentially eligible for the DD waiver, assuming level of care and financial criteria are met.

financial outcomes of underserving this population, stakeholders note, are illustrated by the large share of people in prisons with TBI. According to the Centers for Disease Control, studies have found that 25 to 87 percent of prison inmates report having experienced a head injury or TBI compared to 8.5 percent in a general population.¹⁹

Moreover, some stakeholders feel a sense of urgency to develop better services for people with TBI because of the perceived potential impact of military personnel with TBI returning from the wars in Afghanistan and Iraq. Although the U.S. Department of Defense (DOD) and the U.S. Department of Veterans Affairs (VA) have the primary responsibility for providing services to “wounded warriors,” stakeholders have observed military personnel (both active duty and veterans) relying on local and state-funded programs. Indeed, based on U.S. Department of Veterans Affairs data, Virginia has the highest number of returning veterans from Operation Iraqi Freedom and Operation Enduring Freedom per 100,000 population compared to neighbor states and the national average (see Figure 5.4).²⁰

Though officials from the VA and DOD stated that coverage of LTS for active duty personnel and veterans with TBI was comprehensive, they did note some gaps such as supported housing for nonelderly adults. Further, some military personnel and veterans prefer to utilize non-military services for a variety of reasons. For example, local agencies that provide services may be closer to where they live than VA or DOD providers, and military settings may remind them of traumas they endured during service. Finally, the eligibility criteria for services from the VA are complex and depend upon the type of disability, whether it was service-connected (and to what degree), and the type of military discharge. Thus, some military personnel with TBI may not be covered by the VA system.

In summary, stakeholders’ concerns about Virginia’s ability to serve people with TBI, especially related to military personnel, appear to be well-founded. It would be worthwhile to study the degree to which active duty military personnel and veterans are currently using state-funded LTC services to assess the impact of the return of wounded warriors and continued military conflicts.

Services for People with Intellectual and Developmental Disabilities

Summary of Strengths and Gaps

Stakeholders pointed out numerous strengths with the current LTS system for people with ID/DD. They gave DMAS much credit for transparency in program design by including people with disabilities in the decision-making process. Some described the Virginia legislature as committed to the ID population in particular, as evidenced by the funding of significant numbers of MR/ID waiver slots over the past few budget cycles. Many extolled the dedication of CSB staff and local providers in serving these populations and, as one stakeholder put it, “squeezing every dollar” to provide as much as they could within limited funds. Further, people generally agreed that the MR/ID waiver provides a comprehensive set of services to individuals. Finally, many believe the expansion of DMHMRSAS’ role to include autism spectrum disorders and other developmental disabilities is a very significant step forward for Virginia.

¹⁹ Centers for Disease Control and Prevention, *Traumatic Brain Injury in Prisons and Jails: An Unrecognized Problem*.

²⁰ U.S. Department of Veterans Affairs, OIF/OEF Veterans, February 29, 2008. Based on U.S. Census 2007 American Community Survey, Virginia has a higher share of veterans for the population age 18 and older and age 65 and older compared to its neighbor states and the U.S.

However, stakeholders reported some serious concerns about the overall system for people with ID and DD that primarily fall within five themes:

- inadequacy of funding and unmet demand as evidenced by the waiver waitlists;
- inequity between the MR/ID and DD waivers;
- inequity between Medicaid financing of institutional services compared to HCBS services;
- local variation in the availability of services and waiver spending; and
- gaps in services for those who are not Medicaid-eligible and for young adults aging out of the education system.

Overall, people commented on the lack of funding for LTS for people with ID/DD and were very concerned about the waitlists. The average waiting time for people on the urgent MR/ID waitlist is 2.4 years, and is slightly longer for those on the non-urgent waitlist.²¹ While people on the MR/ID waitlist are eligible to receive services through the Day Support waiver, this small program does not provide the residential supports many individuals need.

Generally stakeholders agreed that the discrepancy between the resources devoted to the MR/ID waiver compared to the DD waiver was unfair and that the two waivers should be merged as they essentially serve the same population. Also noted was the fact that the DD waiver does not cover residential supports.

Stakeholders made observations about the financing structure of Medicaid with respect to ICFs-MR compared to HCBS waivers, pointing out there are two built-in incentives to serve people in ICFs-MR rather than the community. First, given that ICF-MR is a service covered by Virginia's State Plan, whereas waiver slots must be funded through the State's legislative process, there is an incentive to utilize ICFs-MR in order to serve people who cannot access community-based services due to waitlists. CSB staff from one area interviewed for this study explicitly said they felt obliged to build a large community ICF-MR in order to provide services to people on their MR/ID waiver urgent waitlist.

Another factor is that the ICF-MR reimbursement rate, because it is cost-based, allows for a fuller set of services compared to the MR/ID and DD waivers. For example, staff at a community ICF-MR noted that their residents receive dental care and that they (staff) could purchase higher-quality beds, bathtubs and wheelchairs compared to what CSBs could buy for people on the MR/ID waiver.²² The ICF-MR staff believed, in many ways, they could do more for their residents compared to the services they might receive in the community. In its 2008 Biennial Assessment, the VBPD recommended that Virginia better align the supports and services available through the waivers with those provided for in the ICF-MR setting.²³

Stakeholders raised concerns about the unevenness of availability of waiver services among Virginia localities. In analyzing Medicaid MR/ID waiver expenditure data by locality, we found significant

²¹ VBPD, 2008.

²² ICF-MR staff indicated that CSBs were limited in what they could purchase due to concerns about the cost of service plans and meeting federal budget neutrality requirements.

²³ VBPD, 2008.

local variation in per-participant waiver spending. Limiting analysis to those localities with at least 100 MR/ID waiver participants, annual MR/ID waiver spending per participant in FY 2008 varied from a minimum of \$41,000 in Hanover County to a maximum of \$66,000 in Portsmouth.²⁴ The standard deviation from the mean among these twenty localities was over \$6,200. It would be worthwhile to examine these differences to understand what is driving them.

Finally, many stakeholders identified gaps in services for those who are not Medicaid eligible, and for young adults aging out of services provided by the school system as required by the federal Individuals with Disabilities Education Act. The DMHMRSAS study of the ID/MR system in Virginia estimates there are 13,500 community residents who have been identified by CSBs as needing ID services, but who do not qualify for Medicaid and are not on the waiting list for the MR/ID waiver.²⁵ Based on Virginia Department of Education special education data, nearly 600 young adults with an ID, DD or Autism diagnosis will soon age out of the school system.²⁶ According to advocates, some of these young people are “sitting home doing nothing,” while their skills deteriorate. The cost of not providing services to these individuals is the potential for adverse behavioral and medical outcomes, which could end up costing far more than the supports themselves.²⁷

Services for Adults with Mental Illness

Summary of Strengths and Gaps

The State’s efforts to date to transform the mental health system are generally recognized as significant, such that the National Alliance on Mental Illness recently upgraded the state’s system compared to where it was three years ago.²⁸ Among the priorities for action have been expansion of community mental health services, particularly crisis stabilization and response services that can reduce the number of admissions to state psychiatric hospitals. Regional consortia of CSBs are actively engaged in better managing hospital utilization using resources such as DAP. Advocate stakeholders were unanimous about DMHMRSAS’ support of the recovery model for mental health and felt that the challenge was in changing others’ perspectives. (However, they noted that DMHMRSAS doesn’t consistently require CSBs to use state funds received for recovery even if that was the plan.) Due to Virginia’s focus on ACT, several geographic areas benefit from having teams to serve individuals whose illnesses are not effectively remedied by available treatments or the individual resists involvement with services. In addition, knowledge from a supported employment pilot with Medicaid financing will soon be shared more broadly.

Nevertheless, stakeholders consistently expressed concern about the lack of greater access to community-based mental health services. Outpatient services such as case management, psychiatrists and other clinical counseling staff were identified as a gap area that should be the “bread and butter” of community

²⁴ Thomson Reuters analysis of DMAS custom data run of MR/ID waiver spending by locality.

²⁵ DMHMRSAS, *Report of the Study of the Mental Retardation System*, October 17, 2007.

²⁶ Virginia Department of Education, *Special Education Child Count for FY 2007*. We counted young adults with these diagnoses between the ages of 20 to 22.

²⁷ The study referenced above cites out-of-home placements as a service that is more costly than in-home supports.

²⁸ National Alliance on Mental Illness, *Grading the States 2009, A Report on American’s Health Care System for Adults with Serious Mental Illness*, March 2009.

care but currently is not. Pervasive workforce shortages are a factor in some of these gaps, as are reimbursement rates and funding limits (over 90 percent of mental health case managers have case loads of over 25 patients).²⁹ A major piece of the delivery system that is not fully realized is effective crisis stabilization and intervention programs that support people without hospitalization or incarceration and return them to the community. There was also a desire for community-based services to include peer-run recovery programs such as drop-in centers or wellness centers that expand the continuum of care options under a psychosocial model. Individuals residing in rural areas were particularly concerned about lack of workforce (psychiatrists), transportation, and peer education program availability. In fact, the lack of a consistent level of service availability across the state was another theme. As already noted, affordable housing is a very significant concern for Virginians ready to be discharged into the community. Limits on DAP funding mean new enrollment is contingent on deaths, attrition, or less intensive service needs among existing enrollees.

Services for Children with Disabilities

Summary of Strengths and Gaps

Virginia has put in place a variety of special efforts to address the needs of Virginia's children who currently require or are at risk of requiring LTS. These efforts involve several agencies and programs, particularly Medicaid and DMHMRSAS. Parents and child advocates involved with mental health services unanimously felt that Virginia was doing well in increasing self-determination – through both its commitment to person-centered planning and positive behavior supports – and this was starting to spillover onto other disabilities. Stakeholders highlighted community-based mental health services under Medicaid, the CMH Program, CSB budgeting for clinicians specializing in children's mental health, Medicaid waivers available to children and adolescents, and the introduction of intensive care coordination for children in or at risk of entering residential care. Stakeholders believe that even recent "systems of care" progress within the foster care and child welfare systems have some spillover benefit to the LTC system.

At the same time, it is clear that the system that serves children and adolescents with LTC needs is complex. The number of separate access points with which a child with disabilities must interact makes for a fragmented system. And, as noted, the case management system was identified as a potential source of additional complexity, rather than simplification. For children with disabilities, the locally administered aspect of each system (e.g., CSB, special education, CSA) means access is highly variable across services. Parent stakeholders indicated a need for additional supports to keep their children with disabilities living at home. Finally, stakeholders pointed to the need for more evidence-based care and mid-level (i.e., less than residential) services.

²⁹ DMHMRSAS Budget Proposal, Presentation of James Reinhard, Commissioner, to HHR Subcommittee of Virginia Senate Finance Committee, January 21, 2008.

Section 1. Foreword

Description of the State Profile Tool Grant

In federal fiscal year (FFY) 2007, the Centers for Medicare & Medicaid Services (CMS) awarded grants to ten states under the Real Choice Systems Change program to develop profiles of their long-term care (LTC) delivery systems and participate in the process of developing national balancing indicators. The goal of the State Profile Tool (SPT) is to establish a template for states to assess their LTC systems with a focus on progress made in “rebalancing” from heavy reliance on institutional services to increased use of community-based services. SPTs will inform the second phase of the grant; the development of a national set of indicators of a balanced, person-centered LTC system.

Virginia was one of the ten states awarded the SPT grant, and the Virginia Department of Medical Assistance Services (DMAS) contracted with Thomson Reuters to assist with development of the Virginia SPT. Virginia’s SPT will examine the LTC delivery system for five target groups: older adults; adults with physical disabilities; people with intellectual and developmental disabilities; adults with mental illness; and children with disabilities.

Organization of the State Profile Tool Report and Methodology

Virginia’s SPT is organized into two parts: two background sections that provide context for understanding the Commonwealth’s LTC system; and five separate sections describing the system as it pertains to the target groups referenced above. Assessing a state’s LTC delivery system by target group is useful in that it provides a framework for understanding a large, complex system; and helps identify strengths, challenges and gaps that may be unique to subpopulations. However, these distinctions are somewhat misleading in that each target group is heterogeneous, and there is significant overlap among them. For example, many people with intellectual disabilities (ID) have co-occurring mental illness (MI) and/or physical disabilities (PD).

Throughout this report, we use the phrases “long-term care” and “long-term support” (LTS) interchangeably, defined as: “assistance with essential, routine tasks of life – such as bathing, getting around the house, and preparing meals – provided to people who need this assistance because of physical or mental conditions or disability.” This assistance can include therapies or equipment to improve a person’s functional capacity.¹

The authors drew upon numerous sources of information to develop Virginia’s SPT: background reports; national, state and local-level data; stakeholder interviews; site visits; and consumer focus groups. Virginia has a wealth of studies, background reports and summaries of public comment on the topic of its LTC system and the needs of an aging population. We also utilized national data sources such as Thomson Reuters’ annual reports of Medicaid expenditures, U.S. Census population and disability estimates, the University of Minnesota’s compilation of state data on the Developmental Disabilities system, and the U.S. Substance Abuse and Mental Health Services Administration’s state-level reports. We relied on custom data

¹ Susan Rogers and Harriet Komisar, *Who Needs Long-Term Care?* Georgetown University Long-Term Care Financing Project, May 2003.

requests from state agencies to provide most of the utilization and expenditure data specific to the target groups. In addition, we interviewed roughly 35 stakeholder groups including: state agencies; advocacy organizations; provider associations; local agencies (and/or their state associations) such as Area Agencies on Aging (AAAs), Community Services Boards (CSBs) and Centers for Independent Living; Virginia's Transformation Leadership Team and Systems Transformation Grant (STG) workgroup. The stakeholders interviewed for this project are listed in Appendix B. Finally, we conducted three site visits to different parts of the Commonwealth, including a rural area, to observe delivery of LTC services at the local level. During these site visits, we interviewed local agency staff, providers and individuals who use LTC services and their families/caregivers (see Appendix C).

In showing LTC utilization and expenditures, we include some services which are not commonly included in the policy research literature on LTC spending. For example, we have included special education services and community mental health services. Due to the SPT's focus on specific disability groups, we believe it is important to be as comprehensive as possible in considering which services people receive on a long-term basis. However, some of the data sources do not provide sufficient detail to distinguish the services that are truly "long-term," thus utilization and expenditure amounts for some services may be overstated.

Key Components for System Rebalancing

This report also assesses Virginia's LTC system by examining how the system performs on eight components which have been identified by other states that made significant progress in reducing institutionalization and increasing access to community-based services.² The eight components are:

1. Consolidated state agencies – a single agency for both institutional and community services which coordinates policies and budgets to promote community options;
2. Single access points – a clearly identifiable organization managing access to a wide variety of community supports, ensuring people understand the full range of options before receiving more restrictive services;
3. Institution supply controls – mechanisms such as Certificate of Need requirements that enable states to limit or reduce institutional beds;
4. Transition from institutions – outreach to identify institutional residents who want to move and assistance with their transition to the community;
5. A continuum of residential options – availability of support services in a range of options from mainstream single family homes and apartments to integrated group settings for people who need 24-hour supervision;
6. Home and community-based (HCBS) infrastructure development – recruitment and training to develop a sufficient supply of providers with the necessary skills and training to encourage consumer independence;
7. Participant direction – people who receive HCBS have primary decision-making authority over their direct support workers and/or their budget for supports; and

² Steve Eiken, *Technical Assistance Guide to Assessing a State Long-Term Care System*, Thomson Medstat, 2006.

8. Quality management – an effective system that a) measures whether the system achieves desired outcomes and meets program requirements and b) identifies strategies for improvement.

Evaluating Virginia's LTC system based on these components can assist the State in determining the extent to which Virginia has the necessary elements to achieve a balanced and person-centered system.

Section 2. Background

In this section, we present demographic information and basic LTC expenditure, utilization and supply data to provide an overview of the demand for LTC services in Virginia and the delivery system. Despite an increase in the past five years in the number of people at an institutional level of care who are receiving Medicaid-funded LTC services, Virginia has made significant progress in serving a higher share in the community and in shifting Medicaid expenditures accordingly.

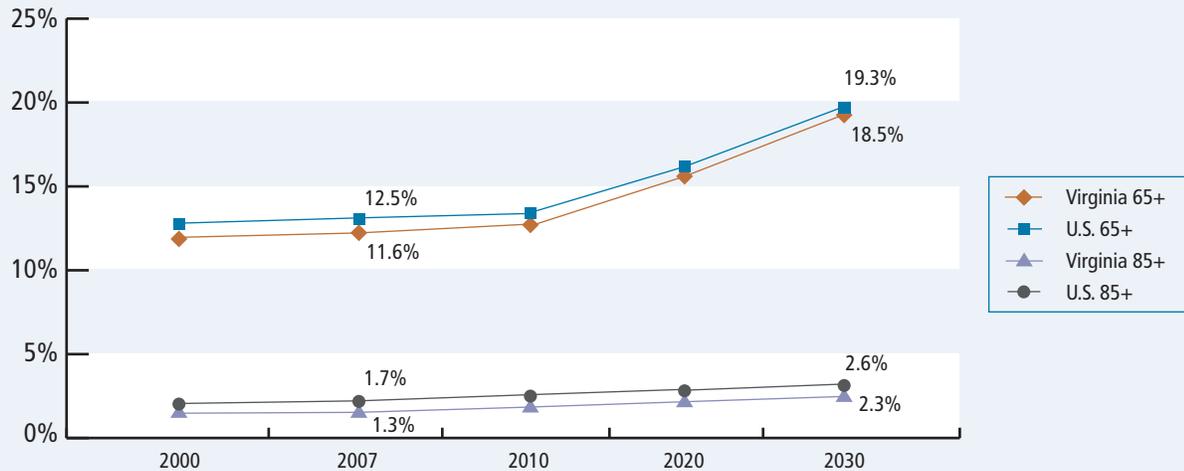
Demographic Information

Based on age, disability and health risk data, Virginians appear to have a slightly lower need for LTC compared to other Americans. Virginia has smaller shares of the population age 65 and older and age 85 and older compared to the U.S., as well as a lower share of people with disabilities. The percentage of the population in Virginia age 65 and older is 11.6 percent, compared to 12.5 percent in the United States as a whole.³ And, Virginia's share of the population age 85 and older is 1.3 percent compared to 1.7 percent for the U.S.⁴ Population projections suggest that Virginia's shares of people age 65 and older and 85 and older are expected to remain lower than the national averages (see Figure 2.1). Maps 1 through 3 in Appendix D show estimates and projections for the 65 and older population by Virginia locality.

³ University of Virginia, Weldon Cooper Center for Public Service, for Virginia population estimates and U.S. Census, 2007 American Community Survey for U.S. population estimates.

⁴ Ibid.

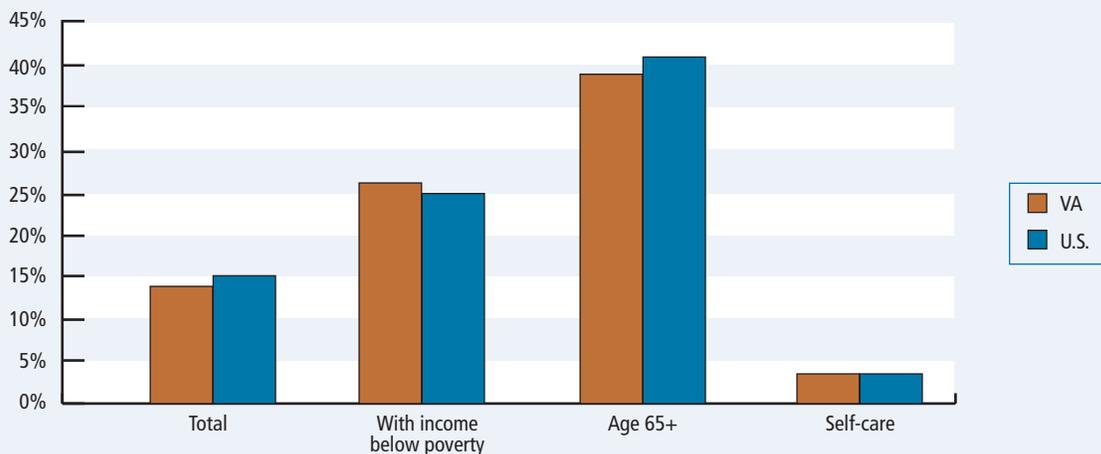
Figure 2.1. Share of Population Age 65+ and 85+: VA Compared to U.S., 2000 - 2030



Source: U.S. Census for all U.S. figures and Virginia 2000. U. of VA Weldon Cooper Center for Public Affairs for Virginia 2007. Virginia Workforce Connections population projections for Virginia 2010 - 2030.

Virginia also generally has lower rates of disability compared to the U.S., with the exception of people with income below the poverty level. Figure 2.2 below compares Virginia's prevalence of disability to that of the U.S. for various subpopulations and specific to self-care disability (which is associated with functional impairment in activities of daily living).⁵ Virginians have lower prevalence of many health risks compared to the U.S., such as: obesity, smoking, diabetes, asthma, hypertension, and people reporting fair or poor health status.⁶

Figure 2.2. Prevalence of Disability by Subpopulation and Self-Care Disability: VA Compared to the U.S. (Age 5 and Older), 2007



Source: Thomson Reuters analysis of U.S. Census, 2007 American Community Survey.

Note: Self-care disability is based on functional impairment and is the Census disability measure most closely associated with the need for LTC.

⁵ U.S. Census, 2007 American Community Survey. The U.S. Census defines self-care disability as a physical, mental, or emotional condition lasting six months or more that makes it difficult dressing, bathing, or getting around inside the house.

⁶ Centers for Disease Control and Prevention, 2007 Behavioral Risk Factor Surveillance Survey.

Prevalence of Mental Illness and Dementia Among LTC Recipients

There is increasing awareness nationally of the prevalence of mental illness (MI) among nursing facility (NF) residents: an important factor in determining the kinds of community supports needed for nursing home transition and diversion. According to CMS' survey and certification data: over half of Virginia NF residents (all payer types) have depression, 18 percent have a psychiatric diagnosis and 46 percent have dementia.⁷ A recent study of MI in nursing homes by state examined new admissions and found that individuals with MI were more likely to become long-stay residents, especially those with either schizophrenia or bipolar disorder.⁸ In Virginia, 44 percent of newly admitted people with MI became long-stay NF residents compared to 23 percent of those with no mental health diagnosis.⁹

There is less information about prevalence of MI and dementia among residents of intermediate care facilities for the mentally retarded (ICFs-MR) and people receiving community-based LTC such as HCBS waiver services. Of Virginians living in large state ICFs-MR in 2006, 62 percent were reported to have a psychiatric disorder.¹⁰ We were able to estimate the prevalence of MI and dementia among participants of these programs through analysis of Virginia's Uniform Assessment Instrument records for people assessed and placed in Medicaid-funded LTC programs in 2008. This analysis showed that over one-third of people assessed for ICFs-MR and over 20 percent of those assessed for NFs and the Elderly and Disabled with Consumer Direction (EDCD) waiver, respectively, had dementia, MI or both.¹¹

Geographic Characteristics

Roughly 28 percent of Virginians live in a rural area, a rate that is somewhat higher than the national average of 23 percent, though much lower compared to some of its neighboring states (e.g. West Virginia, Tennessee, and North Carolina).¹² Virginia's Rural Health Plan uses the Isserman definition of rural areas which includes "rural" and "mixed rural" as this method is believed to best describe Virginia's unique locality structure of counties and independent cities.¹³ According to this definition, 64 percent of Virginia's localities are considered "rural" or "mixed rural."

Demand for publicly-funded LTC services may be higher in Virginia's rural areas given their demographic characteristics. National survey data show a higher share of people living in non-

⁷ American Health Care Association, Medical Condition – Mental Status, CMS OSCAR Current Surveys. This information is self-reported by nursing homes and is not formally audited by inspectors.

⁸ David C. Grabowski, Kelly A. Aschbrenner, Zhanlian Feng and Vincent Mor, "Mental Illness in Nursing Homes: Variations Across States," *Health Affairs*, Volume 28, Number 3.

⁹ Ibid.

¹⁰ Prouty et al (eds.), University of Minnesota, *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2006*, August 2007.

¹¹ DMAS, custom data request. Analysis of other Medicaid-funded LTC programs was not possible due to small populations. Note that this analysis does not reflect prevalence among all people currently receiving these services, just those assessed for the services and placed in FY 2008.

¹² U.S. Census, 2007 American Community Survey.

¹³ Commonwealth of Virginia, Virginia Department of Health, Office of Minority Health and Public Health Policy, *2008 Virginia Rural Health Plan* (see page 37 for a detailed description of the Isserman definition which includes four county geographical classifications: rural, mixed-rural, mixed-urban, and urban.)

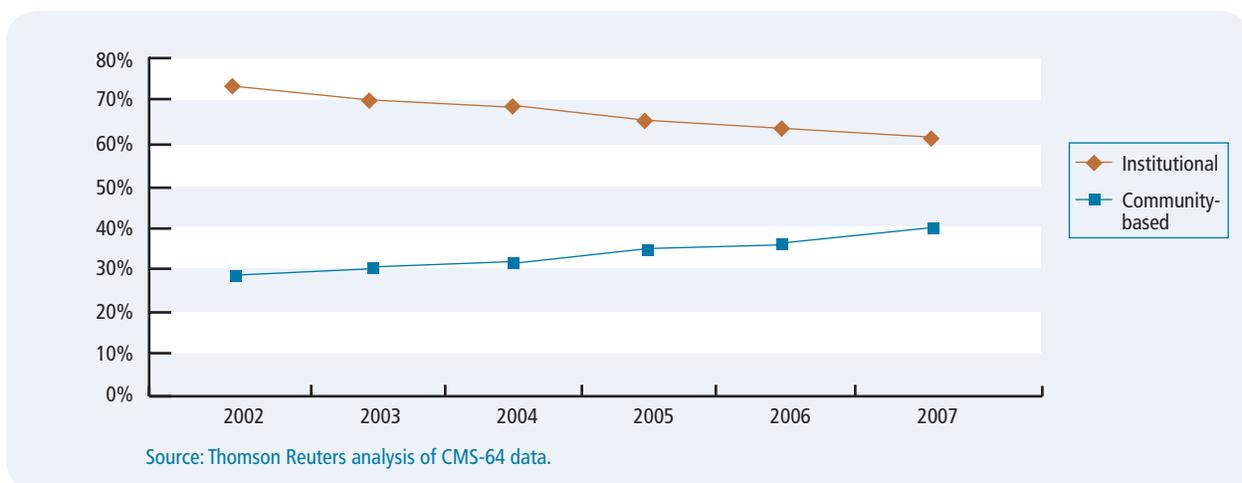
metropolitan areas report “fair or poor” health status compared to those living in metropolitan areas.¹⁴ Rural areas in Virginia have a higher share of people age 65 and older compared to urban areas: 14 percent compared to 11 percent.¹⁵ Older adults living in Virginia’s rural areas are more likely to have a disability and more likely to have income below the poverty level.¹⁶ Disability in general is more prevalent in Virginia’s rural areas (17 percent compared to 12 percent), including a higher share of people with two or more disabilities (nearly 10 percent compared to 6.4 percent).¹⁷ While these characteristics of rural areas are generally similar to national trends, the differences between rural and urban areas in Virginia are larger. Many stakeholders interviewed for this study attested to the challenges of providing LTC services in rural areas. They noted such barriers as lack of running water and electricity, long travel distances between individuals and inaccessible and substandard housing conditions.

Long-Term Care Expenditures, Utilization, and Supply

Expenditures

Medicaid LTC expenditures represented 32 percent of total FFY 2007 Medicaid expenditures in Virginia, nearly identical to the national average. Virginia’s Medicaid LTC expenditures have been increasing by an annual average of over seven percent over the past five years, a rate that exceeds the average annual increase for the U.S. of roughly four percent. Institutional LTC service expenditures represented 60 percent of Virginia’s total Medicaid LTC service expenditures in FFY 2007, exceeding the national average of 58 percent. The share of Medicaid LTC expenditures going toward institutional services has decreased in Virginia by over 17 percent in the past five years, from 73 percent in FFY 2002. Figure 2.3 below shows trends in the balance between institutional and community-based LTC in Virginia over the past five years.

Figure 2.3. Distribution of Medicaid LTC Expenditures in VA: Institutional vs. Community-based, 2002 - 2007



¹⁴ Centers for Disease Control, *Summary Health Statistics for U.S. Adults: National Health Interview Survey, 2007*.

¹⁵ U.S. Census, 2005-2007 American Community Survey 3-Year Estimates. The Census and Isserman definitions of rural differ, but the resulting areas defined as rural by the Census do not appear to be significantly different from those Isserman defines as either rural or mixed rural.

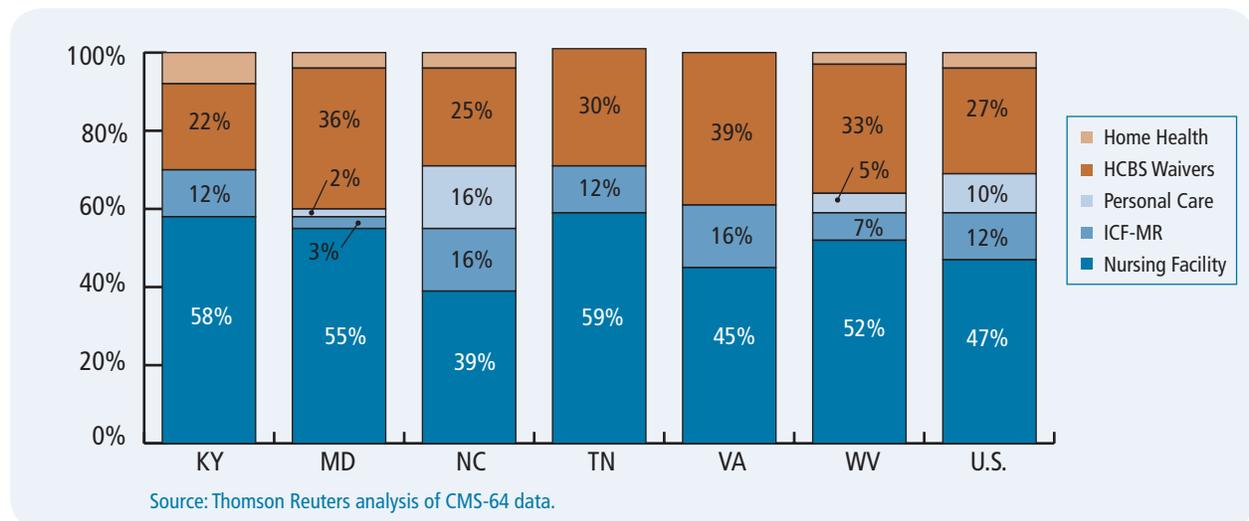
¹⁶ Ibid.

¹⁷ Ibid. Of people age five and older.

This balance between institutional and community-based Medicaid LTC expenditures differs by target group, as described in Sections 4 through 8 of this report. For example, institutional services represent a much higher share of older adults' total Medicaid LTC expenditures as compared to the other target groups. Numerous factors contribute to these differences including historical trends in deinstitutionalization, and variation among groups in the intensity of service needs and HCBS waiver service offerings.

Virginia's spending on HCBS waivers as share of total Medicaid LTC spending has increased dramatically since 2002, from about a quarter of total Medicaid LTC expenditures to nearly 40 percent. Compared to most neighboring states and the U.S., Virginia's share of Medicaid LTC spending on HCBS Waivers is higher, and its share of spending on NF services is lower. However, its share of spending on ICF-MR services is also higher.

Figure 2.4. Distribution of Medicaid LTC Expenditures by Type of Service: VA Compared to Border States & the U.S., 2007

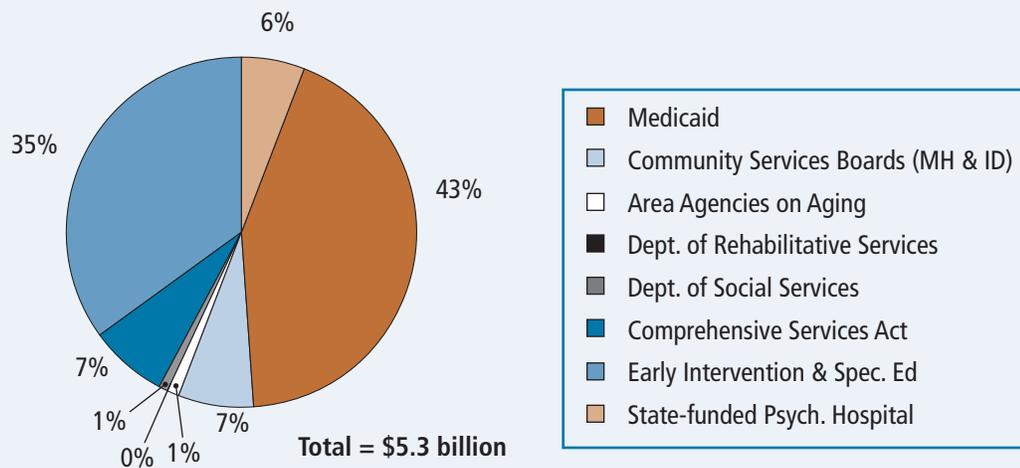


Though Virginia ranks 46th on total Medicaid LTC spending per capita, 47th on home health, and 49th on personal care (not covered in Virginia's State Plan), the Commonwealth ranks towards the middle on ICF-MR and HCBS waiver spending per capita. Table A.1 in Appendix A contains information on Virginia's per capita Medicaid LTC expenditures by service compared to neighboring states and the U.S.

Looking at total public LTC expenditures in Virginia, Medicaid pays the largest portion, followed by early intervention and special education services. Figure 2.5 below shows the distribution of current public LTC spending in Virginia on the five SPT target groups by program.¹⁸ To the extent possible, expenditure data presented here are limited to LTC services and programs.

¹⁸ The Medicaid expenditures shown here are 5.5 percent higher than those cited in the separate target group sections of this report because they include payments made outside of the Medicaid Management Information System (such as consumer-directed services provided under the HCBS waivers). This "offline" payment information is not available at the level of detail needed to allocate the expenditures among the SPT target groups.

Figure 2.5. Distribution of Public LTC Expenditures in VA by Program: FY 2008



Source: Thomson Reuters analysis of CMS-64 data.

Note: Community Services Boards figures are for FY 2007 and are net of Medicaid fee revenue.

Private Financing

Virginians also pay privately for LTC services in their homes and in residential settings such as NFs, assisted living facilities (ALFs) and continuing care retirement communities (CCRCs). People with LTC needs receive unpaid care from informal caregivers and care which they pay for out-of-pocket or have coverage for through private insurance, including long-term care insurance (LTCI). LTCI penetration in Virginia is significantly higher than the national average. A 2005 study ranked Virginia seventh in the nation in LTCI market penetration, with a rate of 14.2 percent.¹⁹ While estimates of private spending for LTC services at the state level are not readily available, the Congressional Research Service estimated that 29 percent of national LTC expenditures in calendar year 2004 were financed through private sources: 19 percent through out-of-pocket expenditures; seven percent through private insurance and three percent through other private payers.²⁰ This study did not assess the economic value of informal (unpaid) care, the primary source of LTC for most people. We discuss the value of informal care later in this section.

Utilization

Virginia appears to rely less on institutional LTC settings compared to neighboring states and the U.S., with the exception of large ICFs-MR. As shown in Table 2.1 below, Virginia has the lowest number of people served per capita in nursing facilities (NFs) and state mental health hospitals among the comparison states and the U.S., but the second highest number served in large (16+ bed) ICFs-MR.²¹

¹⁹ Long Term Care Group, *Index of the Uninsured*, 2005. The LTCI market is defined as those ages 45 and older with income of at least \$20,000.

²⁰ Karen Tritz, *Long-Term Care: Trends in Public and Private Spending*, CRS Report for Congress, Congressional Research Service, April 11, 2006.

²¹ For NFs: CMS Minimum Data Set Active Resident Report, 2nd Quarter 2007, Weldon Cooper Center for Public Affairs population estimate for Virginia, and U.S. Census 2007 American Community Survey population estimates for other states and the U.S. For state mental hospital: National Association for State Mental Health Program Directors Research Institute (West Virginia did not report data and the U.S. average is based on 43 states). And, for ICF-MR: Thomson Reuters analysis of Prouty et al (eds.) University of Minnesota, 2008.

Table 2.1 Use of Institutional LTC Services in Virginia

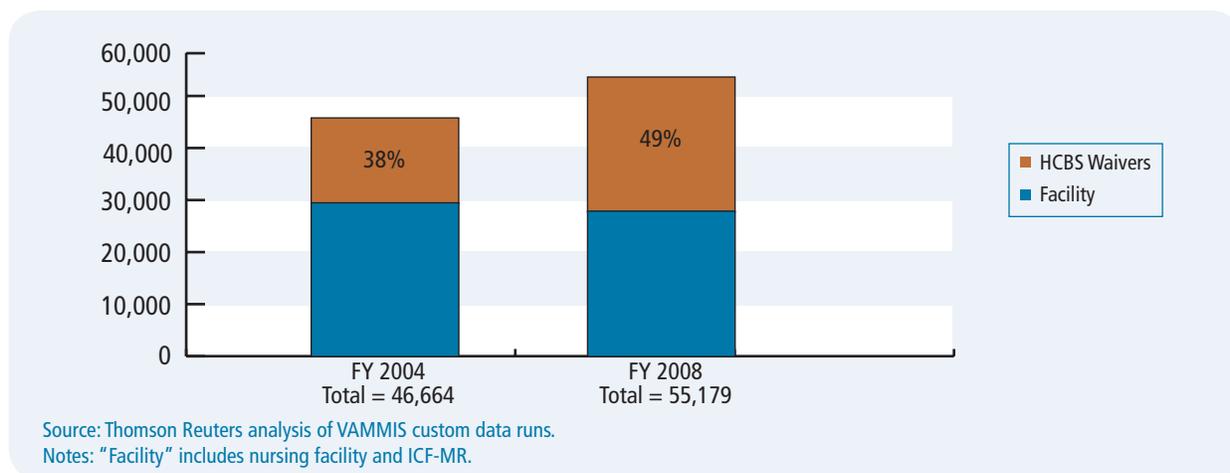
State/U.S.	Number Served in NFs per 1,000 People age 65+ (2007)	State/U.S.	Number Served in State Mental Health Hospitals per 100,000 Population (2006)	State/U.S.	Number Served in Large (16+ bed) ICFs-MR per 100,000 Population (2006)
KY	41.8	MD	21.3	NC	25
TN	41.4	U.S.	15.6	VA	19.2
MD	37.3	TN	13.3	U.S.	18.7
U.S.	36.9	NC	12.2	KY	14.5
WV	35	KY	11.7	TN	11.4
NC	34.3	VA	2.8	MD	6
VA	31.1	WV	N/A	WV	2.6

Source: See footnote 21.

Looking at community-based LTC services, in 2005 Virginia ranked third among its neighbors on the number of HCBS waiver participants per capita as measured both by state population and by the disabled population age five and older.²²

As noted earlier in this section, the number of people at an institutional level of care who are receiving Medicaid-funded LTC services has increased in the past five years, and Virginia is serving a higher share of these people in community-based settings. Figure 2.6 below shows the number of people receiving institutional and HCBS waiver services in FY 2004 as compared to FY 2008: the total number of people served has increased from 46,664 to 55,179 and the share served in HCBS waivers has increased from 38 percent to nearly one-half.²³

Figure 2.6. Number of Virginians at an Institutional Level of Care Receiving Medicaid LTC Services by Type of Care: FY 2004 Compared to FY 2008

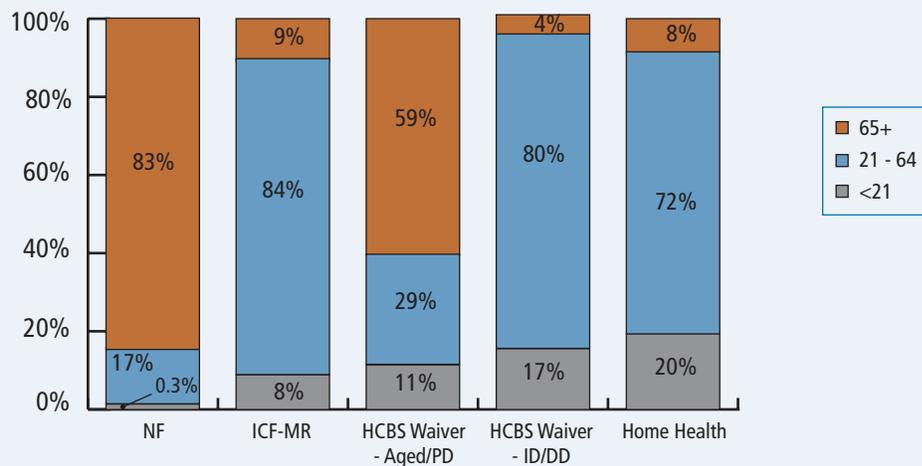


²² Kaiser Family Foundation, statehealthfacts.org, *Medicaid 1915(c) Waiver Participants, by Type of Waiver, 2005*. These are the most recent comparative data available.

²³ People at an institutional level of care receiving long-term mental health services were not included because of the difficulty in identifying people living in the community who require this level of service (other than children and adolescents at a Psychiatric Residential Treatment Facility level of care participating in the Children's Mental Health program).

Use of Medicaid LTC services in Virginia varies significantly by age. Figure 2.7 compares the age distribution of people using select Medicaid-funded LTC services. Older adults utilize NF services and the waiver serving aged/disabled more than other age groups while non-elderly adults dominate the other categories.

Figure 2.7. Age Distribution of Individuals Using Select Medicaid LTC Services in VA, FY 2008



Source: Thomson Reuters analysis of VAMMIS custom data runs.

Note: Waivers included in Aged/PD are EDCD, HIV/AIDS, and Tech. Waivers included in ID/DD are MR/ID, DD and Day Support.

Supply of LTC Providers

The tables below present a snapshot of the supply of community-based and institutional LTC providers in Virginia, based on the most recent data available. However, these data do not address the adequacy of the LTC infrastructure to meet individuals' needs. While there is much information on unmet demand for LTC services (e.g. waitlists for services), to our knowledge, Virginia has not conducted a comprehensive assessment of the supply of HCBS and institutional LTC providers and services to meet demand across the State's LTC populations and programs. Recent initiatives to examine the adequacy of the LTC workforce include: the Governor's Health Care Reform Task Force (which primarily focused on the direct care workforce); and the General Assembly's direction of Virginia's Secretary of Health and Human Resources (HHR) to develop a Blueprint for Aging Services through 2025. The latter report will address infrastructure issues, though limited to older adults.²⁴

²⁴ Commonwealth of Virginia, Office of Community Integration.

Table 2.2 Supply of Select Community-Based LTC Providers and Organizations in Virginia

Provider/Organization	Number	Date
Home Care Organization (state-licensed)	150	2006
Home Health Agency (Medicare-certified)	181	2006
Hospice (state-licensed)	90	2006
Hospice (Medicare-certified)	72	2006
Adult Day Care	72	2008
PACE sites	6	2009
Supported employment programs	73	2009
Case management providers for DD waiver program	28	2009
Group homes for people with ID, ID/MI and MI only (Majority serve people with ID)	229	2009
Supervised living services for people with ID (provider manages physical environment and provides 24-hour supervision and monitoring)	30	2009
Supervised living services for people with MI	26	2009
Day health and rehabilitation service for people with ID	126	2009
Day treatment services for people with MI	45	2009
Partial hospitalization for people with MI	18	2009
Psychiatric unit for people with MI	37	2009

Source: DSS, DMAS, DRS, DMHMRSAS.

With respect to community-based services, stakeholders noted supply gaps in the following areas: high-quality direct care workers (DCWs); accessible and supported independent housing; supported employment (in some regions such as Southside and Southwestern Virginia); providers such as behavioralists, occupational and other therapists; mental health professionals and adult day care.

Table 2.3 Number of Select Types of Institutional and Residential LTC Settings in Virginia

Type of Institution/Residential Facility	Number	Capacity (number of beds)	Date
Nursing Facility	281	31,908	2008
Assisted Living Facility	571	31,778	2008
Continuing Care Retirement Community	53	Not available	2009
ICF-MR	37	2,067	2008
State Psychiatric Hospitals	10	1,765	2008
Private Psychiatric Hospitals	13	Not available	2009
Adult Foster Care Homes	53	159	2008

Source: VDH, DSS, Virginia Bureau of Insurance, DMHMRSAS.

Stakeholders also noted some shortages in institutional services such as NF beds for older adults with challenging mental illness and/or behavioral issues and in residential settings for low-income people. The Commonwealth has studied the feasibility of making its Auxiliary Grant (AG) portable such that it could be used in a greater range of settings than currently allowed. The AG is the state supplement to income for Supplemental Security Income recipients and certain other aged, blind, or disabled individuals

residing in an assisted living facility or an adult foster care home. The current rate is \$1,112 per month (\$1,279 in Northern Virginia).²⁵ A pilot portability program (at level funding) targeting people with MI will start in the summer of 2009. The Office of Community Integration (described below) is exploring the expansion of this initiative beyond people with MI.

Historical and Political Factors Relevant to Long-Term Care in Virginia

The general consensus of stakeholders interviewed in early 2008 was that momentum was building to reform Virginia's LTC system and it appeared to be an opportune time to do so. (It is important to note that these interviews took place before there was a general awareness of the severity of the current recession.) Many felt that the previous and current Administrations were particularly committed to increasing community-based LTC resources (including transformation of the mental health system). Figure A.1 in Appendix A identifies key events related to the expansion of community-based LTC options in Virginia.

Former Governor Warner established the Office of Community Integration (OCI) by Executive Order in 2004, which Governor Kaine has continued through Executive Directive 6 (2007). Through its Implementation Team, the OCI is responsible for ensuring that Virginia complies with the principles espoused by the Olmstead decision and the federal New Freedom Initiative. During the Warner Administration, the Commonwealth also added two new Medicaid HCBS waivers (Day Support and Alzheimer's) and created an enhanced waiver with consumer direction serving older adults and persons with PD by merging two existing waivers (now known as the Elderly or Disabled with Consumer Direction Waiver or "EDCD" waiver). Governor Kaine implemented a task force on health reform which had a LTC workgroup (described later in this section). And, he worked with the General Assembly to establish a Community Integration Advisory Commission (described below).

The Virginia General Assembly has also supported the expansion of community-based LTC in recent years. In 2006, the General Assembly passed legislation officially establishing the Community Integration Advisory Commission in the Code of Virginia. Its creation was seen by the disability community as a legislative recognition of the importance of a cross-disability community integration initiative (the first such recognition since the Olmstead Task Force was created by legislation in 2002).²⁶ The General Assembly has also funded additional waiver slots for the Mental Retardation (MR/ID) and Individual and Family Developmental Disabilities Support (DD) waivers and increased HCBS provider reimbursement rates for some services such as agency-directed personal care and supported employment. It should be noted that the Virginia legislature has published numerous influential studies over the last four decades on the ID, and mental health and substance abuse service systems recommending reforms to prioritize community-based care.²⁷ In March 2009, the General Assembly passed legislation requiring DMAS to develop a plan to eliminate waiting lists for the MR/ID and DD waivers by the 2018-2020 biennium.

²⁵ Virginia Department for the Aging (VDA), *Memorandum to Directors of Area Agencies on Aging*, November 18, 2008.

²⁶ Commonwealth of Virginia, Office of Community Integration.

²⁷ Such as the following Commission studies: Hirst, Bagley, Emick, Hammond and Hall-Gartlan. The Hammond Commission, created by Executive Order under former Governor Gilmore, produced another such study.

Stakeholders believed the combination of political will and demographic pressures were dovetailing to create a unique opportunity to make real change in Virginia's LTC system. However, it is unclear what impact the weak economy will have on this momentum. The declining economy played a role in putting an integrated acute and LTC initiative on hold. Stakeholders also noted that Virginia's requirement of a single-term Governor tends to inhibit progress because it's difficult to sustain focus from one administration to another. Overall, there was consensus that investment of state funds in person-centered community-based LTS will have to be incremental, in keeping with the Commonwealth's values of efficiency in government and fiscal restraint.

Virginia Economy

Virginia has historically had a strong economy, but has been affected by the current economic downturn along with the rest of the country. Virginia has a triple A bond rating, relatively low tax burden, and has been rated the best state for business three years in a row by Forbes.com.²⁸ Although Virginia's current statewide unemployment rate is roughly two percentage points lower than the national average, the unemployment rate of 6.6 percent is the highest it's been since 1996.²⁹ And the unemployment rate varies considerably by region with a high of 12.4 percent in the Danville Metropolitan Statistical Area (MSA) compared to a low of 4.9 percent in the Northern Virginia MSA surrounding Washington, D.C.³⁰ The national unemployment rate for people with disabilities was nearly 13 percent as of April 2009, an increase of two percentage points since October 2008.³¹

In the spring of 2007, recognizing signs of an economic slowdown, Governor Kaine directed state agencies to save money and generally increased scrutiny of agency budgets. In December of 2008, the Governor announced an estimated budget shortfall for FY 2009-10 of \$2.9 billion (later increased to \$3.2 billion). The accompanying 2008-10 budget reduction plan proposed reductions in spending amounting to roughly \$1.8 billion. Some of the proposed cuts directly affected Virginia's LTC programs including the removal of two newly added services from the EDCD and HIV/AIDS HCBS waivers: environmental modifications and assistive technology, among many others.

In the General Assembly's conference committee budget, released at the end of February 2009, many of the proposed cuts related to LTC were restored. Some exceptions were the removal of the two newly added waiver services and a rate cut for residential services in the MR/ID waiver. In addition, the General Assembly added 200 ID waiver slots and increased both agency and consumer-directed personal care rates by three percent. Combined with the aforementioned legislation to eliminate the MR/ID and DD waiver waiting lists, these are noteworthy actions given difficult fiscal times.

²⁸ Governor of Virginia, *Governor Kaine Announces Revenue Reforecast, Plan to Address Shortfall*, and Sahadi, Jeanne, *Tax-Friendly Places 2005*, CNNMoney.com.

²⁹ Virginia Employment Commission, *Virginia's December 2008 Unemployment Rate Rises 0.6 Percentage Point to 5.2 Percent As the Recession Catches Up to Virginia*.

³⁰ [Virginia Workforce Connection](#).

³¹ U.S. Department of Labor, Bureau of Labor Statistics, *Labor Force Statistics from the Current Population Survey*. The Bureau of Labor Statistics does not publish state-level unemployment rates for people with disabilities.

Current Long-Term Care Reform Efforts in Virginia

Virginia has undertaken numerous initiatives to enhance and reform the LTC system: some funded to a large extent by federal grants while others are funded primarily through state general funds. The Governor's Task Force on Health Reform, Money Follows the Person Demonstration and Real Choice Systems Change grants, *No Wrong Door*, Own Your Future, Long-Term Care Partnership, and other initiatives are moving the Commonwealth forward in creating a more balanced and sustainable system.

Governor's Task Force on Health Reform – Long-Term Care Workgroup

Governor Kaine created a Health Reform Commission in July of 2006 with the charge to recommend ways to improve Virginia's health care system. Four workgroups were established within this Commission, one of which was Long-Term Care. The mission of the Long-Term Care Workgroup was to understand Virginia's current LTC system, and recommend ways to improve access to LTC services for all Virginians.³² In the September 2007 Health Reform Commission report, the Long-Term Care workgroup made the following five consensus recommendations:

1. Support and expand services for low-income long-term care consumers;
2. Create accessible and affordable housing for LTC consumers;
3. Ensure consumers, caregivers, and families have adequate information about LTC services and encourage Virginians to plan for their LTC needs
4. Improve home and community-based options for all seniors and persons with disabilities; and
5. Improve state and local coordination.

The Workgroup also recommended the Secretary of HHR establish a state-level LTC Council comprised of state agency staff and other stakeholders. To date, this has not occurred. Given the costs associated with the Workgroup recommendations, estimated at \$96 million, and the current economic climate, the Commonwealth has not formally implemented them.

Other Long-Term Care Initiatives

Money Follows the Person and Real Choice Systems Change Grants

Virginia participates in CMS' Money Follows the Person (MFP) Demonstration and receives Systems Transformation (STG) and SPT grants under CMS's Real Choice Systems Change program. Through MFP, Virginia plans to transition 1,041 people from institutional settings to community-based settings by FY 2011. The total number to be transitioned is divided among three target groups: older adults (325), individuals with PD (358) and individuals with ID/DD (358). Virginia is focusing on three goals in its STG: creating a one-stop LTC information, referral and access system; development and enhancement of person-centered practices and consumer-directed services across all service systems and improvement

³² Roadmap for Virginia's Health, *A Report of the Governor's Health Reform Commission*, September 2007.

of information technology supporting LTC programs. The SPT grant is described in the Foreword to this report.

One-Stop Long-Term Care Information, Referral and Access

Virginia's underlying system supporting one-stop LTC information, referral, and access is called *No Wrong Door (NWD)*. *NWD* is a public/private collaborative effort among Virginia state and local government agencies, 2-1-1 VIRGINIA, *SeniorNavigator* (see "Focus" below), select AAAs, local providers and individuals receiving services.³³ The initiative is partially funded through an Aging and Disability Resource Center grant from the U.S. Administration on Aging and the STG.

The *NWD* initiative will improve the information older adults and people with disabilities receive about available supports, including LTC services. The initiative includes:

- Development of *Virginia Easy Access*, a Web portal that started in August 2008 and connects users to many information sources related to the needs of older adults and people with disabilities (including but not limited to LTC).
- Facilitating secure connections among AAAs and providers using coordinated information, referral and access software called the *NWD Tools*. Ten of Virginia's 25 AAAs are implementing the *NWD Tools* in 2009.
- Establishing a protocol for when 2-1-1 Virginia, the Commonwealth's human services information and referral telephone line, refers people to agencies that specialize in information and assistance for older adults and people with disabilities (e.g. AAAs, CSBs and CILs).

FOCUS: Private/Public Collaboration to Provide Information on LTC Services Through *SeniorNavigator* and *VirginiaNavigator*

Prior to the implementation of the *NWD* program, a private/public collaborative started a one-stop Web-based resource for health and aging information called *SeniorNavigator*. Launched in 2001 and originally designed to serve the needs of older adults and their caregivers, *SeniorNavigator* expanded in 2005 to include information relevant to adults with physical disabilities. *SeniorNavigator* provides its services through a Web site consisting of a database with over 21,000 programs and services in Virginia and bordering states and informative articles. The Web site also features an "ask an expert" section whereby individuals can ask questions confidentially to a specialist.

Individuals can access the *SeniorNavigator* database directly via the Internet, and with assistance from trained staff at over 586 centers around the state. Centers are established through partnerships with community organizations such as senior centers and meal sites, libraries, hospitals, police stations, religious institutions, and more. Since *SeniorNavigator* launched its Web site, there have been over 3 million "visits," defined by *SeniorNavigator* as an incident of use lasting at least 12.5 minutes. Nearly 50 percent of Web searches relate to LTC.

³³ VDA.

Virginia's *NWD* program utilizes a modified version of the database, referred to as *VirginiaNavigator*, in its Web Portal. Nineteen public and private partners participating in *NWD* now use *VirginiaNavigator* for their information and referral system.

Helping Virginians Plan for Long-Term Care Needs

In the past few years, Virginia has embarked on two initiatives designed to encourage people to plan for their LTC needs: the Own Your Future (OYF) Campaign; and the Long-Term Care Partnership (LTCP). OYF is a joint federal-state LTC awareness campaign featuring a toolkit for individuals to help them plan for their LTC needs. Virginia was one of the first of 19 states participating in the campaign. Launched in January 2005 and again in 2008 with a media campaign, Virginians have ordered over 67,000 toolkits thus far.³⁴ The response rate in Virginia to the campaign is nearly 11 percent, which exceeds the average response rate of nine percent for all states participating in the campaign.

Virginia also started a LTCP in September of 2007. This collaborative program between state government and private insurers permits individuals to buy LTCI policies with asset protection. Individuals who buy Partnership-qualified policies may retain assets equal to the amount the policy pays out for LTC benefits if they eventually apply for Medicaid. This allows individuals to obtain coverage for LTC without having to deplete their assets to the levels allowed under Medicaid eligibility guidelines. Eighteen insurers in Virginia currently offer products meeting LTCP requirements, and at least 3,000 policies have been sold since the program began.³⁵

In addition, the Commonwealth of Virginia offers group LTCI policies to state employees and permits tax deductions to its citizens for the purchase of LTCI. Virginia residents can deduct 100 percent of the sum of all premiums paid for a LTCI policy in a given year, provided that no deductions have been taken for the taxpayer's LTCI on the federal income tax claim for the given tax year.³⁶ In 2007, there were nearly 200,000 Virginians with LTCI, paying premiums of \$2.8 billion for the year.³⁷

Integrated Health and Long-Term Care Programs in Virginia

Virginia's Medicaid program is making efforts to expand the use of integrated acute and LTC in the Commonwealth. Virginia has six programs based on the Program of All-Inclusive Care for the Elderly (PACE) model, one of which is among the first rural PACE sites in the U.S. (operated by Mountain Empire Older Citizens in Big Stone Gap, Virginia). There are nearly 300 people participating in Virginia's PACE programs. DMAS also obtained waiver approval from CMS to operate the Virginia Acute and Long-Term Care Integration program. This program would manage acute and LTC services for dual-eligibles and participants in Virginia's EDCD waiver and was to be piloted July 2009 in the Tidewater area. However, the project is on hold due to funding constraints.

³⁴ U.S. Department of Health and Human Services.

³⁵ Virginia State Corporation Commission, *Companies with Approved Long-Term Care Partnership Policies in Virginia*, Revised 2/10/09 (for number of insurers participating in the program). DMAS personal communication (for number of LTCP policies sold). This figure may be understated as formal federal reporting criteria for the program were not released until January 2009.

³⁶ Kaiser Family Foundation, *Long-Term Care Insurance Tax Incentives Offered by States*, 2008.

³⁷ National Association of Insurance Commissioners.

PROMISING PRACTICES: Integrated Acute and LTC Programs

States such as Wisconsin, Minnesota, Massachusetts, Texas, New Mexico, Arizona, and New York have implemented integrated acute and LTC programs which use managed care organizations to provide Medicare- and Medicaid-covered services to people with LTC needs. While features of the programs differ in terms of populations served, services provided, service area size, and whether they are mandatory or voluntary, they all seek to improve upon the “fee-for-service” system by coordinating acute and LTC services to achieve higher quality and better outcomes, and to decrease rates of institutionalization. Recent findings from an evaluation of NF entry in the Massachusetts Senior Care Options program show that program participants have lower rates of NF entry and shorter NF stays compared to a control group.

Long-Term Care Workforce in Virginia

Informal Caregivers

Informal caregiving refers to unpaid care provided to people needing LTC, usually by relatives, friends, or neighbors. Nationally, the majority of informal caregivers are women, a large share being age 65 and older.³⁸ The average caregiver is age 46, female, married and working.³⁹ A number of trends are converging which are expected to diminish the pool of informal caregivers for the baby boomer generation: women’s overall increased labor force participation, an increase in women working at older ages, and decreased number of children per family.

AARP estimates of the number of informal caregivers in Virginia, neighboring states, and the U.S. and associated economic value are shown in Table 2.4 below.⁴⁰ Authors of the study estimate the number of caregivers and hours of care provided based on prevalence data taken from five nationally representative surveys (examining care provided by adults to adults with limitations in daily activities), adjusted to reflect state variation. They estimate the economic value per hour at the state level as a weighted average of the state minimum wage, home health aide median wage and average private pay hourly rate for hiring a home health aide. There are an estimated 900,000 informal caregivers in Virginia providing nearly \$10 billion in care. On a per capita basis, the number of caregivers in Virginia is close to the national average, and slightly lower than the average across the Commonwealth and its five neighboring states. The estimated economic value of informal care as share of total Medicaid LTC expenditures is higher in Virginia compared to neighboring states and the nation, reflecting Virginia’s relatively low Medicaid LTC expenditures.

³⁸ National Caregiver Alliance, *Women and Caregiving: Facts and Figures*, undated.

³⁹ Ibid.

⁴⁰ Ari Houser and Mary Jo Gibson, *Valuing the Invaluable: The Economic Value of Family Caregiving, 2008 Update*, AARP Public Policy Institute, November 2008.

Table 2.4 Caregiving Statistics: Virginia Compared to Border States and the U.S., 2007

State	Number of Caregivers	Caregivers per Capita	Economic Value per Hour	Economic Value (billions)	Economic Value as Share of Medicaid LTC
KY	520,000	.124	\$9.48	\$5.4	4.2
MD	600,000	.107	\$9.79	\$6.3	3.8
NC	1,080,000	.122	\$9.14	\$10.7	4.0
TN	770,000	.127	\$8.71	\$7.2	3.8
VA	900,000	.118	\$10.18	\$9.9	5.7
WV	270,000	.149	\$8.30	\$2.5	3.0
U.S.	34,000,000	.114	\$9.63	\$350	3.7

Source: Houser and Gibson (2008), AARP Public Policy Institute.

Virginia has one program specifically designed to support informal caregivers: the VDA Family Caregiver Support Program. In FY 2008, Virginia served over 2,000 caregivers (unduplicated count) with expenditures of \$5.1 million.⁴¹ The Virginia Department of Social Services had a caregiver grant program, but the program was eliminated in 2009. The Commonwealth also supports informal caregivers through services provided under HCBS waivers.

Supporting caregivers has economic benefits to society overall in that the majority of family caregivers are employed people whose earnings and productivity suffer due to their care responsibilities.⁴² A 2006 MetLife study estimated costs to businesses nationwide of over \$33 billion for full-time employees resulting from absenteeism, workday interruptions, and reduction in hours to accommodate employees' caregiving responsibilities.⁴³ In addition, there are opportunity costs to caregivers in loss of lifetime earnings either by deferring promotions or reducing hours of work or time in the labor force. This, in turn, affects tax revenue to states and the federal government.

Paid Long-Term Care Workforce

The LTC workforce is commonly thought of as direct care workers (DCWs) such as home health aides and personal care attendants. However, there are many other types of personnel who are critical to the provision of LTC services, such as: social workers; behavioralists, and other mental health professionals; physical, occupational, speech and other therapists; and staff who work at group homes and psychosocial and other day support programs. It can be challenging to measure the supply of these other types of providers.

Virginia's supply of DCWs appears to be lower than the national average, as measured by the number of workers per 100,000 people age 65 and older. For example, the number of home health aides in Virginia

⁴¹ Virginia Department for the Aging, *FY 2008 Utilization and Expenditure Profiles*.

⁴² Donna L. Wagner, "Paid Work and Care Work: Employed Caregivers in the U.S.," Towson University, Towson, Maryland, presented at *Informal Care of the Frail Elderly: Policy and Practices to Support Family Caregivers*, National Health Policy Forum, September 21, 2007.

⁴³ MetLife Mature Market Institute, *The MetLife Caregiving Cost Study: Productivity Losses to U.S. Business*. July 2006.

per 100,000 people age 65 and older is 39 percent lower than the national average. Table A.2 in Appendix A shows the number of workers per capita in Virginia, neighboring states, and the U.S. in a number of occupations which are key to providing services to older adults and people with disabilities.

Virginia's average hourly wages for DCWs are also low compared to the national average, and most other states. According to Bureau of Labor Statistics occupational data, Virginia ranks 33rd on wages for nursing aides, 38th on wages for home health aides, and 44th on wages for personal care workers.⁴⁴

PROMISING PRACTICES: Strengthening the LTC Workforce

There are a variety of efforts in place to recruit and retain LTC DCWs. Many states have professional associations that can provide support, training, recognition and networking opportunities for members of the direct care workforce.⁴⁵ In fact, Virginia is among one of the first states to have its association launched by direct care workers themselves, who recognized the needs of their colleagues.⁴⁶ In addition, providers such as Golden Care Academy in San Diego, California and Mather Pavilion at Wagner in Evanston, Illinois are offering career ladders, often in the form of tiered credentialing with increasing pay rates, for DCWs. The National Alliance of Direct Support Professionals also offers a three-tier, online national credentialing system that enables workers to become bachelor degree-level direct support professionals.⁴⁷

A collaborative recruitment effort has also been successful throughout much of New England. Rewarding Work Resources, a non-profit corporation, maintains an online database that enables available DCWs to submit information regarding when they are able to work.⁴⁸ Then, consumers who subscribe to the service (up to \$90 annually) can access a database to find workers who can meet their level of care needs. A database that started with 2,000 potential workers in early 2000 has now expanded to include nearly 20,000.

Stakeholders described challenges related to the Virginia direct care workforce. Some people with disabilities said it was very difficult to find reliable DCWs. However, they also noted that the bad economy was working in their favor as the pool of workers had expanded. Some rural community-based organizations described problems with finding adequate numbers of DCWs who pass criminal background checks.

⁴⁴ Bureau of Labor Statistics, *Occupational Employment Statistics*, May 2007.

⁴⁵ Paraprofessional Healthcare Institute, Workforce Tools, *Direct Care Worker Associations: Empowering Workers to Improve the Quality of Home- and Community-Based Care*, Number 3, Spring 2004.

⁴⁶ Ibid.

⁴⁷ National Alliance of Direct Support Professionals website, <http://www.nadsp.org/credentialing/index.asp> and Paraprofessional Healthcare Institute, Workforce Tools, *The Right Start: Preparing Direct Care Workers to Provide Home- and Community-Based Care*, Number 2, Winter 2004.

⁴⁸ Centers for Medicare & Medicaid Services, *Promising Practices in Home and Community Based Services: Massachusetts – Recruiting Direct Service Professionals/Personal Assistants in a Competitive Environment*, updated 12/17/04 and Rewarding Work website, <http://www.rewardingwork.org/AboutRewardingWork/Default.asp>.

FOCUS: Strengthening the Direct Care Workforce through Training and Career Pathways

The Commonwealth has embarked on a training initiative for DCWs serving people with intellectual disabilities and mental health and substance abuse issues called the Virginia College of Direct Support (CDS) Partnership Program. This Web-based training program, subsidized by DMHMRSAS, started in 2004 as a pilot consisting of two state ICFs-MR, five CSBs, and nine private provider organizations. The CDS offers 79 lessons on topics such as safety in the home and community, person-centered planning, positive behavior supports, individual rights and choices, and many others. There are also modules for supervisors and managers.

With positive evaluation results, the program was implemented state-wide in state facilities in 2006 and subsequently to all DMHMRSAS system stakeholders in 2007. Currently, the program has expanded to more than 8,600 learners, state-wide, across disabilities, and more than 50 organizations. The success of the program has resulted in development of a career pathway program for DCWs, which has enhanced competencies of direct support staff and made staff feel more valued. DMHMRSAS hopes to continue to expand the partnership to all service providers, parents and individuals with disabilities across Virginia.

Section 3. Administrative Structure for Long-Term Care in Virginia***Key State Agencies in the Long-Term Care System***

The lead agencies with authority over the LTC system in Virginia are within the Secretariat of HHR. The organization chart in Figure A.2 in Appendix A shows the lead agencies within HHR as well as the OCI and other state agencies with a key role in the LTC system. In 2007, the Virginia General Assembly passed legislation designating the Secretary of HHR as the lead for coordinating and implementing LTC policy for the Commonwealth, although some note HHR had already assumed this role.

DMAS, by virtue of housing Virginia's Medicaid program, has the lead role in financing LTC and administering the HCBS waivers and federal rebalancing grants such as MFP, STG and SPT. DMAS coordinates with the Department of Mental Health, Mental Retardation and Substance Abuse Services (DMHMRSAS) on administering the Intellectual Disability (MR/ID) and Day Support waivers.

DMHMRSAS oversees and provides services to people with ID, and those needing mental health and substance abuse services. DMHMRSAS partners with 39 community services boards (CSBs), and one behavioral health authority to provide these services. (For simplicity, we refer to all 40 agencies as CSBs.) CSBs are single points of entry into Virginia's publicly-funded mental health, ID, and substance abuse service systems. Established by local governments, CSBs have authority and responsibility for assessing individual needs, accessing services and supports on behalf of individuals (community-based and state

facilities), and managing services in collaboration with state agencies such as DMAS. CSBs either directly deliver community-based services or coordinate service delivery through private and public providers. DMHMRSAS also licenses 26 kinds of providers and operates 16 facilities serving their target populations.

As of July 1, 2009, DMHMRSAS' name will change to the Department of Behavioral Health and Developmental Services. The General Assembly changed the name, according to the agency's Web site, "to more broadly reflect the department's mission, to be flexible enough for the department to grow into other service areas, like autism spectrum disorders, and to move away from the stigma associated with the term 'mental retardation.'"

The Virginia Department for the Aging (VDA) funds and oversees aging services through contracts with 25 Area Agencies on Aging (AAAs). VDA is also the lead agency for the *NWD* initiative.

The Department of Rehabilitative Services (DRS) provides vocational rehabilitation, personal assistance, case management, and other services for people with disabilities. A majority of people receiving services have physical or sensory disabilities, but some programs serve people regardless of the type of disability. For example, the largest share of people served in the DRS Vocational Rehabilitation program by primary impairment were those with cognitive impairments (41 percent).⁴⁹ DRS also conducts disability determinations for the Social Security Administration. DRS partially funds 16 local Centers for Independent Living (CILs) and four satellite centers which provide training in independent living skills, peer counseling, information and referral, and advocacy to people with disabilities. Disability Services Boards (DSBs) are other DRS local partners and are comprised of local governments, consumers, and businesses. DSBs assess local needs and priorities for people with physical and sensory disabilities.

The Virginia Department of Social Services (DSS) has many roles in the LTC system including functional and financial eligibility determination, licensing of providers and service provision. Local DSS staff, in conjunction with local public health nurses, conduct the functional screening for Virginia's LTC institutional services and some of the HCBS waivers. Local DSS offices also determine eligibility for Medicaid, food stamps and other public assistance programs. DSS funds some LTS such as companion and chore through its adult home-based services program and administers the Auxiliary Grant program (discussed in the previous section). Finally, DSS licenses assisted living centers and adult day care centers, certifies adult foster care homes, and oversees child and adult protective services.

The Virginia Department of Health (VDH) is the State's public health agency and has many roles in the LTC system. In addition to conducting the functional screen for NF care and some HCBS waivers, VDH licenses NFs and home health organizations. It also serves as the state survey agency for NFs, ICFs-MR, Home Health Agencies, and Hospices.

The Virginia Board for People with Disabilities (VBPD) is the state Developmental Disabilities Council and advises the Governor, HHR, the Virginia legislature, and other constituent groups on issues relating

⁴⁹ Commonwealth of Virginia, *Virginia State Rehabilitation Council 2008 Annual Report*. Over one-third of those served in the Vocational Rehabilitation program had a primary impairment that was mental/emotional/psychosocial in nature and only 18 percent had a primary impairment that was physical. These are federal fiscal year 2008 data.

to the developmental disabilities community. Overall, the VBPD serves an advocacy role for people with disabilities and publishes a very comprehensive biennial assessment of the entire service system.

The Office of the Comprehensive Services Act (CSA) pools eight funding streams to better serve emotionally/behaviorally troubled and at-risk children whose needs span multiple agencies. Most of these children are in the foster care system or at-risk for foster care.

The Virginia Department of Health Professions (DHP) licenses health care professionals and paraprofessionals. Specific to the LTC system, the DHP certifies nurse aides and licenses mental health professionals, therapists, and LTC and ALF administrators.

While having all of the lead agencies within one Secretariat enhances the potential for coordination of LTC services, stakeholders noted that there is considerable fragmentation in the system. This fragmentation has two forms. There are “silos” in that older adults and people with certain types of disabilities are served primarily by separate agencies and programs. And, at the same time, people using LTC services are typically served by multiple agencies, making navigation of the system confusing and difficult. As noted above, many state agencies have varying roles in the LTC system. These roles, as they pertain to the five SPT target groups, are described in greater detail in Table A.3 in Appendix A. On a positive note, many stakeholders commented that collaboration among the state agencies with key roles in the LTC system has improved significantly in recent years.

Long-Term Care Commissions

As noted in Section 2, in 2006 the Virginia General Assembly established a Community Integration Advisory Commission in the Code of Virginia. This Commission monitors state agencies’ progress in integrating people with disabilities into the community. Specifically, the Commission oversees and initiates much of the work conducted by the OCI Implementation Team and makes recommendations to the Governor. Commission members are appointed by the Governor, Speaker of the House, and Senate Rules Committee. Stakeholders viewed the codification of the Commission in state law as an important step forward in advancing the principles of community integration.

The Transformation Leadership Team (TLT) is another advisory body that plays an important role in Virginia’s rebalancing efforts. The TLT was originally put in place to oversee the development and implementation of the STG. However, the State expanded the TLT’s advisory role to include the MFP and SPT grants. In addition, members of the TLT wanted to play a more proactive role in systems transformation by expanding the Team’s responsibilities related to communications on rebalancing initiatives and exploring the development of funding to ensure sustainability of HCBS initiatives.

Role of Localities in the Long-Term Care System

Localities in Virginia have a very strong role in coordinating and delivering LTC services. The Code of Virginia requires each locality to have a LTC coordinating committee comprised of local agencies such as AAAs, CSBs, Department of Social Services, and public health. In 2008, the General Assembly passed

a law to require representation by housing and transportation agencies on the coordinating committees. While many localities designate this task to the local AAA, some, such as Fairfax County and Chesterfield County, form their own local government LTC Coordinating Councils.

As noted above, the key local partners to state agencies in LTC planning, access, and delivery are: AAAs, CSBs, CILS, local DSS offices, local Departments of Public Health, and DSBs. In addition, local Community Action Agencies and faith-based organizations play a role in helping some individuals with LTC needs, but there is no centralized tracking of these efforts to gauge the significance of their role in the LTC system.

Organizations that play a role in Virginia's LTC system define local catchment areas differently, which can create challenges in LTC planning and delivery. For example, there are 25 AAAs, 40 CSBs, 35 local health districts, 120 local DSS offices and various planning districts within these categories. The lack of alignment of these catchment areas can make it difficult to coordinate efforts locally and to assess LTC needs across target populations.

As is true in many states, much of LTC in Virginia is “local” in that services are, for the most part, overseen and provided at the local level and the types of services available can depend upon local conditions. Stakeholders noted many strengths and weaknesses to the prominence of localities in Virginia's LTC system. On the positive side, many commented on the resourcefulness and commitment of local agency staff. And, some localities have exemplary programs reflecting very effective local coordination (see “FOCUS” below). On the other hand, stakeholders also noted the variation in local funding could adversely impact services in that localities with low levels of local funding were more constrained in what they could provide compared to areas with high levels of local funding. Map 4 in Appendix D provides an example of this variation: it shows local funding as share of total CSB funding by CSB. Further, some areas simply don't have services which are offered in other areas (e.g. peer support in mental health care and supported employment).

FOCUS: Mountain Empire Older Citizens' Mission to Leverage Results Through Local Needs Assessment and Coordination

Mountain Empire Older Citizens (MEOC), an AAA and public transit organization in rural Southwestern Virginia, is an example of a community-based organization that has excelled in coordinating with local stakeholders to provide outstanding services to residents, including an award-winning regional transit system and one of the nation's first rural PACE sites. MEOC was recently honored by the U.S. Department of Transportation as a recipient of the 2009 United We Ride National Leadership Award for leadership in developing a high-quality, coordinated health and human services transportation system. MEOC has won numerous awards and honors for its programs, including an invitation from The Carnegie Institute-United Kingdom to consult with them on community-based rural initiatives. According to MEOC staff, their success is based on a number of strategies: commitment to assessing the larger needs within the community; coordination with a wide range of local human service organizations and other stakeholders and resourcefulness in identifying a large and diverse array of funding sources to sustain their programs (MEOC reported having 90 different funding sources).

The Role of Advocates in the Long-Term Care System

Advocacy groups in Virginia, including self-advocates, have been essential in moving the LTC system forward, especially in expanding and strengthening community-based services. Many stakeholders described advocates for people with disabilities and older adults as having a large influence on the LTC policymaking process. Advocates have worked to educate policymakers regarding long-term supports, a key factor in increasing HCBS waiver slots and provider reimbursement rates, transforming the public mental health system to one that is more recovery-oriented and decreasing the number of people with DD living in large state ICFs-MR (training centers). Advocates have also played a significant role in workgroups to plan state initiatives such as the MFP Demonstration and the STG.

The Role of Individuals in the Long-Term Care System: Person-Centered Practice

The Commonwealth has made a strong commitment to making its publicly-funded LTC programs more person-centered by increasing participants' choice and control over their services and more globally ensuring that person-centered practices infuse the system. This is being accomplished through a number of efforts, many of which fall under the STG. As noted in Section 2, one of the three goals of Virginia's STG is development and enhancement of the self-directed delivery system. Self or participant direction generally refers to an approach that shifts "the locus of decision-making and control away from payers and providers toward program participants or policyholders."⁵⁰ As it pertains to publicly-funded LTC, participant direction has most commonly been used for services such as personal care, homemaker/chore and respite, but may be used for other services as well.⁵¹ States that offer participant-directed Medicaid LTS use a variety of strategies. A number of them offer program participants the choice to employ their personal care providers and individualized budgets out of which they can purchase personal assistance services, including assistive technologies or home modifications.

Virginia has included self direction in its HCBS waiver program since 1997,⁵² preceded by the DRS personal assistance program. Currently, Virginia offers self-directed personal care and other services in the following HCBS waivers: EDCD, DD, MR/ID, and HIV/AIDS. In Virginia's self-directed program, participants employ and schedule their own attendants and develop their care plans with the assistance of a service facilitator. Participants use a fiscal agent contracted with DMAS to handle administrative processes related to employment and payment of attendants. DMAS' program gives participants the option of using a combination of agency-directed and consumer-directed services. As of March 2009, 5,183 individuals were using consumer-directed services, the majority of whom were in the EDCD waiver.⁵³

⁵⁰ Pamela Doty (U.S. Department of Health and Human Services, Assistant Secretary for Planning and Evaluation), *Consumer-Directed Home Care: Effects on Family Caregivers*, Policy Brief, Family Caregiver Alliance, October 2004.

⁵¹ Pamela Doty and Susan Flanagan, *Highlights: Inventory of Consumer-Directed Support Programs*, U.S. Department of Health and Human Services, Assistant Secretary for Planning and Evaluation, 2002.

⁵² The first of Virginia's HCBS waiver to have consumer direction was the Consumer-Directed Personal Attendant Services waiver which became the EDCD waiver in 2005.

⁵³ DMAS personal communication.

Through the STG, the Commonwealth is exploring adding individualized budgets to the existing self-direction program and has promoted person-centered practice guidelines and principles by developing educational documents, conducting trainings and reviewing Virginia policy, regulations and legislation. Examples of progress made on incorporating person-centered practice are the General Assembly's change of the term "Mental Retardation" to "Intellectual Disabilities" and development of the MFP Protocol, which is written from the perspective of program participants.⁵⁴ More detailed information on participant direction in Virginia's LTC programs by target group is included in Sections 4 through 8 of this report.

How People Are Informed of Long-Term Care Options and Programs

People typically get information about their LTC options by contacting the lead agency for their particular target group (e.g. CSBs for those with mental illness or intellectual disabilities). In the regions of Virginia served by the NWD system, people with LTC needs can find out about services and programs they may be eligible for through NWD. People can obtain information on LTC services through the *Virginia Easy Access* system, but the *VirginiaNavigator* database has not been completely developed yet for people with disabilities.

Data Systems and Reporting

Numerous stakeholders complained that the state agency data systems in Virginia "don't talk to each other," making analysis of the LTC system difficult. In gathering data for this report, the authors noted much variation in agencies' capabilities of providing basic unduplicated utilization and expenditure data over a five-year historical period. And, in some cases, it is very challenging to disaggregate financing sources so as not to "double count" revenue streams such as Medicaid. Further, it can be hard to identify the users of LTC services. While it is very clear-cut in the case of people at an institutional level of care using Medicaid services such as nursing facility, ICF-MR or HCBS waiver, it is less clear who the users of LTC services are among people using community-based mental health services or among children receiving services through special education or the early and periodic screening, diagnosis, and treatment (EPSDT) program. The Commonwealth would be well-served by developing a coordinated and consistent approach to data collection to support the identification of people using LTC services, use and provision of LTC services, LTC expenditures, and unmet need.

⁵⁴ Beth Jackson, Suzanne Crisp and Steve Eiken, *Evaluation of Virginia's System Transformation Grant: Year 2 Interim Report*, April 8, 2009.

Section 4. Services for Older Adults

“I am independent, I admit that. But, I also realize, more and more each day that I have limitations. And, as time progresses, if I don’t do better, if I worsen, then of course I’ll need more. I realize that.” – Older adult from Tidewater area

Overview

People age 65 and older comprise nearly 12 percent of the Virginia population, and account for a relatively large share of the Commonwealth’s Medicaid expenditures due to this age group’s higher burden of illness.⁵⁵ Older adults comprise 11 percent of people receiving Medicaid services, but drive nearly one-quarter of Virginia’s total Medicaid spending and 50 percent of Medicaid spending on LTC services.⁵⁶ These findings are consistent with national trends.⁵⁷ When AAA and other public expenditures are included, public LTC expenditures and related supports for older adults in Virginia totaled \$888 million in FY 2008. Older adults also pay for a significant share of their LTC expenditures out-of-pocket: 33 percent in 2004 (based on a national estimate).⁵⁸

The Commonwealth and the private sector have implemented some important programs designed to help older adults and their families navigate the system, such as *NWD* and *Virginia Easy Access* (described in Section 2). In addition, there is increased focus within CSBs on the mental health needs of older adults, with innovative programs providing wraparound mental health supports and services to help transition older adult residents of state psychiatric hospitals back to the community and avoid out-of-community and out-of-home placements. These programs are located in a number of planning districts and mental health regions, particularly in Northern Virginia, Tidewater, and mid-Virginia based in the Culpeper area. Region II in Southwestern Virginia has been developing partnerships and services as well.

⁵⁵ Richard G. Kronick, Melanie Bella, Todd P. Gilmer and Stephen Somers, *The Faces of Medicaid II: Recognizing the Care Needs of people with Multiple Chronic Conditions*, Center for Health Care Strategies, Inc., October 2007.

⁵⁶ Department of Medical Assistance Services, FY 2006 Statistical Record, Annual Expenditures for Medical Services by Type of Medical Service and Age Group. Medicaid “Long-term care” expenditures include the following Statistical Record categories: nursing facility, ICF-MR, home health, personal care, hospice and home health community services.

⁵⁷ Kronick et al 2007 and Anna Sommers, Mindy Cohen and Molly O’Malley, *Medicaid’s Long-Term Care Beneficiaries: An Analysis of Spending Patterns*, Kaiser Commission on Medicaid and the Uninsured, November 2006.

⁵⁸ Congressional Budget Office, *Financing Long-Term Care for the Elderly*, April 2004. This estimate excludes the value of informal care. State-level estimates are not available.

FOCUS: Regional Coordination to Transition Older Adults Out of Mental Health Facilities through the Raft Program

The RAFT program, a Northern Virginia mental health program funded through State and Federal Block Grants, works with two regional state mental health facilities and area nursing facilities (NFs) to transition older adult psychiatric patients back to the community. RAFT provides training and technical assistance to help both the mental health facilities and the NFs manage the transition, at times providing NFs with on-site staff to help the facilities manage care for people with challenging psychiatric or behavioral needs. The RAFT program addresses a need for better communication and understanding among all parties involved in serving older adults with mental illness who also have LTC needs.

Virginia has not decreased the number of people residing in NFs over the past five years, though the increase is slightly lower for people age 65 and older compared to all age groups.⁵⁹ Virginia is making concerted effort to transition people from NFs and to prevent people from entering them by offering community-based support services through HCBS waivers, the MFP Demonstration, the recently-awarded Nursing Facility Diversion Grant, AAAs and other state agencies. However, waitlists for home-based supports suggest that more progress could be made if there were additional funding for programs serving older adults who are not yet at a nursing home level of care.

Programs and Services

Older adults in Virginia receive LTC services and supports through a variety of public programs and agencies depending upon need, Medicaid status and level of functional impairment.

Tables 4.1 and 4.2 show the major public programs through which older Virginians receive LTC services and trends in expenditures and use. As shown in Table 4.2, Virginia has made some progress over the past five years in reducing the number of older people receiving Medicaid-financed NF services, while increasing the share receiving HCBS waiver services.

⁵⁹ Centers for Medicare & Medicaid Services, *2008 Nursing Home Data Compendium*.

Table 4.1 Public LTC Expenditures for Older Adults: SFYs 2004 and 2008

	2004	2008	Average Annual Percentage Change	Percent of Total 2008 Expenditures
Medicaid				
Nursing Facility	\$485,549,457	\$571,399,014	4%	
ICF-MR	\$16,482,181	\$20,842,119	6%	
Mental Health Facility	\$39,136,814	\$40,462,640	<1%	
EDCD Waiver	\$75,846,993	\$120,298,392	12%	
Other waivers combined	\$8,326,113	\$22,004,579	28%	
Home health	\$411,291	\$405,383	4%	
MH Community (includes case management)	\$5,591,977	\$11,424,256	20%	
Case management (all types)	\$939,465	\$1,347,517	10%	
Hospice	\$5,728,985	\$23,908,597	46%	
PACE	\$3,596,304	\$4,342,468	9%	
Total Medicaid	\$641,609,580	\$816,434,965	N/A	92%
Other Public Programs				
AAA (age 60 and older)	\$44,415,465	\$44,600,000	<1%	
DSS Auxiliary Grant*	\$9,881,000	\$12,177,000	5%	
DSS Adult Services**	\$16,100,000	\$14,500,000	-3%	
Total Other Public Programs	\$70,396,465	\$71,277,000	N/A	8%
Total Public Expenditures	\$712,006,045	\$887,711,965	N/A	N/A

Notes: * estimate based on 41% share that older adults represent of Auxiliary Grant recipients. ** SFY 2007 was most current information available, trend calculated since FY 2002, estimate based on 67% share that older adults represent of Adult Services recipients. Older Virginians also receive LTC services through the Virginia Department of Rehabilitative Services Personal Assistance and Community Rehabilitative Case Management Services programs, as well as ID and MH services through CSBs. However, expenditures for these programs by age group are not available. Source: DMAS, VDA, DSS.

Table 4.2 Number of Older Virginians Receiving Public LTC Services: SFYs 2004 and 2008

	2004	2008	Annual Percentage Change
Medicaid			
Nursing Facility	23,334	21,804	-2%
ICF-MR	143	157	2%
MH Facility	527	494	-1%
EDCD Waiver	7,666	10,382	8%
Other waivers combined	203	369	16%
Home health	483	351	-4%
Case management	1,352	1,452	10%
Hospice	932	2,212	30%
PACE (started in 2008 with pre-PACE programs in effect prior)	Not available	188	N/A
Other Public Programs			
AAA (age 60 and older)	51,460	57,835	3%
DSS Auxiliary Grant	2,618*	2,236	-4%
DSS Adult Services**	3,596	4,280	4%
CSB ID Services	510	593	5%
CSB MH Services	5,937	6,252	1%
DRS State Personal Assistance Services program	Not available	21	N/A
DRS Community Rehabilitative Case Management Services	Not available	122	N/A

Source: DMAS, VDA, DSS, DMHRSAS, DRS. Notes: *estimate based on 41% of total caseload. ** SFY 2007 was most current information available, trend calculated since FY 2003, estimate based on 67% share that older adults represent of home-based adult services.

Medicaid Services

The primary public systems through which older adults receive LTC are: Medicaid; AAAs; CSBs; and local DSS offices. The majority of older adults receiving Medicaid-financed LTC are served in NFs: nearly 22,000 people in SFY 2008.⁶⁰ As shown in Table 4.2, older adults receiving Medicaid-financed LTC reside in other institutional settings such as ICFs-MR and mental health facilities, but in much smaller numbers compared to NFs. Older adults also receive Medicaid-financed community-based services, with the majority served in the EDCD waiver. This waiver is described in Section 5.

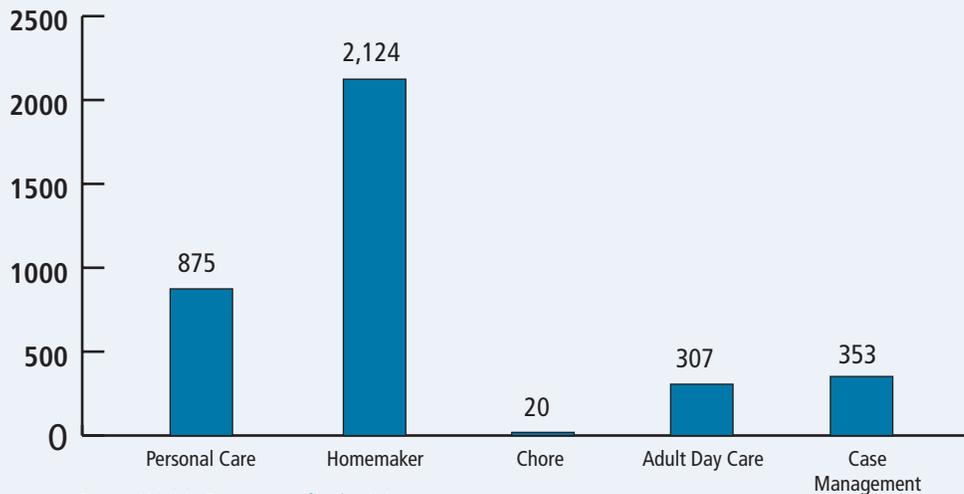
Other Public Programs

“AAA has been like a lifeline . . . There are just so many things they do to help us that I can’t just tell you right now all of the things that mean so much to you when you’re handicapped.”

– Older Virginian receiving AAA services

In addition to community-based services funded by Medicaid, older adults receive LTC and supports through 25 AAAs. AAAs must provide a core set of services to people age 60 and older such as meals and in-home supports to comply with Older Americans Act funding requirements. This funding requires that AAAs prioritize certain groups of older adults, such as frail elderly who are low-income or live in rural or geographically isolated areas.⁶¹ Many AAAs augment the core “registered” services with additional services such as transportation, Medicaid personal care and insurance counseling. Figure 4.1 shows the unduplicated number of people who received select AAA LTC services in FFY 2008.

Figure 4.1. Unduplicated Count of People Receiving Select LTC Services Through VA AAAs: FFY 2008



⁶⁰ DMAS, VAMMIS custom data run, February 2009.

⁶¹ VDA, Agency Strategic Plan.

In addition, VDA received grant funds of over \$4 million from the Administration on Aging and the Veterans Administration (VA) for nursing home diversion.⁶² VDA is currently developing policies and procedures for the program and will begin enrollment in July 2009.⁶³

AAAs' main focus as measured by the number of people served and dollars spent is meals: over 13,519 people received home-delivered meals in FFY 2008, and 14,742 received congregate meals. The combined spending for these two services in FFY 2008 was over \$17 million, 43 percent of total AAA service expenditures.

The Commonwealth provides additional LTS through DSS, which finances support services such as companion, chore and homemaker within limited funding. As described in Section 3, DSS also provides Auxiliary Grants to people receiving supplemental security income to help pay the monthly cost of care in ALFs and adult foster care homes.

Demographic and Utilization Trends

The age 65 and older population in Virginia has increased by roughly 99,000 people since 2000, however the share older adults represent of the total Virginia population has not changed significantly during this time period (from 11.2 in 2000 to 11.6 percent in 2007).⁶⁴ As described in Section 2, the share of older adults in Virginia is expected to grow dramatically over the next 20 years. Figure 2.1 in Section 2 shows these trends statewide, and maps 1 through 3 in Appendix D show trends by locality over time.

Virginia's 65 and older population appears to be "younger" compared to the national average in that the shares of people who are in the "oldest" age groups (age 75 to 84 and 85 and older) are smaller. The median age of Virginians age 65 and older is 74 compared to 74.7 for the nation.

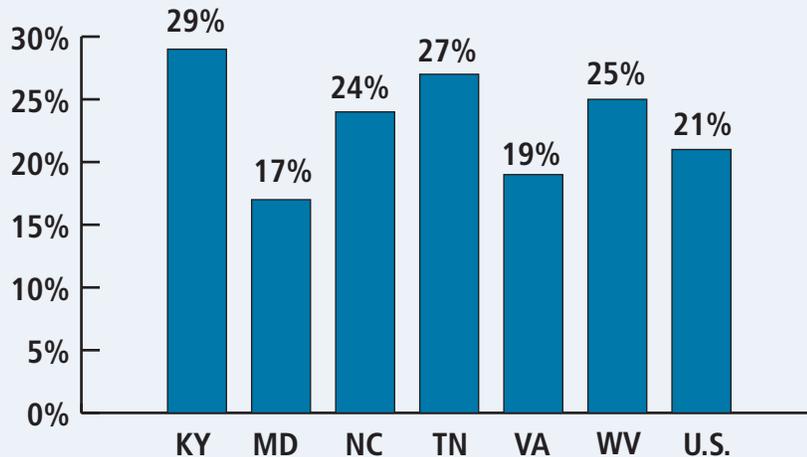
Virginia's older adult population appears to be financially better off compared to neighboring states and the U.S., with the exception of Maryland. As shown in Figure 4.2, the share of older Virginians below poverty is lower than the national average and all border states but Maryland. And, older Virginians have higher average annual income from earnings, Social Security and retirement income compared to the national average and all border states but Maryland.

⁶² U.S. Administration on Aging, press release, *HHS Announces \$36 Million to Help Older Americans and Veterans Remain Independent*, September 29, 2008.

⁶³ VDA, personal communication.

⁶⁴ U.S. Census. Decennial Census 2000 Summary File, Table P12, Sex by Age (for year 2000) and Weldon Cooper Center for Public Service (for year 2007).

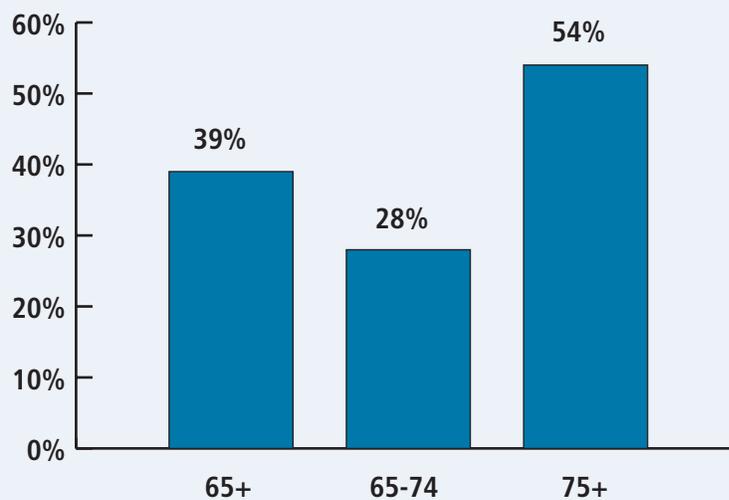
Figure 4.2. Share of Older Adults with Income Below 150% of Poverty: VA Compared to Border States and the U.S., 2007



Source: U.S. Census, American Community Survey, 2007.

As noted in Section 2, a much higher share of older adults report having at least one disability as compared to the general population, and disability prevalence increases with age (shown in Figure 4.3). Thirty-nine percent of Virginians age 65 and older reported having a disability of any kind, and 10 percent reported having a “self-care” disability which resulted in functional impairment.⁶⁵ Also, it is notable that by 2010 an estimated 13 percent of Virginians age 65 and older will have Alzheimer’s Disease.⁶⁶

Figure 4.3. Share of Older Virginians with a Disability by Age Group: 2007



Source: U.S. Census, 2007 American Community Survey.

⁶⁵ U.S. Census, 2007 American Community Survey.

⁶⁶ 2009 *Alzheimer’s Disease Facts and Figures*, “Table 2: Projections by Region and State for Total Numbers of Americans Aged 65 and Older with Alzheimer’s,” Alzheimer’s Association.

An important demographic characteristic relating to the provision of LTC is the growth in the share of older Virginians who are minorities. This share has grown from 18 percent in 1980 to 21 percent in 2007 and is expected to continue to grow in the coming decades.⁶⁷ This trend points to the need to ensure that cultural competency is part of the current provision of LTC and development of new programs. Also, older Americans in certain minority groups have higher rates of poverty and lower educational attainment,⁶⁸ which could increase demand for publicly funded LTC.

Components Associated with Rebalancing

Consolidated State Agency

Virginia does not have a single state agency that coordinates policies and budgets related to institutional and community-based LTS for older adults. DMAS is the main public agency that oversees and finances institutional care in NFs (the institutional setting used most by older adults), while both DMAS and VDA oversee and finance community-based services. DMHMRSAS also plays a major role in provision of LTS for older Virginians through direction of policy related to ICFs-MR, community services for people with ID, mental health facilities (including a state geriatric facility), and community mental health and substance abuse services. As shown in Table A.3 in Appendix A, other agencies also play a role, albeit lesser, in providing community-based services to older adults. For example, DSS provides home-based services such as companion and chore.

Single Access Points

Virginia has made significant progress in the past few years on creating a single access point for older adults seeking information about LTS. Through the *NWD* initiative, older Virginians living in six regions of the state can visit a resource center to get information about and referrals to providers and services. The number of *NWD* regions is expected to increase to ten by the end of SFY 2009. Also, as mentioned previously, older adults can use *Virginia Easy Access* and *VirginiaNavigator* to access information about LTS in their area.

Institution Supply Controls

As the vast majority of older adults who are in institutional settings are in NFs, this section focuses on these facilities. Virginia has an NF certificate of public need program whereby VDH assesses the need for beds annually within each of the 21 planning districts.⁶⁹ If VDH determines there is need for additional beds based on the inventory of beds, current utilization and expected demand, the agency puts out a request for applications (RFA).⁷⁰ Since SFY 2005, the VDH has received authorization to put out RFAs for 210 beds.

⁶⁷ University of Virginia, Weldon Cooper Center for Public Service, Demographics & Workforce, Stat Chat, *Older Virginians*, January 2009.

⁶⁸ U.S. Administration on Aging, *Statistical Profiles of Black, Asian, and Hispanic Older Americans Aged 65+*, updated January 2009.

⁶⁹ VDH, Certificate of Public Need Program.

⁷⁰ *Ibid.*

Compared to neighboring states and the U.S., Virginia has fewer certified NF beds and NF residents per 1,000 state residents age 65 and older.⁷¹ Virginia has not reduced its supply of NF beds over the past 10 years, as have some states. However, the Commonwealth's seven percent increase in the number of beds is in line with the national increase.⁷² Of the five states that border Virginia, two – Tennessee and West Virginia – have reduced their number of nursing home beds since 1998.⁷³

Transition from Institutions

Virginia's notable efforts to transition people from NFs thus far have predominantly helped people under age 65. A nursing home transition program operated by the Virginia Association of Centers for Independent Living through a grant from VBPD focused mainly on the under-65 population. As noted previously, under the MFP Demonstration the Commonwealth plans to transition 325 older adults from NFs by the end of federal fiscal year 2011.⁷⁴ One older adult, a 96-year old woman, has been transitioned through the program since it started. Some stakeholders commented that there aren't many NF residents who could transition to the community due to their high acuity and lack of a community support network. Another reason for the low number of NF residents who could transition home is that Virginia was the first state in the country to develop a prescreening process for all people seeking Medicaid-funded NF or community care. This program diverts several thousand people each year from NF placement through placement in HCBS waiver programs.

A Continuum of Residential Options

"I lived upstairs for 22 years in a seniors apartment complex and I had to get on the waiting list and wait six months to be downstairs. Even if a doctor says you've got to be downstairs, you still have to wait it out." – Older Virginian receiving AAA services

Many stakeholders noted a shortage of supported senior housing for older Virginians of low and moderate means. As described in the Section 2, there are many ALFs and CCRCs in Virginia. However, the cost of these settings can be quite high. The average monthly rate at an ALF in Virginia is estimated to be \$2,886,⁷⁵ slightly lower than the national average of roughly \$3,000.⁷⁶ CCRCs are also beyond the means of low-income people and many middle-income people. They typically require one-time entrance fees in the range of \$20,000 to \$400,000 and monthly payments that vary depending upon the services provided and amenities of the community.⁷⁷ Roughly 2,200 low-income older Virginians receive

⁷¹ Centers for Medicare & Medicaid Services, *2008 Nursing Home Data Compendium*.

⁷² American Health Care Association, *Nursing Facility Beds by Certification Type, CMS OSCAR Data Current Surveys, December 2008* (for 2008 figures), and American Health Care Association *2001 Facts and Trends: The Nursing Facility Source Book* (for 1998 figures).

⁷³ American Health Care Association.

⁷⁴ Commonwealth of Virginia, *Money Follows the Person Program Operational Protocol/Program Guidebook, A.2. Benchmarks*.

⁷⁵ Genworth Financial *2008 Cost of Care Survey: Home Care Providers, Adult Day Health Care Facilities, Assisted Living Facilities and Nursing Homes*, Genworth Financial. The average monthly rate is \$3,140 in Richmond.

⁷⁶ Genworth estimates monthly ALF costs in 2008 of \$3,008 and MetLife estimates \$3,030.

⁷⁷ AARP.org, *Continuing Care Retirement Communities*.

Auxiliary Grants to help with the costs of residing in ALFs and Adult Foster Care Homes. The vast majority of older adults receiving these grants live in ALFs.

Stakeholders commented that the Commonwealth could invest in low-cost ways to keep older Virginians living independently in their homes. For example, some noted that people just needed some home repairs or modifications to make their homes accessible and safe. Others thought regular “checking in” on frail people would make a big difference in their ability to remain in their homes. Some AAAs struggle to afford relatively inexpensive supports such as personal emergency response systems for their clients who do not qualify for Medicaid.

HCBS Infrastructure Development

Older adults receive LTC services from a variety of providers ranging from DCWs and durable medical equipment providers to medical professionals. Though the Virginia General Assembly has increased reimbursement rates for HCBS providers in recent years, many stakeholders noted they are not sufficient to achieve an adequate and stable workforce. As described in Section 2, Virginia’s direct care workforce, on average, is lower paid compared to most other states.

Specific to the older adult population, stakeholders commented that the lack of case management in the EDCD waiver (beyond the transition coordination service that is available for one year for individuals who transition from an institutional setting) was a major weakness of that program. Care coordination for the EDCD waiver was part of the integrated care model that was put on hold due to the current fiscal climate. The Commonwealth is currently exploring the feasibility of adding case management to the waiver.

Participant Direction

Section 2 provides an overview on Virginia’s efforts related to person-centered planning and participant direction. Older adults using publicly-funded LTC services primarily receive consumer-directed services through the EDCD waiver, though this option is offered in other waivers as well and in the DRS personal assistance program. Of the 3,852 EDCD waiver participants who were using consumer-directed services in November 2008, a significant share (42 percent) were people age 65 and older.⁷⁸ Some local AAAs noted that older adults in their respective areas weren’t availing themselves of consumer direction either due to lack of education on the model or fear amongst their families of the potential for exploitation of older adults in a self-directed arrangement.

⁷⁸ DMAS, unpublished data on waiver participants as of November 2008. This count was based on “active” waiver participants, meaning those who were currently receiving waiver services. Waiver participants can use consumer-directed services simultaneously with agency-directed services.

Quality Management

Quality assurance and measurement strategies in Virginia differ by oversight agency and LTC service. Licensing of LTC providers is divided primarily between three state agencies. The VDH licenses NFs, home health agencies (HHAs), and hospice programs. VDH also conducts regular surveys of NFs, HHAs, hospices, and ICFs-MR. DSS licenses ALFs and Adult Day Care Centers, and certifies Adult Foster Care homes. And, DMHMRSAS licenses providers serving its target populations, including ICFs-MR, group homes and over 20 other types of service providers.⁷⁹

DMAS is responsible for quality oversight of Medicaid-financed LTC services and officials note increased efforts in the past few years related to assessing and assuring quality of these services. The State's quality strategy is shifting more towards measuring consumers' health, safety and welfare, and away from focusing mainly on review of provider compliance. DMAS is in the process of updating its quality measures for HCBS waivers in accordance with CMS' HCBS waiver quality framework. DMAS also administers annual customer satisfaction surveys to participants in the consumer-directed program. Results of the most recent survey for which data are available, conducted in 2007, showed that individuals were generally very satisfied with the consumer-directed program, especially the ability to recruit their own attendant (with 97 percent reporting satisfaction).⁸⁰ For NF, home health, durable medical equipment and hospice services, DMAS subcontracts review to the VDH.

DMAS recently implemented a quality improvement program for NFs, called the Virginia Gold QIP project, aimed at creating or enhancing a supportive workplace.⁸¹ Selected participants in the project receive grant funding to implement their QI plan, training and access to resources and information on how to increase staff retention and otherwise create a more supportive work environment. This program also benefits non-participants in that all NFs in the state may avail themselves of the training offered to participants, as well as a best practices web site that features a self-assessment tool and other resources related to quality improvement and a supportive work environment.

Virginia does not maintain its own quality rating system for nursing homes, as do some states. Thus, CMS's *NH Compare* is the only source for information on quality of care in NFs in Virginia (and across states). *NH Compare*, a database designed to help consumers compare nursing homes, contains quality measures derived from CMS Minimum Data Set assessments, in addition to other information such as deficiency findings from recent surveys, certification status, and staffing data. Though these data sources have limitations, and results should be interpreted with caution, they are the only cross-state nursing home quality data available.⁸² Based on the most recent quality data available on *NH Compare* for long-stay skilled nursing facility residents, Virginia's performance is fairly close to the U.S. average, though slightly worse on numerous measures (comparing current status to the last quarterly assessment), including: the percentage of people who were more depressed or anxious; the percentage who lose control of bowel or bladder and the percentage whose mobility got worse.

⁷⁹ DMHMRSAS, *Comprehensive State Plan: 2008-2014*, December 6, 2007, and Licensing Rules and Regulations.

⁸⁰ Consumer Recipient Satisfaction Survey: 2007 Executive Summary, Public Partnerships, LLC, September 2007. The fiscal agent noted limitations of the survey: the instrument has not been validated and demographic variables were not collected, precluding analysis by age, gender or other characteristic.

⁸¹ DMAS.

⁸² Survey findings can vary across states and within states based on factors such as surveyor training and experience and state resources devoted to survey activities (well-documented by The Government Accountability Office).

Summary of Strengths and Gaps

Virginia's LTC system for older adults has many strengths. The Commonwealth has devoted considerable attention in recent years to LTC in general, and the impacts of the aging population on state and local programs. As noted previously, the Governor's task force on health reform established a workgroup to examine LTC issues and make recommendations. And, the General Assembly directed the Joint Legislative Audit and Review Commission to study the impact of the aging population on state agencies. In addition, some important public-private collaborations have developed in the past few years aimed at helping older adults navigate the services system, planning for the impact of the "age wave" and addressing the mental health needs of older adults. Further, Virginia has grown its PACE program significantly over the past few years from one program in 2007 to six programs as of February 2009.⁸³ Enrollment in PACE has increased by 50 percent since SFY 2008 to 288 participants. Last, Virginia's reliance on NF care is lower than most of its neighbor states and the nation as measured by the number of nursing home beds and residents per 1,000 state residents age 65 and older, and the percentage of state residents age 65 and older with at least one nursing home stay.⁸⁴

Despite a wide array of community-based LTC services for older adults, there is still significant unmet need for LTS and much variation in services available and the funding of services by locality. As of October 2008, AAAs reported nearly 24,000 people either unserved or underserved (most were underserved) for home-delivered meals and over 2,000 with unmet needs for homemaker services.⁸⁵ Further, the lack of affordable, accessible supported housing and funding for home modifications and/or repairs, as well as gaps in public transit have been repeatedly identified as major barriers to aging in place. Thus, where an older adult lives in many ways determines the extent to which supports are available.⁸⁶

"I can't get into the bathroom to take a bath . . . So, I carry a big Tupperware bowl with water in my wheelchair into my bedroom and then I do part of the cleaning in the wheelchair and then I get on the bed and do the rest." – Older Virginian who receives AAA services

DMAS was unable to implement its integrated care program due to declining economic conditions and changes in Medicare health plan requirements, which is unfortunate in that, outside of the PACE program, Virginia's Medicaid program does not generally have a strong care management component for the elderly to prevent or delay the need for institutional care. As noted, the EDCD waiver does not cover case management services, and only six of the 25 AAAs offer these services, billable as targeted case management under the Medicaid State Plan. Only two percent of EDCD waiver participants receive case management services.

⁸³ DMAS.

⁸⁴ Centers for Medicare & Medicaid Services, *2008 Nursing Home Data Compendium* (number of beds per 1,000 people age 65 and older and percentage of population age 65 and older with a nursing home stay).

⁸⁵ VDA.

⁸⁶ This refers mainly to older adults who are low- or middle-income, who are more apt to use publicly-funded LTS. The report does not attempt to assess whether there are sufficient supported residential settings and other LTS for higher-income people.

PROMISING PRACTICES: Leveraging Community Resources to Age in Place

“Aging in Place” initiatives are a burgeoning trend across the country. Residents of many communities have developed, or are developing, neighborhood-based support programs for aging in place to complement existing support services. In these programs, neighbors pool their resources to provide a range of services that enable people to stay in their homes. Supports range from sharing recommendations on reliable contractors to arranging for direct care and services through a volunteer or reduced fee system. Typically there is a fee associated with membership in such programs. One of the most well-known neighborhood-initiated programs started in Beacon Hill, an affluent section of Boston. Residents formed a non-profit organization to help people age 50 and older “enjoy safer, healthier and more independent lives in their own homes.” The program provides its members with access to information about in-home providers and other services, and an array of in-home services ranging from home repairs, meal deliveries, and errands, to skilled nursing care and medical transport.⁸⁷ Based on the level of interest in its model, the organization developed a how-to manual which it sells on its website. Another such model, Support Network at Penn National in Fayetteville, Pennsylvania, particularly focuses on using volunteer services to bring down the cost of services to its members. While we were not able to identify formal Aging in Place communities in Virginia, the Charlottesville Chamber of Commerce sponsors an Aging in Place Business Roundtable. Additional general information on Aging in Place initiatives can be found on the Aging in Place Initiative web site at <http://www.aginginplaceinitiative.org/>.

Section 5. Services for Adults with Physical Disabilities

Overview

It is difficult to pinpoint services and expenditures devoted to adults with physical disabilities (PD) in Virginia because state agencies don’t tend to track utilization and spending specifically for this group. While Virginia’s Medical Assistance program finances a significant amount of services for people with disabilities, the Medicaid information system is not set up to identify services provided to people with PD. Thus, to some extent the data reported in this section reflects services presumed to be received by adults with PD.

Programs and Services

Adults with PD using publicly-funded LTS are primarily served by programs funded through Virginia’s Medicaid program (DMAS), the DRS and DSS. AAAs also provide some services to this population.

In the past federal fiscal year, VDA estimates that Virginia AAAs served over 2,000 people under 60, most receiving meals and other services for which they qualified as spouses of older adults receiving services.⁸⁸ Tables 5.1 and 5.2 show the major public programs in Virginia through which nonelderly adults with

⁸⁷ Beacon Hill Village website, <http://www.beaconhillvillage.org/index.html>.

⁸⁸ VDA.

physical disabilities receive LTC services and trends in use and expenditures. Medicaid, DRS and DSS programs and services are described below.

Table 5.1 Public Expenditures LTC Expenditures for Nonelderly Adults with Physical Disabilities: SFYs 2004 and 2008

	2004	2008	Average Annual Percentage Change	Percent of Total 2008 Expenditures
Medicaid				
NF	\$90,957,226	\$125,328,841	8%	
EDCD waiver	\$31,140,848	\$53,404,952	14%	
Tech waiver	\$4,169,485	\$6,215,122	11%	
HIV/AIDS waiver	\$563,726	\$516,255	-2%	
Home Health	\$2,084,042	\$4,629,346	24%	
Hospice	\$2,432,593	\$7,353,455	37%	
Total Medicaid	\$131,347,920	\$197,447,971	N/A	85%
Other Public Programs				
DRS Personal Assistance Services	\$2,600,000	\$2,600,000	0.0%	
DRS Community Rehabilitative Case Management Services	\$507,700	\$507,700	0.0%	
DRS Voc Rehab Supported Employment	Not available	\$8,022,847	N/A	
Auxiliary Grant*	\$14,200,000	\$17,551,663	5.4%	
DSS Adult Home-Based Services**	Not available	\$6,715,505	N/A	
Total Other Public Programs	Not available	\$35,397,715	N/A	15%
Total Public Expenditures	Not available	\$232,845,686	N/A	

Source: DMAS, DRS and DSS. Notes: *This is estimated based on the 59 percent share that adults with PD represent of Auxiliary Grant recipients. **This is estimated based on the 33 percent share that adults with PD represent of Adult Services recipients.

Table 5.2 Number of Nonelderly Adults with Physical Disabilities Receiving Public LTC Services: SFYs 2004 and 2008

	2004	2008	Average Annual Percentage Change
Medicaid			
NF	3,944	4,369	3%
EDCD waiver	2,986	4,987	14%
Tech waiver	58	80	9%
HIV/AIDS waiver	292	65	-29%
Home Health	2,231	2,643	5%
Hospice	397	793	24%
Total Medicaid	9,908	12,937	N/A
Other Public Programs			
DRS PAS	199 (FY 2006)	133	N/A
DRS CRCMS	562 (FY 2007)	682	N/A
DRS Voc Rehab Supported Employment	1,541	1,713 (FY 2007)	3.8%
DSS Auxiliary Grant**	3,193*	3,189	-1.9%
DSS Adult Home-Based Services***	2,888	2,529	-2.6%

Source: DMAS, DRS and DSS. Notes: There could be some duplication across Medicaid services categories. *Estimate is based on the assumption that 59 percent of recipients are age 18 to 64. **Average monthly cases. ***Estimate based on the assumption that 33 percent of recipients are ages 18 to 64.

Medicaid

Medicaid finances 85 percent of LTC for adults with physical disabilities, providing both institutional care in NFs and community-based services, mainly through the HCBS waiver programs but also through home health and hospice. Medicaid also funds personal care for adults with disabilities participating in Virginia's Medicaid Buy-In program, *Medicaid Works*.⁸⁹ *Medicaid Works* allows working people with disabilities to have income and resource amounts that exceed Medicaid eligibility thresholds and still retain their Medicaid coverage by paying a premium to participate in the Medicaid program. The program began enrolling participants in FY 2008 (expenditure data are not yet available).

Virginia has three HCBS waivers serving the PD population: EDCD; the Technology Assisted (Tech) Waiver; and the HIV/AIDS Waiver. These waivers are operated by DMAS.

The EDCD waiver covers personal care and respite care (agency and consumer-directed), adult day health care, personal emergency response system (including medication monitoring), consumer-directed services facilitation, transition coordination, and transition services. DMAS added assistive technology and environmental modifications to the EDCD waiver in FY 2009, which many stakeholders believe will make the waiver much stronger. However, they will be removed and no longer funded in FY 2009 due to the declining economy. These services are still available for MFP participants in the EDCD waiver for 12 months after transition. As mentioned in Section 4, the EDCD waiver does not cover case management beyond the transition coordination service that is available for one year for individuals who transition from an institutional setting. Stakeholders characterized this as a significant weakness of the waiver for the PD population as well.

The Tech Waiver serves people with needs for substantial ongoing skilled nursing care and who are dependent at least part of the day on a ventilator or meet complex tracheostomy criteria. The waiver covers personal care, private duty nursing, respite, transition services, case management, personal emergency response systems, environmental modifications, and assistive technology.

The HIV/AIDS waiver serves people with HIV or AIDS who require a hospital level of care. The waiver covers personal care and respite (agency- or consumer-directed), private duty nursing, enteral nutrition, case management, transition services, personal emergency response system, and consumer-directed services facilitation. As noted above for the EDCD waiver, DMAS added assistive technology and environmental modifications to this waiver, but the services will be removed due to funding constraints (though they will still be available for MFP participants for 12 months after transition in the HIV/AIDS waiver).

Virginia has been considering implementation of a brain injury waiver, but it was not funded in the recent legislative session. People with traumatic brain injury (TBI) can enroll in the EDCD waiver as long as they meet the waiver criteria. People with TBI are discussed further at the end of this section.

Virginia has made significant progress in serving a higher share of adults with PD who are at an

⁸⁹ Virginia amended its State Plan to add personal care services for participants in Medicaid Works through federal authority under §1937(b) created by the Deficit Reduction Act of 2005 which permits states to offer alternative benefits to specified populations. Working individuals with disabilities were established as a covered group under the federal Ticket to Work – Work Incentives Improvement Act of 1999.

institutional level of care in the community over the past five years. The balance has shifted from FY 2004, when the majority of adults with PD at an institutional level of care were served in NFs, to the majority being served in HCBS waivers in FY 2008. Expenditures have shifted accordingly, with NF services comprising a decreasing share of total Medicaid LTC expenditures for this population: from 69 percent in FY 2004 to 63 percent in FY 2008.

Other Public Programs

Adults with PD receive other public services funded mainly through DRS and DSS. Both agencies have very limited funding and waitlists for community-based services.

DRS serves people with a variety of disabilities: physical, sensory, cognitive, and mental-health related. The majority of DRS funding goes toward its Vocational Rehabilitation (VR) program, which helps adults and youth with disabilities prepare for and obtain employment but does not pay for ongoing supports necessary to help maintain employment.⁹⁰ The primary “long-term” supports the agency provides are through its Community Based Services: Personal Assistance Services (PAS) and Community Rehabilitation Case Management Services (CRCMS). Affiliated with DRS are local partners: CILs and DSBs (described in Section 3).

The state-funded PAS program serves people with personal care needs who do not have ongoing nursing care needs.⁹¹ Income and asset limits for PAS are much higher than those in the Medicaid program. People cannot receive services from both programs. In FY 2008, this program served 133 people with a budget of \$6.2 million. PAS is a consumer-directed program, predating consumer direction in DMAS’ HCBS waiver programs. The program budget includes administrative costs associated with consumer direction payroll services.

The CRCMS program assists people with physical disabilities and sensory disabilities achieve “quality of life of their choosing through self-direction, support, and community resources.”⁹² The program provides a large array of services to help people live independently. Currently, only those with the highest level of need (e.g. risk of institutionalization) are eligible for services due to funding constraints. In FY 2008, the program served 682 adults under age 65 with a budget of \$508,000.⁹³

The Virginia DSS serves adults with PD through its Home-Based Services and its AG program (described in Section 2). Companion, chore, and homemaker services are available through the home-based services program, but funding is very limited and resources are shared with older adults. The same is true of the AG program.

⁹⁰ Commonwealth of Virginia, *Virginia State Rehabilitation Council 2008 Annual Report*.

⁹¹ DRS operates three PAS programs: one funded through its Vocational Rehab program, intended for short-term use, the state-funded program described above and a program for people with brain injuries.

⁹² DRS, *Community Rehabilitation Case Management Services, Overview*.

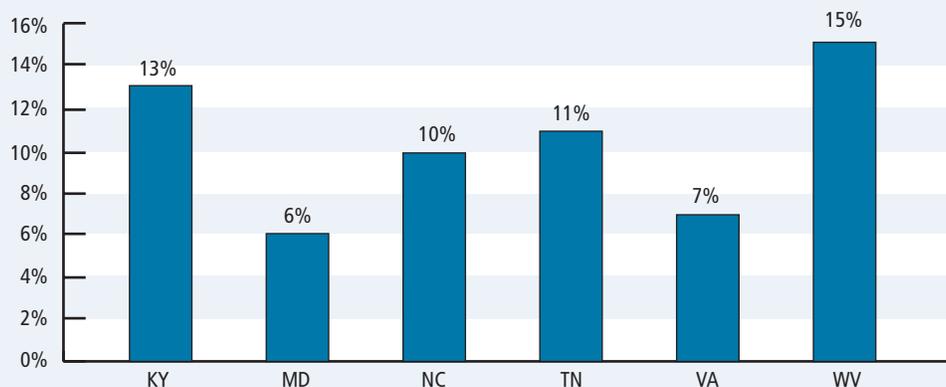
⁹³ DRS personal communication.

Demographic and Utilization Trends

Based on 2007 U.S. Census estimates, there are roughly 317,000 non-institutionalized people ages 21 to 64 with PD in Virginia: seven percent of the population within that age range.⁹⁴ Another 3,600 people under the age of 65 were nursing home residents that year (many of whom are presumed to have physical impairments).⁹⁵ Physically disabled adults are significantly more likely than non-disabled adults to have income below the poverty level: 22 percent of people ages 21 to 64 with PD reported having income below the poverty level in 2007 compared to seven percent of those with no disabilities.⁹⁶

Compared to neighboring states, Virginia has a relatively low share of non-elderly adults with PD, as shown in Figure 5.1.

Figure 5.1. Percentage of Adults Ages 21 to 64 with Physical Disabilities: VA Compared to Border States, 2005-2007 3-yr Average



Source: Thomson Reuters analysis of U.S. Census, American Community Survey 2005-2007 3-Year Estimates.

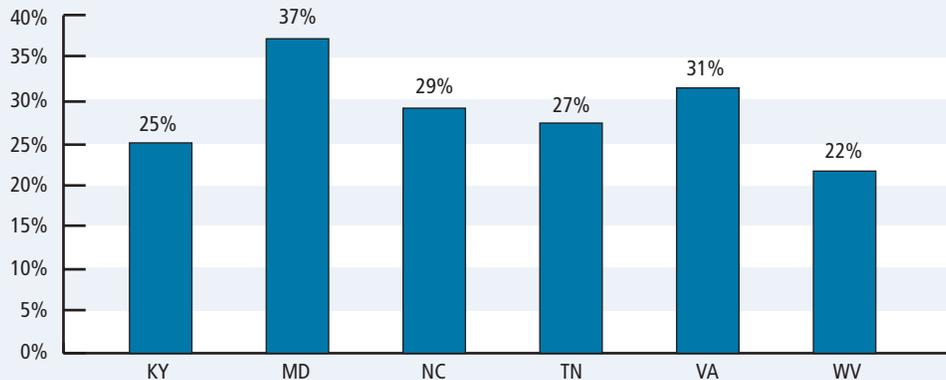
Virginia has a low unemployment rate compared to most border states and this carries over into employment of people with PD. Virginia and Maryland both have unemployment rates for the general population of 6.8 percent whereas Kentucky, North Carolina, Tennessee and West Virginia have unemployment rates ranging from 7.5 percent to 10.8 percent. As shown in Figure 5.2, a relatively high share of Virginians ages 16 to 64 with PD are employed, ranking second after Maryland among the six comparison states.

⁹⁴ U.S. Census, 2007 American Community Survey, Table B18022: Physical Disability by Sex by Age by Employment Status for the Civilian Noninstitutionalized Population 16-64 Years.

⁹⁵ Centers for Medicare & Medicaid Services, Minimum Data Set Active Resident Report, 2nd Quarter 2007. This is a point in time estimate as of June 30, 2007. There was a cumulative total of 8,500 nursing home residents between the ages of 22 and 64 in calendar year 2007 according to CMS's 2008 Nursing Home Data Compendium.

⁹⁶ U.S. Census, 2007 American Community Survey, Table B.18032: Physical Disability by Sex by Age by Poverty Status for the Civilian Noninstitutionalized Population 5 Years and Over.

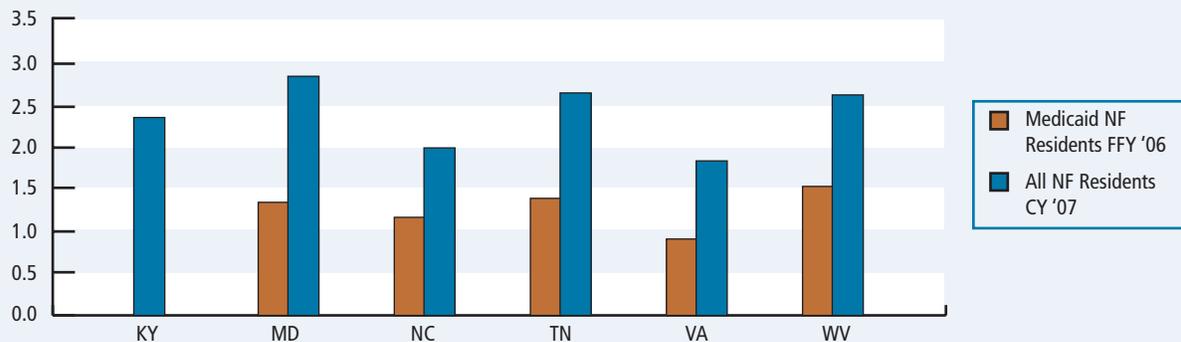
Figure 5.2. Percentage of People Ages 16 to 64 with Physical Disabilities Who Are Employed: VA Compared to Border States, 2007



Source: Thomson Reuters analysis of U.S. Census 2007 American Community Survey.

Virginia has the lowest utilization of NFs for people ages 18 to 64 of its neighboring states. As shown in the Figure 5.3 below, this is true both of all NF residents and Medicaid NF residents.

Figure 5.3. NF Residents Ages 21 to 64 per 1,000 State Population: Medicaid Residents and All NF Residents, VA Compared to Border States



Source: Thomson Reuters analysis of MSIS State Summary Datamart for Medicaid NF Residents, MDS for all NF Residents, U.S. Census Population Estimates for State Populations Ages 18-64.

Note: KY did not report to the MSIS State Summary Datamart in FY '06. The MDS lower age limit is 22 (for the "All NF Residents" calculation).

Although people with brain or spinal cord injury may be served through programs offered by a variety of state agencies, DRS is the designated state agency for coordinating rehabilitative services. The Brain Injury and Spinal Cord Injury Services (BI/SCIS) unit manages specialized services offered through 14 programs statewide. The largest share – 56 percent – of the DRS allocation for brain injury services in FY 2007 was for case management provided by state contractors.⁹⁷

⁹⁷ JLARC, *Access to State-Funded Brain Injury Services in Virginia*, Senate Document No. 15, 2007.

Virginia's DRS started one of the first statewide mandatory registries for people with brain injury in 1984 based on hospital admissions and emergency room visits.⁹⁸ The General Assembly eliminated the DRS registry (which included spinal cord injury) as of July 2008 and, instead, directed VDH to maintain a Virginia Statewide Trauma Registry. Accordingly, the DRS registry is being merged with the VDH registry. Based on DRS registry data, over 5,700 people sustained brain injuries in FY 2008. One limitation of the new statewide registry is reports are based on hospital admissions only. As the vast majority of people who incur brain injuries are treated in emergency rooms and then released,⁹⁹ the registry will significantly understate the actual number of incidents.

Employment is a critically important goal of adults with PD. DRS provides employment training and support through its VR program, and the LTS provided through PAS and CRCMS. As of September 2008, DRS had nearly 18,000 open VR cases, 44 percent of whom were "transition age" clients between 16 and 21 years of age.¹⁰⁰ Over 4,000 individuals became successfully employed in a competitive job in FY 2008, a seven percent decrease compared to 2007. DRS partners with over 60 employment services organizations throughout the State.¹⁰¹

Components Associated with Rebalancing

Consolidated State Agency

There is no single state agency serving adults with PD. As noted above, DMAS, DRS, DSS and even VDA provide LTC services to this population. While many stakeholders note that collaboration and communication have improved in recent years among the agencies involved in providing LTS, there is no formal process by which the agencies serving adults with PD must coordinate. One example of coordination is between DMAS and DRS on consumer direction. DRS aligns its personal care payment rates with DMAS' rates so as not to disadvantage participants in its PAS program. Also, the two agencies and the Office of Community Integration Implementation Team sponsored a focus group recently related to consumer-direction to gain input on a possible policy change which would allow the use of spouses and parents as caregivers.

Single Access Points

There is no single point of entry in Virginia for adults with PD, although the *No Wrong Door*, *2-1-1 Virginia*, and *Virginia Easy Access* are designed to serve as a single access point for information and assistance across disability groups. *VirginiaNavigator* does not yet have a full set of resources geared toward adults with disabilities.

⁹⁸ DRS personal communication.

⁹⁹ Brain Injury Association of America Web site, *About Brain Injury* (citing 2006 Centers for Disease Control data).

¹⁰⁰ Commonwealth of Virginia, *Virginia State Rehabilitation Council 2008 Annual Report*.

¹⁰¹ DRS, *Supported Employment in Virginia*.

Institution Supply Controls

Section 4 describes the COPN program for NFs.

Transition from Institutions

As of February 2009, five adults with PD who were residing in NFs have transitioned to the community through the MFP Demonstration, and four more are awaiting transition. Prior to MFP, the Virginia Association of Centers for Independent Living transitioned 42 people from NFs through a program funded by a grant from the Virginia Board for People with Disabilities (36 during the grant period and six after the grant period ended).¹⁰² The grant period was July 2006 through October 2007 and award amount was \$270,000.

A Continuum of Residential Options

Statistics on where Virginians with PD live are not readily available. The VBPD 2008 Biennial Assessment describes a number of programs in Virginia designed to increase housing options for people with disabilities, ranging from investment in subsidized housing to a \$500 tax credit for new construction for existing residential units to make them more accessible (and 25% for retrofitting up to \$2,000). The main Virginia state agencies with oversight of housing are the Department of Housing and Community Development and the Virginia Housing Development Authority. The former agency has authority over housing policy and the latter over finance.

Availability of appropriate and affordable housing for Virginians with disabilities is a significant issue in achieving community integration. In its 2008 Update and Progress Report, the Virginia Office of Community Integration cites housing as one of its critical success factors and outlines a number of action items to increase people with disabilities' access to accessible housing.¹⁰³ However, the Community Integration Implementation Team acknowledges that progress has been stymied by restrictions within the Auxiliary Grant (AG) program and lack of rent supports.¹⁰⁴ As noted previously, the Commonwealth is considering making the AG portable, such that the funding would follow people with disabilities into the setting of their choice. The Team notes there isn't a single locality in Virginia where an SSI recipient can rent a 1-bedroom apartment using 30 percent of his/her SSI income.¹⁰⁵ Further, the Team urges the Commonwealth to establish a fund to provide non-profit organizations with low-financing incentives to build accessible housing.

¹⁰² VBPD personal communication.

¹⁰³ See the *Money Follows the Person Demonstration Annual Housing and Transportation Action Plan* at <http://www.olmsteadva.com/mfp/downloads/AnnualHousingTransportationActionPlan.doc>.

¹⁰⁴ Community Integration Implementation Team and Community Integration Advisory Commission, *Virginia's Comprehensive Cross-Governmental Strategic Plan: 2008 Update and Progress Report*.

¹⁰⁵ Ibid.

HCBS Infrastructure Development

“I have to go through fifty-plus people to find someone halfway decent.”

- Individual with physical disabilities (referring to personal care attendants)

People with PD receive LTS from a variety of providers ranging from direct care workers (DCWs) and durable medical equipment providers to medical professionals. Section 4 discusses Medicaid rate increases for HCBS providers in recent years and the adequacy of rates for DCWs.

The concerns raised about the direct care workforce are not unique to Virginia: low wages; lack of health insurance and other benefits and lack of a career ladder. Individuals with PD described how difficult it was to find a well-trained and reliable direct care worker, but also noted that the bad economy was working in their favor as it has expanded the pool of applicants.

Stakeholders commented on an overall paucity of supported employment programs. In the South-Central part of the state, a stakeholder noted there were no such programs. Up until recently, there was a significant rate differential between the VR and Medicaid payments for supported employment, making it hard for waiver participants to find supported employment services. The General Assembly required DMAS to align its rate effective FY 2009.

FOCUS: STEPS provides State-of-the-Art Job Training and Employment to People with Disabilities in an Integrated Setting

Southside Training, Employment, and Placement, known as “STEPS,” is a unique supported employment program serving nine counties in South Central Virginia. STEPS provides job training and employment opportunities at two work sites to adults with physical disabilities, mental illness, developmental disabilities, and traumatic brain injuries. STEPS-Farmville provides recycling services and STEPS-Victoria manufactures goods such as Army Combat Uniform jackets. While the vast majority of STEPS employees are people with disabilities, nearly 30 percent are people who do not have disabilities. STEPS staff have found that the integrated setting has educational benefits for both groups and promotes greater understanding of disabilities within the local community.

Participant Direction

Section 2 provides an overview on Virginia’s efforts related to person-centered planning and participant direction. Related to people with PD, Virginia offers a consumer-directed program for participants in the EDCCD and HIV/AIDS waivers. Of the 3,900 EDCCD waiver participants using consumer-direction, 56 percent are under 65 years old.¹⁰⁶ And, five of the 65 participants in the HIV/AIDS waiver use consumer-direction. In addition, *Medicaid Works* offers consumer-directed personal care.

¹⁰⁶ DMAS.

Quality Management

Given that numerous agencies provide LTS to adults with PD, quality practices vary. VDH is the designated state survey agency to inspect NFs, HHAs and hospice agencies and make sure they are in compliance with federal and state regulations. DMAS conducts quality reviews for the EDCD, Tech and HIV/AIDS waivers. As noted in Section 6, DMAS is in the process of retooling its waiver quality assurance system to comply with CMS' HCSBS waiver quality guidelines. DMAS' annual consumer-direction customer satisfaction surveys are described in Section 4. DRS and DSS conduct quality review of their respective programs.

Summary of Strengths and Gaps

Virginia has shown commitment to increasing community integration for adults with PD in a number of ways. As described earlier in this section, the share of people with PD requiring the nursing facility level of care who are living in the community has shifted from a minority of people served to a majority. And, stakeholders give DMAS much credit for transparency in program design by including people with disabilities in the decision-making process. Clearly, Virginia's continued commitment to its OCI demonstrates a strong effort to improve access to community-based services for all people with disabilities.

However, stakeholders are concerned that the fragmented nature of Virginia's LTC delivery system causes some groups to "fall through the cracks." For example, many people report people with TBI are underserved. While DRS has some funding devoted to this population, stakeholders believe people with TBI are not well-served by the HCBS waivers.¹⁰⁷ As noted, plans to implement a Brain Injury waiver were put on hold due to a lack of funding. The adverse social and financial outcomes of underserving this population, stakeholders note, are illustrated by the large share of people in prisons with TBI. According to the Centers for Disease Control, studies have found that 25 to 87 percent of prison inmates report having experienced a head injury or TBI compared to 8.5 percent in a general population.¹⁰⁸

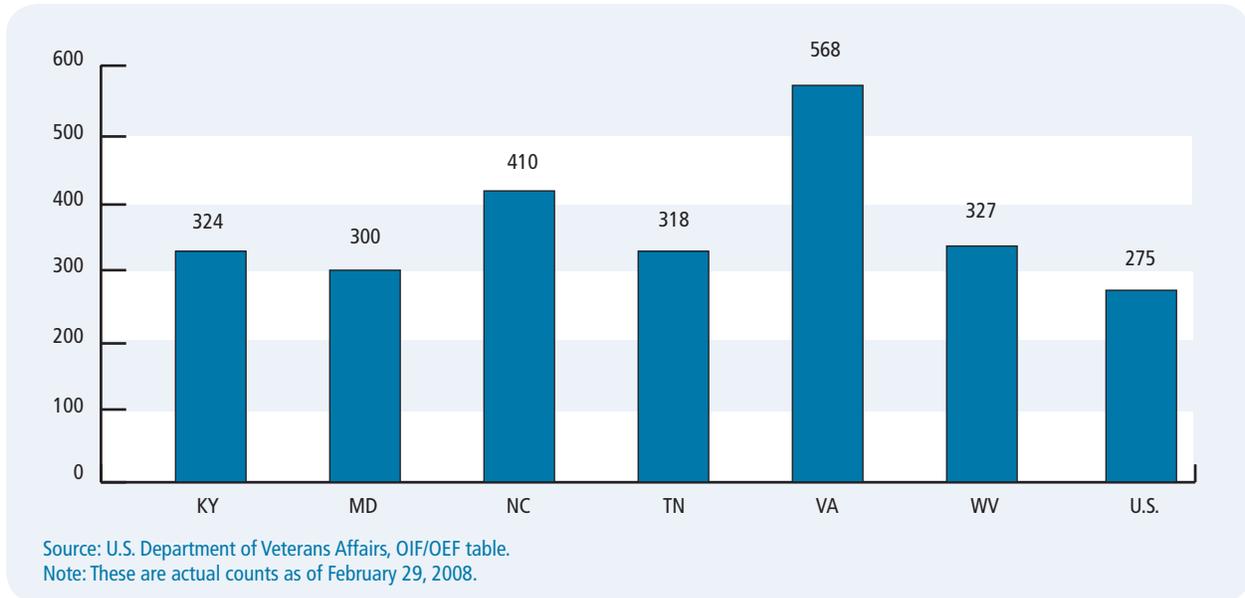
Moreover, some stakeholders feel a sense of urgency to develop better services for people with TBI because of the perceived potential impact of military personnel with TBI returning from the wars in Afghanistan and Iraq. Although the U.S. Department of Defense (DOD) and the U.S. Department of Veterans Affairs (VA) have the primary responsibility for providing services to "wounded warriors," stakeholders have observed military personnel (both active duty and veterans) relying on local and state-funded programs. Indeed, based on U.S. Department of Veterans Affairs data, Virginia has the highest number of returning veterans per 100,000 population from Operation Iraqi Freedom and Operation Enduring Freedom compared to its neighbor states and the national average, as shown below.¹⁰⁹

¹⁰⁷ A person who incurs a TBI before the age of 22 is potentially eligible for the DD waiver, assuming level of care and financial criteria are met.

¹⁰⁸ Centers for Disease Control and Prevention, *Traumatic Brain Injury in Prisons and Jails: An Unrecognized Problem*.

¹⁰⁹ U.S. Department of Veterans Affairs, OIF/OEF Veterans, February 29, 2008. Based on U.S. Census 2007 American Community Survey, Virginia has a higher share of veterans for the population age 18 and older and age 65 and older compared to its neighbor states and the U.S.

Figure 5.4. Number of Wounded Warriors Returning from Wars in Afghanistan and Iraq per 100,000 Population, 2008



Though officials from the VA and DOD stated that coverage of LTS for active duty personnel and veterans with TBI was comprehensive, they did note some gaps such as supported housing for nonelderly adults. Further, some military personnel and veterans prefer to utilize non-military services for a variety of reasons. For example, local agencies that provide services may be closer to where they live than VA or DOD providers, and military settings may remind them of traumas they endured during service. Finally, the eligibility criteria for services from the VA is complex and depends upon the type of disability, whether it was service-connected (and to what degree), and the type of military discharge. Thus, some military personnel with TBI may not be covered by the VA system.

In summary, stakeholders' concerns about Virginia's ability to serve people with TBI, especially related to military personnel, appear to be well-founded. It would be worthwhile to study the degree to which active duty military personnel and veterans are currently using state-funded LTC services to assess the impact of the return of wounded warriors and continued military conflicts.

Section 6. Services for People with Intellectual and Developmental Disabilities

“Thoughts of college weren’t even in my mind because of my intellectual learning disability. I was already thinking where would I work and what kind of career would I have? . . . I really wanted to be an actress or a gymnast but those careers are hard to come by so I began a very long journey of little pay and lots of different careers. . . I have learned that it is very important to like a career and have the right support regardless of an ability.” – Individual with autism

Overview

Virginia has long had a state agency (DMHMRSAS) and funding stream devoted to people with ID, but no such agency for people with other DD. Virginia is at the beginning stages of creating a single service system for people with all types of DD, to be housed within DMHMRSAS (renamed the Department of Behavioral Health and Developmental Services effective July 1, 2009).¹¹⁰ A separate agency, the Virginia Board for People with Disabilities, provides advocacy for people with DD in its role as State DD council. For simplicity, this section will refer to the combined group of people with ID and people with DD as “ID/DD” unless otherwise noted.

Programs and Services

People with ID using publicly-funded community LTS are primarily served through Virginia’s 40 CSBs (described in Section 3). CSBs both provide services directly and arrange for their provision through private providers, and this mix varies by CSB. People with other DD using publicly-funded LTS are primarily served by DMAS, typically from providers not affiliated with CSBs. Table 6.1 shows Medicaid and Other Public Services expenditures for people with ID/DD. The Medicaid program is the primary payer for LTS for people with ID/DD, accounting for 83 percent of public ID/DD LTC spending. Table 6.2 shows the number of participants for all publicly-funded ID/DD services, and trends over time, as available.

¹¹⁰ Commonwealth of Virginia, Office of the Secretary for Health and Human Resources, *Implementation Plan Submitted by the Secretary to the Joint Commission*, October 16, 2008. The two positions designated to lead this change were funded by the 2009 General Assembly.

Table 6.1 Public LTC Expenditures for People with ID/DD: SFYs 2004 and 2008

	2004	2008	Average Annual Percentage Change	Percent of Total 2008 Expenditures
Medicaid				
ICF-MR - Public	\$193,460,808	\$195,927,393	1%	
ICF-MR - Private	\$24,507,422	\$42,286,354	15%	
ID waiver	\$231,310,558	\$417,193,378	19%	
DD waiver	\$2,620,043	\$6,141,163	26%	
Day Support waiver*	N/A	\$3,097,396	N/A	
MR/ID Waiver Case Management	\$22,486,761	\$26,745,332	6%	
DD Waiver Case Management	\$633,719	\$1,002,326	14%	
Total Medicaid	\$475,019,311	\$692,393,342	N/A	83%
Other Public Programs				
CSB ID Expenditures**	Not available	\$137,092,848	Not available	
Total Other	Not available	\$137,092,848	Not available	17%
Total Public	Not available	\$829,486,190	Not available	N/A

Source: DMAS (Medicaid data) and DMHMRSAS (CSB date).

*The Day Support Waiver started in FY 2006. The EDCD waiver also serves individuals with autism, however expenditure figures specific to this group are not available.

**The CSB ID expenditures reported here are from 2007 and are net of fee revenue received from Medicaid so as not to double-count Medicaid expenditures for ID services.

Table 6.2 Number of Virginians Receiving Public ID/DD LTC Services: SFYs 2004 and 2008

	2004	2008	Average Annual Percentage Change
Medicaid			
ICF-MR - Public	1,619	1,412	-3%
ICF-MR - Private	281	358	6%
MR/ID waiver	5,782	7,500	7%
Day Support Waiver	N/A	285	N/A
DD Waiver	314	596	17.8%
MR/ID Case Management	9,667	7,385	-5%
DD Case Management	338	616	12%
Total Medicaid	7,996	10,151	
Other Public Programs			
CSB (ID)	23,925	27,619**	5%

Source: DMAS (ICF-MR and waivers) and DMHMRSAS (CSB)

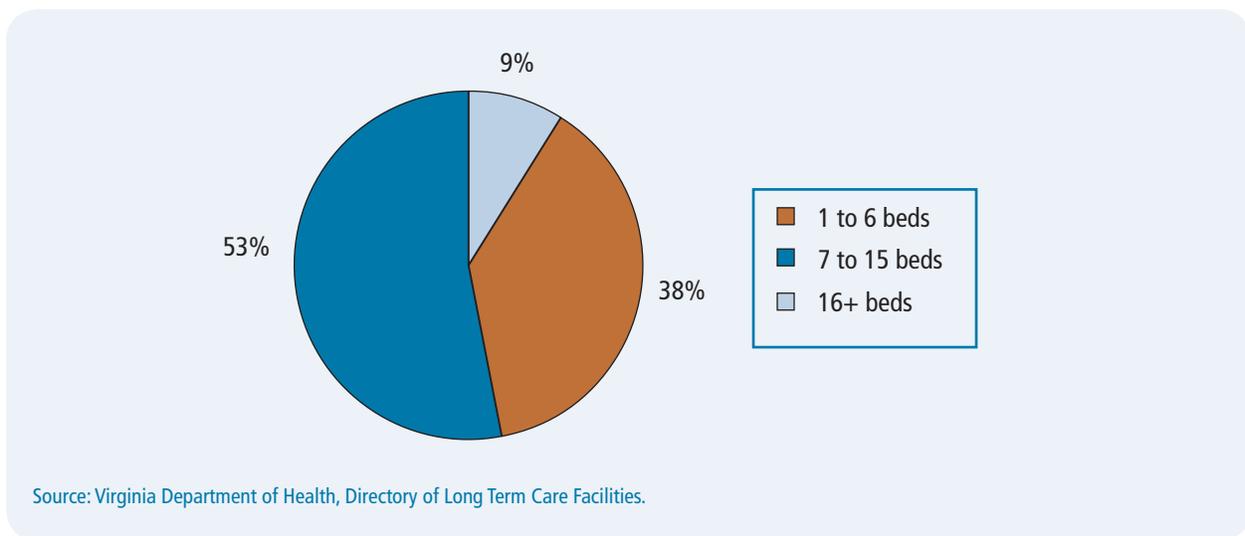
Notes: The Day Support Waiver started in 2006. The EDCD waiver serves individuals with autism spectrum disorders, however enrollment figures specific to this group are not available. People receiving case management services are not included in the total participating in Medicaid programs because most are receiving them through the waivers.

**FY 2007 data were used due to recoding of some services in FY 2008 which prohibits comparison to previous years.

Medicaid Services

Medicaid funds three primary LTS for people with ID/DD: ICF-MR; HCBS Waivers; and case management. ICFs-MR provide housing, habilitation and medical services. Virginia has five large state ICFs-MR, referred to as “training centers.” These facilities range in size from 200 to 600 beds and account for over 1,700 ICF-MR beds in the State.¹¹¹ In addition, CSBs and other non-State providers operate over 30 in-State, or “community,” ICFs-MR with roughly 360 beds.¹¹² The chart below shows the distribution of non-State ICFs-MR by bed size.

Figure 6.1. Distribution of Non-State ICFs-MR in Va by Bed Size: 2008



Virginia has two HCBS waivers serving the ID population: the Mental Retardation/Intellectual Disability Waiver (MR/ID); and the Day Support Waiver. These waivers are operated by DMHMRSAS in collaboration with DMAS. The MR/ID waiver serves people age six and older diagnosed with ID, and those under six who are at developmental risk for ID, who need an ICF-MR level of care. Waiver participants receive a comprehensive range of services and receive case management through CSBs (funded through the Medicaid State Plan case management service). The MR/ID waiver currently serves 7,500 people.¹¹³ Statewide, there are nearly 4,600 people on the ID/MR waiver waitlist, half of whom are on an “urgent” list.¹¹⁴ People on the “urgent” list get served first. The average waiting time for people on the MR/ID urgent waitlist is 2.4 years. MR waiver slots are allocated to localities based on each locality’s share of individuals on the statewide urgent waiting list.

The Day Support Waiver provides a limited set of services to people on the MR/ID waiver waitlist on a “first-come, first-served” basis. Available services are: day support; prevocational services and supported employment. It does not provide supports in residential settings.

¹¹¹ DMHMRSAS, Office of Intellectual Disability Supports.

¹¹² VDH, Office of Licensure and Certification, *Directory of Long Term Care Facilities* (undated).

¹¹³ Virginia Department of Medical Assistance Services, custom data run.

¹¹⁴ Virginia Department of Mental Health, Mental Retardation, and Substance Abuse Services. The waitlist figure is as of February 2009.

Virginia has one waiver serving the non-ID population of individuals with DD, operated by DMAS: the Individual & Family Developmental Disabilities Support Waiver (DD). This waiver serves people age six and older who have a DD diagnosis, but not an ID diagnosis, who require an ICF-MR level of care. The DD waiver provides a similar set of services to the MR/ID waiver except the DD waiver does not provide support in congregate settings and includes family and caregiver training.¹¹⁵ Another very important difference is that case managers in the DD waiver are prohibited from serving in other functions such as conducting eligibility assessments or providing services. The DD waiver currently serves 596 people, and there are 704 people on a statewide waitlist.¹¹⁶

Finally, Medicaid pays for targeted case management services for MR/ID and DD waiver participants, for people on the MR/ID waiver waitlist who are Medicaid-eligible, and for people with MR/ID who are Medicaid-eligible but not waiver-eligible.¹¹⁷

Other Public Programs

As noted above, CSBs are the primary providers of other public services for people with ID. Whereas roughly 7,000 individuals were on the MR/ID waiver in FY 2007, CSBs served an additional 20,000 people with ID that year.¹¹⁸ As there is no single point of contact for people with DD, we cannot estimate the number of people receiving Other Public DD Services, nor the associated expenditures. Some people with DD receive case management and vocational rehabilitative services through DRS. Some receive services through local Centers for Independent Living. These services are described in greater detail in Section 5.

Demographic and Utilization Trends

DMHMRSAS estimates there are 69,470 Virginians age six and older with ID and 18,622 infants, toddlers, and young children with developmental delays requiring early intervention services.¹¹⁹ Based on data collected by the National Residential Information Systems project on Residential Services, there were over 9,800 Virginians receiving Medicaid-funded ID/DD services in 2007 (including ICF-MR, HCBS waiver, and NF services). And, as stated previously, that same year CSBs served over 36,000 individuals with ID (including those receiving Medicaid-funded services).

People with ID/DD may also have serious physical disabilities and/or MI. Based on diagnostic information from the CSB waitlist for ID services, roughly 16 percent of people on the waitlist had a concurrent major medical condition or chronic health problem and 11 percent were either

¹¹⁵ VBPD, 2008 Biennial Assessment, Section IV Community Living Supports.

¹¹⁶ DMAS, Division of Long-Term Care.

¹¹⁷ VBPD, 2008 Biennial Assessment, Section IV Community Living Supports.

¹¹⁸ Waiver enrollment figure from DMAS, CSB MR/ID consumers served figure from DMHMRSAS. Some of these people are those on the MR/ID waiver waitlist for whom CSBs are providing Medicaid-funded case management services. Thus, the figure of 20,000 people with ID receiving non-Medicaid services is overstated.

¹¹⁹ DMHMRSAS, *Comprehensive State Plan 2008-2014*.

non-ambulatory or had major difficulty in ambulation. Twelve percent of people on the waitlist with a primary diagnosis of ID had a co-occurring diagnosis of MI and/or substance abuse.

Utilization

Virginia provides Medicaid services to fewer people with ID/DD than most neighboring states and the U.S., when controlling for population as shown in Table 6.3.

Table 6.3 Number of People with ID/DD Receiving Medicaid-Funded Services Per 100,000 Population: 2007

State	HCBS Waiver	ICF-MR	Total
WV	212.6	26.3	238.9
U.S.	166.3	32	198.3
MD	183.2	6	189.2
NC	102.7	45.5	148.3
TN	117.7	19.9	137.5
VA	97.5	21.8	119.4
KY	71.5	15	86.5

Source: Prouty et al (eds.), University of Minnesota.

Virginia has relatively high utilization of large ICFs-MR (16+ beds) and relatively low utilization of settings with six or fewer people when compared to most neighboring states and the U.S., as shown below.

Figure 6.2 Number of People with ID/DD Living in Large ICFs-MR (16+ beds) per 100,000 Population: VA Compared to Border States and the U.S., 2007



Source: Thomson Reuters analysis of Prouty et al (eds.), University of Minnesota.

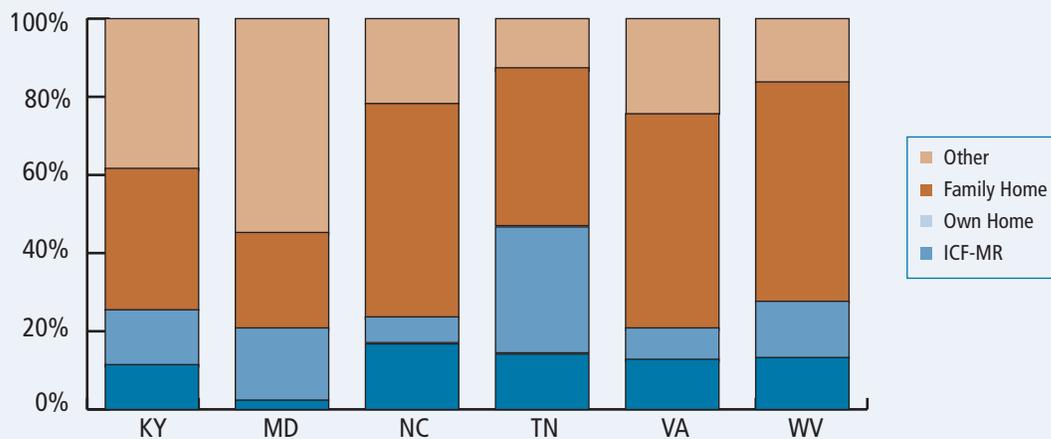
Table 6.4 Number of People with ID/DD Receiving Services in Residential Settings with Six or Fewer Beds, per 100,000 Population, June 30, 2007

State	Non-ICF-MR Community	ICF-MR	Total
MD	120.8	0	120.8
U.S.	98.5	6.4	104.9
NC	74.8	16.6	91.4
WV	76	4.1	80.1
KY	79	0	79
VA	62.5	.9	63.4
TN	59.6	2.1	61.7

Source: Thomson Reuters analysis of Prouty et al (eds.), University of Minnesota.

However, looking at living arrangements among people with ID/DD receiving publicly-funded services, Virginia ranks in the middle for share of people living in ICFs-MR (Figure 6.3).¹²⁰ Virginia has a high share of people living in homes with their families compared to neighboring states, and a relatively low share of people living in their own homes. Included in the “other” category are 634 people with ID/DD living in non-specialized NFs.¹²¹

Figure 6.3 Living Arrangements of People Receiving ID/DD Services: VA Compared to Border States, 2007



Source: Thomson Reuters analysis of Prouty et al (eds.), University of Minnesota.

Note: “Other” includes non-ICF-MR congregate care settings and foster care homes.

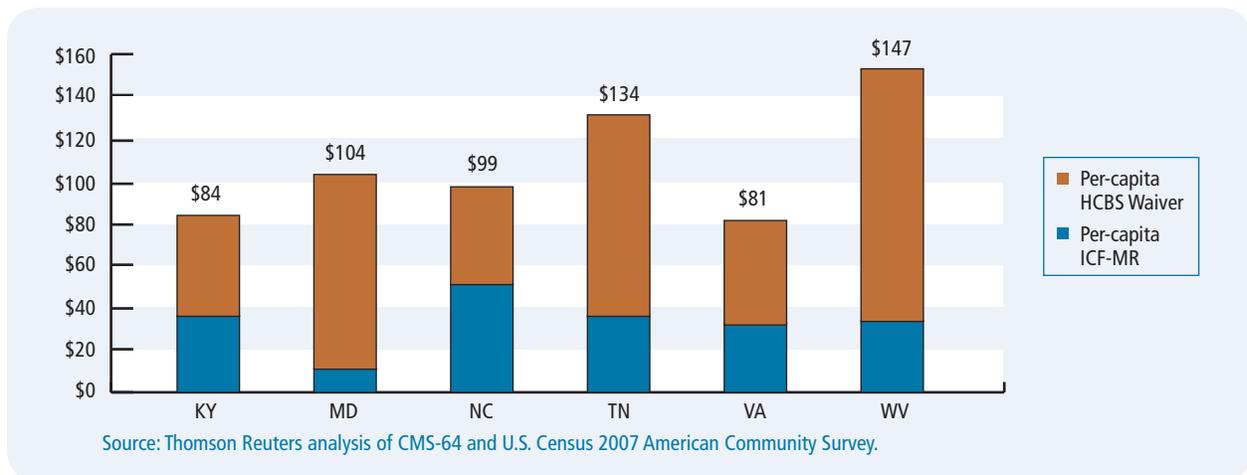
¹²⁰ Prouty et al (eds.), University of Minnesota.

¹²¹ Ibid.

Expenditures

As shown below, Virginia spends less per state resident than its neighbors on services for people with ID/DD, and less than all neighboring states except North Carolina on HCBS ID/DD waivers.¹²²

Figure 6.4 ICF-MR and HCBS Waiver Expenditures per State Resident: VA Compared to Border States, 2007



Similarly, when looking at Medicaid spending per ID/DD recipient, Virginia ranks fairly low among its neighbors (4th out of six states). Virginia ranks 5th on HCBS waiver spending per ID/DD recipient, and 3rd on ICF-MR spending. Within Virginia, per-participant MR/ID waiver spending varies considerably by locality. This is discussed in greater detail at the end of this section.

Components Associated with Rebalancing

Consolidated State Agency

As noted at the beginning of this section, Virginia has announced a plan to expand DMHMRSAS' scope to include autism spectrum disorders and other DD.¹²³ The first step in the transition is the hiring of two staff people to lead the initiative (by summer 2009). This change is not without controversy: there has been opposition to making DMHMRSAS the agency home for people with autism and other DD, primarily from one group of parents of children with autism. The overriding concern is that the agency will conform the DD waiver to the MR/ID waiver model in which the individual's choice of case manager is limited to the CSB. In the MR/ID waiver, CSBs may provide case management services themselves to participants or they can use a non-CSB provider to be the case manager. In practice, only a few CSBs use non-CSB case managers.¹²⁴

¹²² Thomson Reuters analysis of CMS-64, and U.S. Census American Community Survey population estimates.

¹²³ DMAS. As per the 2008 recommendation of a Joint Commission on Health Care workgroup on autism, DMHMRSAS will be the "home" agency for ASD as well as the broader umbrella of DD.

¹²⁴ DMHMRSAS personal communication.

Single Access Points

There is currently no single point of entry in Virginia for people with all types of DD, although this may change when Virginia transitions DMHMRSAS to become an umbrella state agency for all people with DD.

CSBs are the single point of entry for people with ID who are seeking LTS. People with DD interact with a range of state and other agencies, including local child development centers for level of care screening and DMAS for general administration of the DD waiver and information on available case managers. CILs are another major resource for people with DD, as they are for people with PD. Finally, the NWD initiative, including the *Virginia Easy Access Web Portal*, is intended to improve information and assistance across disability groups.

Institution Supply Controls

ICFs-MR are subject to a Certificate of Public Need requirement; however, this process does not apply to facilities with less than 12 beds, contributing to the increase in smaller ICFs-MR in recent years. Since 2002, the number of ICFs-MR has increased by 21, including 15 ICFs-MR with six or fewer beds.¹²⁵ Only one new ICF-MR has been built since 2002 with 12 beds or more (West Neck ICF-MR in the Virginia Beach area).

The vast majority of people living in ICFs-MR in Virginia live in 16+ bed facilities -- 88 percent -- whereas only four percent live in facilities with six beds or under (and eight percent live in facilities with seven to 15 beds). Virginia has made some progress in shifting towards smaller ICFs-MR in that the share of people living in ICFs-MR of 16+ beds has dropped from over 94 percent in 2002.¹²⁶

Transition from Institutions

As of February 2009, 15 individuals with ID who were residing in state training centers have transitioned to the community through the MFP program. Seven more are awaiting transition pending the finalization of their transition plan.

Stakeholders interviewed for this report raised serious concerns regarding the deteriorating conditions of some of the training centers, which were built in the 1970s or earlier. There is controversy whether to close or replace the training centers. The Governor proposed closing the Southeastern Virginia Training Center (SEVTC), a 200-bed facility in Chesapeake, in his December 2008 *Budget Reduction Plan*. While Virginia is developing plans to close the 200-bed facility, the 2009 General Assembly decided to rebuild a 75-bed ICF-MR on the SEVTC campus, in addition to funding smaller community ICFs-MR and group homes.

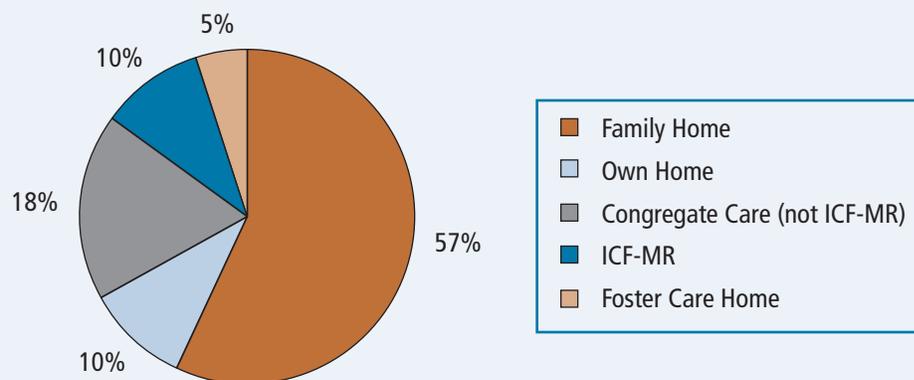
¹²⁵ VDH, Office of Licensure and Certification, Division of Long Term Care, unpublished Construction and Development Listing, February 19, 2009. This number includes some conversions of existing group homes.

¹²⁶ Prouty et al (eds.), *Residential Services for Persons with Developmental Disabilities: Status and Trends through 2007*, University of Minnesota, July 2008.

A Continuum of Residential Options

People with ID/DD live in a variety of settings: their own homes or family homes; group homes and other non-ICF congregate settings; ICFs-MR; and Family Foster Care homes. The following chart shows the distribution of Virginians with ID/DD receiving publicly-funded services by living arrangement. As noted above, compared to neighboring states, Virginians with ID/DD who receive public services are more likely to live in family homes and less likely to live in their own homes.

Figure 6.5 Distribution of People with ID/DD Receiving Services in Va by Living Arrangement: 2007



Source: Thomson Reuters analysis of Prouty et al (eds.), University of Minnesota 2008.

As is true for all disability groups and people with low-income, availability of appropriate and affordable housing for people with ID/DD is a significant issue. A recent study of the ID system in Virginia identifies as one of its 21 recommendations the need to “develop and implement a consistent, coordinated housing policy among state agencies.”¹²⁷ The Housing section of the study cites numerous barriers to enabling individuals with ID to make choices with regards to housing, including: a lack of affordable housing; a lack of rental assistance funds; and a lack of supports to make independent living feasible for people with ID. Several stakeholder groups interviewed for this project raised concerns about the lack of independent housing for people with ID/DD, as well as concerns about people with ID/DD living with aging parents who would soon not be able to care for them. Some stakeholders also raised concerns about inappropriate group home placements for people with autism (e.g. age mismatches or placements in settings primarily serving people with MI).

¹²⁷ DMHMRSAS, *Report of the Study of the Mental Retardation System in Virginia*, October 17, 2007.

FOCUS: Hope House Foundation Leverages Private Funds to Support Independent Living for Individuals with Developmental Disabilities

Hope House Foundation, a private, non-profit organization in Norfolk, believes all individuals – no matter what their impairments -- can live independently in the community with the right supports. Hope House Foundation provides individualized supported living services to over 130 people in the Tidewater area in their own homes or apartments. The Foundation is funded through Medicaid waivers, the Comprehensive Services Act, CSBs, and private donations. Individuals who are supported through Hope House Foundation lead their lives based on their own preferences and interests. Many have formed close friendships with non-disabled neighbors, and work at paying jobs.

HCBS Infrastructure Development

As noted in Section 3, the General Assembly recently passed legislation stating its intent to eliminate the MR/ID and DD waiver waiting lists by the 2018-2020 biennium.¹²⁸ To accomplish this, the legislation requests DMAS to add 400 MR/ID waiver slots and 67 DD waiver slots per year starting in FY 2010. Thus, it is incumbent upon the Commonwealth over the next ten years to ensure there are adequate community services and resources to support thousands of individuals currently on the waitlists.

People with ID/DD receive LTS from a variety of providers ranging from direct care workers and group home supervisors to medical professionals. Though the Virginia General Assembly has increased rates for HCBS providers in recent years, DMHMRSAS' 2007 study on the ID system notes "the comparatively low reimbursement rates for many of the services make it difficult to attract and retain qualified staff and highly trained professionals."¹²⁹

Stakeholders raised numerous concerns about the HCBS infrastructure for people with ID/DD. Some of these are consistent with general issues with the direct care workforce (low pay, no health insurance or other benefits, insufficient training and lack of career ladder). Many stakeholders identified problems with finding medical providers who accept Medicaid, let alone providers trained to serve people with ID/DD.

Also, stakeholders agreed there is a shortage of supported employment programs. Almost all stakeholders emphasized the importance of addressing shortcomings with the Medicaid transportation service, and public transportation generally, to make community living possible. Specific concerns raised about Virginia's Medicaid transportation contractor, LogistiCare, mainly related to the pre-approval process and reliability.¹³⁰

Stakeholders also suggested ways in which providers could be used more creatively to address issues such as the aging of the ID population. For example, a CSB administrator felt there should be more flexibility

¹²⁸ Chapter 303, Virginia Administrative Code, approved March 27, 2009.

¹²⁹ DMHMRSAS, Report of the Study of the Mental Retardation System in Virginia.

¹³⁰ DMAS has set up a task force to deal with problems experienced with LogistiCare services.

in the MR/ID waiver to allow nurses to make brief home visits to aging or medically-compromised individuals. She believes these visits would be cost-effective in that they could prevent flare-ups of chronic medical problems. Currently, nursing home visits are allowed under the MR/ID waiver, but must be billed in increments of one hour. CSBs would like to have the ability to bill in 15-minute increments, and DMAS is evaluating the request for this change which would affect all HCBS waivers.

Participant Direction

Section 2 provides an overview on Virginia's efforts related to person-centered planning and participant direction. Virginia offers consumer-directed services for participants in the MR/ID and DD waivers; however, use of consumer direction differs significantly between the two waivers. Nearly three-quarters of people enrolled in the DD waiver participate in the consumer-direction program, compared to 15 percent of MR/ID waiver participants. Some stakeholders believe the DD waiver's firewall between case management and service provision promotes more individualized planning because the case manager does not have a vested interest in the provision of services. Others believe CSB case management is effective in assuring choice and leveraging supports and services, noting there are safeguards in place to ensure CSBs are fully accountable to individuals with ID and their families and to local governing bodies. MR/ID waiver case managers are required to use person-centered planning tools to develop service plans, but stakeholders noted inconsistency in the use of person-centered planning principles and tools.

Quality Management

Quality review and assurance practices for ID/DD services differ between institutional and community-based services. VDH is the designated state survey agency to inspect ICFs-MR and make sure they are in compliance with Federal regulations. DMHMRSAS also inspects ICFs-MR (as part of its oversight of state MR and MH facilities), licenses non-state ICFs-MR and investigates abuse, neglect, and other human rights complaints. Further, DMHMRSAS monitors use of seclusion and restraints in state facilities.

DMAS is the lead agency on quality review and assurance for the HCBS waivers, in collaboration with DMHMRSAS for the MR/ID and Day Support waivers. DMAS has a quality review system called Quality Management Review (QMR). The two agencies are currently developing quality measures for the MR/ID waiver renewal consistent with CMS' HCBS waiver quality framework. DMAS will model quality measures for the other HCBS waivers on those developed for the MR/ID waiver. As noted in Section 4, DMAS also administers satisfaction surveys to participants in the consumer-directed program.

Summary of Strengths and Gaps

Stakeholders pointed out numerous strengths with the current LTS system for people with ID/DD. They gave DMAS much credit for transparency in program design by including people with disabilities in the decision-making process. Some described the Virginia legislature as committed to the ID population in

particular, as evidenced by the funding of significant numbers of MR/ID waiver slots over the past few budget cycles. Many extolled the dedication of CSB staff and local providers in serving these populations and, as one stakeholder put it, “squeezing every dollar” to provide as much as they could within limited funds. Further, people generally agreed that the MR/ID waiver provides a comprehensive set of services to individuals. Finally, many believe the expansion of DMHMRSAS’ role to include autism spectrum disorders and other developmental disabilities is a very significant step forward for Virginia.

However, stakeholders reported some serious concerns about the overall system for people with ID and DD that primarily fall within five themes:

- inadequacy of funding and unmet demand as evidenced by the waiver waitlists;
- inequity between the MR/ID and DD waivers;
- inequity between Medicaid financing of institutional services compared to HCBS services;
- local variation in the availability of services and waiver spending; and
- gaps in services for those who are not Medicaid-eligible and for young adults aging out of the education system.

Overall, people commented on the lack of funding for LTS for people with ID/DD and were very concerned about the waitlists. The average waiting time for people on the urgent MR/ID waitlist is 2.4 years, and is slightly longer for those on the non-urgent waitlist.¹³¹ While people on the MR/ID waitlist are eligible to receive services through the Day Support waiver, this small program does not provide the residential supports many individuals need.

Generally stakeholders agreed that the discrepancy between the resources devoted to the MR/ID waiver compared to the DD waiver was unfair and that the two waivers should be merged as they essentially serve the same population. Also noted was the fact that the DD waiver does not cover residential supports.

Stakeholders made observations about the financing structure of Medicaid with respect to ICFs-MR compared to HCBS waivers, pointing out there are two built-in incentives to serve people in ICFs-MR rather than the community. First, given that ICF-MR is a service covered by Virginia’s State Plan, whereas waiver slots must be funded through the State’s legislative process, there is an incentive to utilize ICFs-MR in order to serve people who cannot access community-based services due to waitlists. CSB staff from one area interviewed for this study explicitly said they felt obliged to build a large community ICF-MR in order to provide services to people on their MR/ID waiver urgent waitlist.

Another factor is that the ICF-MR reimbursement rate, because it is cost-based, allows for a fuller set of services compared to the MR/ID and DD waivers. For example, staff at a community ICF-MR noted that their residents receive dental care and that they (staff) could purchase higher-quality beds, bathtubs and wheelchairs compared to what CSBs could buy for people on the MR/ID waiver.¹³² The ICF-MR staff believed, in many ways, they could do more for their residents compared to the services they might

¹³¹ VBPD, 2008.

¹³² ICF-MR staff indicated that CSBs were limited in what they could purchase due to concerns about the cost of service plans and meeting federal budget neutrality requirements.

receive in the community. In its 2008 Biennial Assessment, the VBPD recommended that Virginia better align the supports and services available through the waivers with those provided for in the ICF-MR setting.¹³³

Stakeholders raised concerns about the unevenness of availability of waiver services among Virginia localities. In analyzing Medicaid MR/ID waiver expenditure data by locality, we found significant local variation in per-participant waiver spending. Limiting analysis to those localities with at least 100 MR/ID waiver participants, annual MR/ID waiver spending per participant in FY 2008 varied from a minimum of \$41,000 in Hanover County to a maximum of \$66,000 in Portsmouth.¹³⁴ The standard deviation from the mean among these twenty localities was over \$6,200. It would be worthwhile to examine these differences to understand what is driving them.

Finally, many stakeholders identified gaps in services for those who are not Medicaid eligible, and for young adults aging out of services provided by the school system as required by the federal Individuals with Disabilities Education Act. The DMHMRSAS study of the ID/MR system in Virginia estimates there are 13,500 community residents who have been identified by CSBs as needing ID services, but who do not qualify for Medicaid and are not on the waiting list for the MR/ID waiver.¹³⁵ Based on Virginia Department of Education special education data, nearly 600 young adults with an ID, DD or Autism diagnosis will soon age out of the school system.¹³⁶ According to advocates, some of these young people are “sitting home doing nothing,” while their skills deteriorate. The cost of not providing services to these individuals is the potential for adverse behavioral and medical outcomes, which could end up costing far more than the supports themselves.¹³⁷

¹³³ VBPD, 2008.

¹³⁴ Thomson Reuters analysis of DMAS custom data run of MR/ID waiver spending by locality.

¹³⁵ DMHMRSAS, *Report of the Study of the Mental Retardation System*, October 17, 2007.

¹³⁶ Virginia Department of Education, *Special Education Child Count for FY 2007*. We counted young adults with these diagnoses between the ages of 20 to 22.

¹³⁷ The study referenced above cites out-of-home placements as a service that is more costly than in-home supports.

Section 7. Services for Adults with Mental Illness

Overview

Historically, Virginia's mental health delivery system has been heavily slanted toward inpatient state psychiatric hospitalization, in part due to disproportionately high number of facilities and beds (compared to other states) and a lack of adequate community alternatives. However, important reforms to mental health law and financing in the state are in the process of being implemented. Most significantly, as a result of an initiative started earlier this decade, Virginia's publicly-funded mental health system is undergoing a major transformation aimed at creating a recovery- and resilience-oriented and person-centered system of services and supports. In addition, the incident at Virginia Tech highlighted major gaps in service capacity across the state, particularly in the areas of emergency and crisis stabilization, outpatient, and case management services. The work of the Commission on Mental Health Law Reform, convened by the Supreme Court of Virginia in the fall of 2006 to examine the state's civil commitment laws and procedures, also led to changes the 2008 General Assembly made in the way people with MI may be treated on an involuntary basis.

Programs and Services

Though LTC generally excludes acute care services, we took a broader approach to defining LTC for people with MI compared to some of the other target groups because it is difficult to distinguish between short-term and long-term mental health service needs. Thus, some of the data presented in this section, such as community mental health, include both short-term and LTC services, overstating expenditures and utilization. On the other hand, the data under-represent spending and use for Virginians with MI to the extent they exclude services for people with ID, a growing share of which have a dual diagnosis of MI. In addition, the Medicaid data presented exclude Medicaid managed care (see description below) and prescription drugs for managing mental health conditions. It was not possible to disaggregate managed care and drug spending specific to adults with MI within the SPT timeframe. Wherever possible, the authors have removed substance abuse services from expenditure and utilization data.

DMHMRSAS, soon to be renamed the Department of Behavioral Health and Developmental Services, is Virginia's state authority for mental health services. Its public mental health services system includes nine state mental health facilities providing inpatient treatment and habilitation and 40 Community Services Boards (CSBs). Established by local governments, the CSBs either directly deliver community-based mental health services or coordinate service delivery through licensed private and public providers.

Publicly-funded mental health expenditures for people of all ages in Virginia are comprised of payments for Medicaid services, services provided through CSBs, and state psychiatric facility services, as well as funds for educational programs. Table 7.1 presents expenditures by category. Whereas Medicaid data could be extracted by age group, data for other public programs by age were not readily available. Accordingly, only the Medicaid data presented in Tables 7.1 and 7.2 below are specific to non-elderly adults (those ages 21 to 64). As noted in the table, Medicaid community mental health services grew

substantially faster between 2004 and 2008 than did Medicaid facility services, resulting in a distribution of Medicaid mental health expenditures for non-elderly adults that was 96 percent community-based and four percent facility. By comparison, the distribution of Medicaid mental health expenditures for people of all ages was 71 percent community-based and 29 percent institutional.

Table 7.1 Public Expenditures Targeted to Non-Elderly Adults with Mental Illness: SFYs 2004 and 2008

	2004	2008	Average Annual Percentage Change	Percent of Spending, 2008
Medicaid				
Community Services	\$65,459,430	\$125,092,801	18%	
Facility Services	\$5,199,843	\$5,122,840	<1%	
Total Medicaid	\$70,659,273	\$130,215,641	N/A	19%
Other Public Services				
Community Service Boards	Not available	\$269,860,262	N/A	
State Psychiatric Hospitals	\$232,185,102	\$294,877,048	6.2%	
Non-CSB contracts to support consumer and family education	Not available	\$2,178,145	N/A	
Total Other Public Services	N/A	\$566,915,455	N/A	81%
Total Public Expenditures	N/A	\$697,131,096	N/A	100%

Source: DMAS, DMHMRSAS.

Notes: Medicaid "community services" include: State Plan Rehabilitation Option, mental health clinic and mental health case management. Data for "Other Public Services" are not available by age, thus they are not specific to non-elderly adults. The CSB MH expenditures reported here are from FY 2007 and are net of Medicaid fee revenue so as not to double-count Medicaid expenditures for MH services (FY 2008 data on Medicaid fees by CSB program were not available).

Table 7.2 below shows the number of non-elderly adults using public mental health services during the most current time period available. These categories cannot be totaled due to duplication of individuals across service categories. But, the table shows the substantially higher use of community-based mental health services compared to institutional services.

Table 7.2 Number of Non-Elderly Adults Receiving Public Mental Health Services: SFYs 2004 and 2008

	2004	2008	Average Annual Percentage Change
Medicaid			
Community Services	20,992	26,205	4%
Facility Services	499	166	-16%
Total Medicaid not available due to potential duplication across services	N/A	N/A	N/A
Other Public Services			
Community Service Boards (2007)	109,175	126,632	5.2%
State Psychiatric Hospitals (2007)*	6,890	5,814	-1.4%

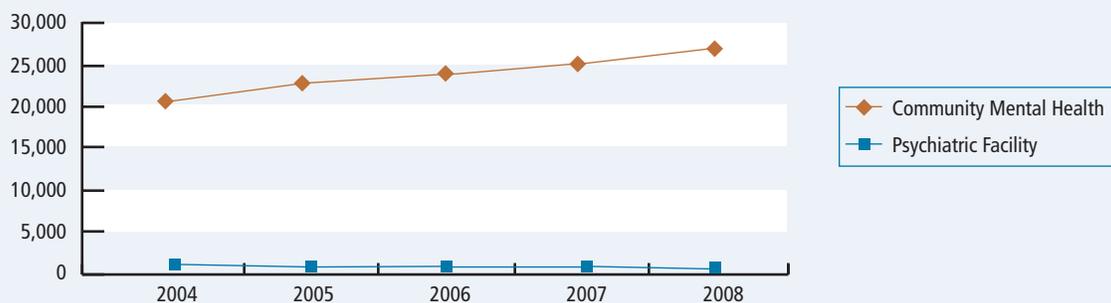
Source: DMAS, DMHMRSAS.

Notes: CSB and State Psychiatric Hospital Data are not available by age group, thus they are not specific to non-elderly adults. *represents average daily census.

Medicaid Services

Most Virginia Medicaid enrollees are required to receive medical care through a managed care program, if available in their geographic area. As of November 2008, 64 percent of total enrollees were enrolled in either the Primary Care Case Management Program (PCCM program called MEDALLION) or the comprehensive, capitated program (Medallion II).¹³⁸ Exceptions to mandatory managed care enrollment include people in NFs, ICFs-MR, and long-stay hospitals (including state psychiatric hospitals). Those not enrolled in managed care are served in the traditional fee-for-service (FFS) system. Medicaid enrollees in the PCCM program may obtain mental health services on a FFS basis without a referral from their primary care provider. Those enrolled in Medallion II may access certain services through any FFS Medicaid provider, and all others through the managed care organizations (MCOs). Mental health service providers are expected to coordinate service delivery with the MCO.

Figure 7.1. Number of Adults Ages 21 to 64 Receiving Medicaid MH Services by Setting: FYs 2004-2008



Source: Thomson Reuters analysis of VAMMIS.

As shown in Table 7.2 and Figure 7.1, the number of adults ages 21 to 64 receiving Medicaid mental health services in the community has increased each year over the past five years and the number using facility services has decreased. In FY 2008, roughly 99 percent of nonelderly adults receiving Medicaid-funded mental health services received them in the community.

In addition to the services that states are federally mandated to cover through their Medicaid programs (such as inpatient hospital care and physician services), Virginia has chosen to cover several categories of optional services that are important to adults with MI. These include the rehabilitation option, other licensed mental health professional services, targeted case management, and outpatient prescription drugs. Through the Rehabilitation Option, people with MI can receive community mental health services such as mental health day treatment, psychosocial rehabilitation, partial hospitalization and crisis stabilization. Substance abuse services, a critical benefit for individuals with MI and co-occurring substance use disorders, were added in 2007.

Coverage of inpatient hospital care depends upon type of facility and age group (for state mental health facilities). Stays in an Institution for Mental Diseases (IMD), referred to as state mental health facilities

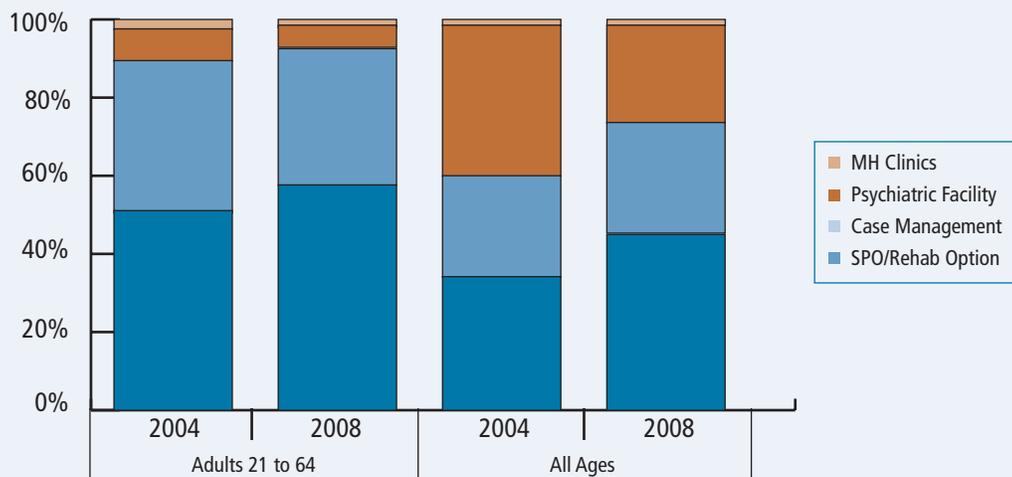
¹³⁸ DMAS, *The Virginia Medicaid Program At a Glance*, January 2009.

in Virginia, are covered only for recipients over age 65 years and for children under age 21 if identified as necessary through the EPSDT program and pre-authorized by DMAS. Inpatient care in psychiatric units of general acute care hospitals are available regardless of age. Medicaid does not reimburse case management services for people ages 21 to 64 in IMDs.

Increased use of community-based Medicaid mental health services, such as those available through the Rehabilitation Option as well as case management, occurred in conjunction with efforts to decrease facility-based care in Virginia, e.g., by downsizing state mental health facilities.

As shown in Figure 7.2, the Rehabilitation Option has played an increasingly important role over time in Medicaid mental health benefits reflecting State policy aimed at reducing institutionalization of individuals with MI. Spending for mental health services under the Rehabilitation Option increased from 50 percent (\$35.4 million) of total Medicaid mental health spending for nonelderly adults in FY 2004 to 58 percent (\$76.1 million) in FY 2008. This increase accounted for nearly two-thirds of the total increase in Medicaid FFS mental health spending during that time period. As a result, the distribution of Medicaid mental health services for people of all ages shifted from about one-third Rehabilitation Option in FY 2004 to 43.5 percent in FY 2008.

Figure 7.2 Distribution of Medicaid MH Spending for Adults Ages 21 to 64 and All Ages: FY 2004 Compared to FY 2008



Source: Thomson Reuters analysis of VAMMIS.

Virginia Medicaid's prescription drug benefit provides access to a key component of treatment for persons with MI. Psychiatric drugs are exempt from the preferred drug list requirement, which limits most drugs to generic legend drugs except when the physician specifies "brand necessary" name drugs. In 2005, Medicaid introduced a Behavioral Pharmacy Management System to improve the quality of antipsychotic prescribing practices and corresponding patient utilization in the FFS program by

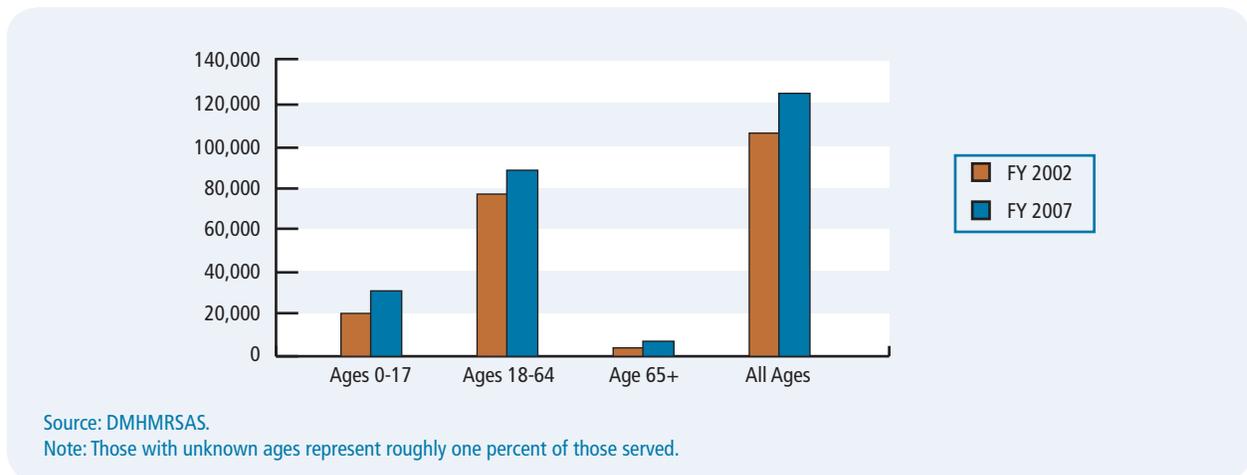
analyzing pharmacy claims data and sending quality indicators to prescribing physicians on a regular basis.¹³⁹

Other Public Programs

CSBs are single points of entry into Virginia's publicly funded mental health services; they have responsibility and authority for assessing individual needs (including pre-admission screening and discharge planning for inpatient care), accessing services and supports on behalf of individuals and managing non-Medicaid community-based services.

In FY 2007, CSBs served 126,632 persons for mental health services, representing an 18 percent increase in persons served compared to FY 2002 (see Figure 7.3).¹⁴⁰ Non-elderly adults are by far the largest age group among those receiving CSB mental health services, yet only grew 13 percent during the time period compared to the more dramatic growth rate of 40 percent among children receiving mental health services.

Figure 7.3 Unduplicated Number of Individuals Receiving MH Services from CSBs by Age Group: FY 2002 and FY 2007



Eligibility for mental health services provided by CSBs is determined by clinical criteria for each local program. Emergency services are available to anyone in the geographic area served by the CSB, while other services are usually targeted. Case management services are also mandated, but CSBs may establish a waiting list if funding is not available. CSBs' core services are:

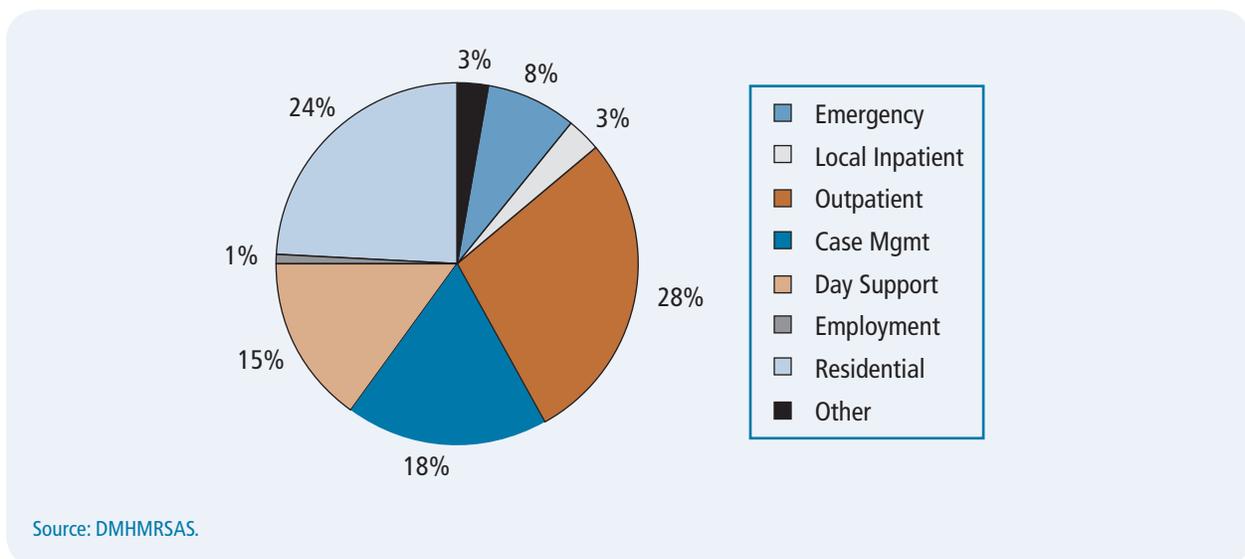
¹³⁹ Letter to prescribers from Directors of DMAS and DMHMRSAS, April 7, 2005.

¹⁴⁰ DMHMRSAS, 2008 *Overview of Community Services Delivery in Virginia*, July 22, 2008, and Table 4: *FY2002 Unduplicated Numbers of Consumers Served by Program Area by Age and Gender* provided through personal contact with DMHMRSAS staff, February 23, 2009. Consumer-run services are not included.

1. Emergency (mandated)
2. Local inpatient
3. Outpatient
4. Case management
5. Day support
6. Supported employment
7. Residential
8. Prevention and Early Intervention
9. Services managed and provided by individuals (e.g., peer support for services and supports that are integral to recovery)

As shown in Figure 7.4, the largest shares of CSB mental health spending are accounted for by outpatient services (driven by the units of service provided) and residential services (driven by the cost per person served), each comprising about one-quarter of expenditures.¹⁴¹ Case management and day support services also represented a substantial share of CSB mental health spending in FY 2008. In general, CSBs are not allowed to require individuals to receive case management services in order to receive other services they provide, though certain circumstances constitute exceptions such as if the person is an adult with a serious mental illness (SMI).¹⁴²

Figure 7.4 CSB Spending by Core Service: FY 2008



Both the U.S. Substance Abuse and Mental Health Services Administration (SAMHSA) and CMS have identified evidence-based practices (EBP) for the treatment of SMI in adults. These include illness management and recovery, medication management, family psychoeducation, supported employment

¹⁴¹ Thomson Reuters analysis of FY 2008 4th Quarter Report – Total Statewide for CSBs. 2008 expenditures for “services outside of a program area” were allocated to mental health based on distribution of units of service by program area in FY2007, as reported in *2008 Overview of Community Services Delivery in Virginia*, July 22, 2008. Other includes prevention and early intervention services, limited services, and the Discharge Assistance Project.

¹⁴² DMHMRSAS, FY 2009 Community Services Performance Contract, May 6, 2008.

and assertive community treatment. In addition to “new generation” mental health medications being generally accessible to individuals through CSBs and state facility programs, Virginia appears to be focusing its mental health EBP efforts on assertive community treatment (ACT). There were 19 ACT teams that served 1,373 individuals across 18 of the 40 CSBs in FY 2006.¹⁴³ An additional 315 adults were on CSB waitlists for ACT from January through April 2007. These programs have reduced recipients’ use of state hospital services by over 75 percent and increased other outcomes important to consumers such as housing stability.¹⁴⁴ Stakeholders noted that most individuals receiving services in the public mental health system do not have consistent access to other EBPs.

A larger share of Virginia adults with SMI than adults in neighboring states were served by programs using ACT (Table 7.3). By comparison, the EBPs of supported employment and supported housing served smaller shares of adults with SMI in Virginia than in neighboring states.

Table 7.3 Penetration of Evidence-based Practices for Adults with Serious Mental Illness, FY 2006

	Percent of SMI Client Population Served		
	Assertive Community Treatment	Supported Employment	Supported Housing
Virginia	3.1%	0.30%	0.1%
<i>United States</i>	2.8%	2.7%	5.5%
Maryland	3.8%	4.445%	14.4%
North Carolina	2.3%	---	---
West Virginia	0.63%	0.34%	0.62%
Tennessee	0.23%	0.28%	0.68%
Kentucky	---	1.79%	0.3%

Source: SAMHSA, 2006 CMHS Uniform Reporting System (URS) Tables, August 20, 2007. Tennessee figures are based on a survey of community provider agencies. U.S. figures are based on 36 states for ACT, 34 states for Supported Employment, and 32 states for Supported Housing.

“My biggest concern is being able to sustain my recovery in my later years. I’m doing fine now. Since the onset of my illness, I was like a revolving door – I was in and out of the hospital many times. But, right now I have the right tools to manage my illness, in addition to the more recent medications.” - Individual with mental illness

¹⁴³ DMHMRSAS, *Comprehensive State Plan 2008-2014*, December 6, 2007.

¹⁴⁴ DMHMRSAS, *Community Mental Health Services Block Grant Application, FY 2009*, August 2008.

Demographic and Utilization Trends

DMHMRSAS estimates that approximately 308,037 Virginia adults (5.4 percent) have had an SMI at any time during the past year.¹⁴⁵ SMI is defined by the state authority as “a severe and persistent mental or emotional disorder that seriously impairs the functioning of adults, 18 years of age or older, in such primary aspects of daily living as personal relations, self care skills, living arrangements, or employment.”¹⁴⁶ Additional criteria are defined in terms of diagnosis, level of disability, and duration of illness. This definition also includes individuals with SMI who have a diagnosed substance abuse disorder or an ID. Adults with SMI accounted for a larger share of individuals receiving CSB mental health services in FY2006 (60 percent) than in FY 2002 (50 percent), indicating that the acuity of those served by CSBs is increasing.¹⁴⁷

Individuals with MI often experience other disabilities or health conditions that make their situations complex and serving their needs a challenge. For example, 29 percent of adults on CSB waiting lists for mental health services in January through April 2007 also had a major medical condition or chronic health condition and eight percent had high or extensive physical or personal care needs.¹⁴⁸

In general, supply and use of inpatient psychiatric services in Virginia is declining. Between FY 1976 and FY 2007, the average daily census (ADC) at state mental hospitals in Virginia decreased from 5,967 to 1,511.¹⁴⁹ More recently, ADC increased from 1,478 in FY 2005 to 1,511 in FY 2007, even as total operating capacity (beds) decreased slightly from 1,686 to 1,671.¹⁵⁰ There have also been declines over the last five years in capacity at private psychiatric hospitals and specialty psychiatric units in general hospitals in Virginia.¹⁵¹ This contraction of bed supply is not unique to Virginia: over the last five years, 22 states reported a decrease in the number of their state hospital beds, and only four states plan to increase the size of one or more hospital.¹⁵² Still, when compared to people in neighboring states, Virginians with MI were much less likely to be in state institutions in FY 2006, as shown in Table 7.4. Furthermore, Virginia adults discharged from state psychiatric hospitals were less likely to return quickly than individuals in neighboring states (Table 7.5).

¹⁴⁵ DMHMRSAS, December 6, 2007. Based on applying prevalence rates from national epidemiological studies and the 2004 and 2005 National Household Surveys on Drug Use and Health to 2005 Final Estimated Population data.

¹⁴⁶ State Mental Health, Mental Retardation, and Substance Abuse Services Board, Definitions of Serious Mental Illness, Serious Emotional Disturbance, and At Risk of Serious Emotional Disturbance, Policy 1029 (SYS) 90-3.

¹⁴⁷ DMHMRSAS, December 6, 2007, and DMHMRSAS, *Comprehensive State Plan 2004-2010*, December 12, 2003.

¹⁴⁸ DMHMRSAS, December 6, 2007.

¹⁴⁹ DMHMRSAS, December 6, 2007. These numbers exclude Hiram Davis Medical Center and Virginia Center for Behavioral Rehabilitation.

¹⁵⁰ DMHMRSAS, *Community Mental Health Services Block Grant Application, FY 2009*, August 2008, and DMHMRSAS, *Community Mental Health Services Block Grant Application, FY 2007*, August 2006.

¹⁵¹ National Association of State Mental Health Program Directors Research Institute, Inc. (NRI), *Virginia 2007*, NRI Report, October 2008.

¹⁵² NRI, *State Psychiatric Hospitals: 2006*, State Profile Highlights, No. 06-4, November 21, 2006.

Table 7.4 Number of People in State Hospitals for People with Mental Illness per 100,000 Residents, last day of SFY 2006

	State MI Hospital Residents per 100,000
Virginia	2.8
Kentucky	11.7
North Carolina	12.2
Tennessee	13.3
<i>United States</i>	<i>15.6</i>
Maryland	21.3

Source: NRI, *State Mental Health Agency Profiling System: System: 2007*, October 2008. West Virginia was one of eight states that did not report data. United States figure is based on 43 states.

Table 7.5 Percentage of Adults Age 18 or Older Discharged from State Hospitals for People with Mental Illness Readmitted within 30 Days, 2006

	Percentage of Readmissions
North Carolina	12.0%
Tennessee	10.7%
West Virginia	9.7%
<i>United States</i>	<i>9.4%</i>
Kentucky	8.2%
Virginia	7.6%
Maryland	6.4%

Source: SAMHSA, *2006 CMHS Uniform Reporting System (URS) Tables*, August 20, 2007. Refers to civil "non-forensic" clients only. United States figure is based on 47 states.

While the proportion of people with MI who are in state psychiatric hospitals is relatively low, Virginians' likelihood of using any inpatient psychiatric units during the year – either private or public – was very close to the national average (Table 7.6).

Table 7.6 Psychiatric Hospital Utilization per 1,000 Residents, 2006

	Persons Served per 1,000
Tennessee	2.18
Maryland	2.02
Virginia	2.02
<i>United States</i>	<i>2.01</i>
West Virginia	1.95
Kentucky	1.88
North Carolina	1.42

Source: SAMHSA, 2006 CMHS Uniform Reporting System (URS) Tables, August 20, 2007. Refers to both state hospital and other psychiatric inpatient utilization. United States figure is based on 39 states that reported admissions to both public and private hospitals.

Looking at community-based services, the picture is not dramatically different. Virginians overall, and non-elderly adults, are substantially less likely than residents of most neighboring states to receive public mental health services (Table 7.7).

Table 7.7 Public Mental Health Services Penetration Rate per 1,000 Residents, 2006

	Persons Served per 1,000	
	All Ages	Age 21-64
Kentucky	30.6	29.0
West Virginia	29.44	30.0
North Carolina	29.17	30.7
Tennessee	26.61	31.0
<i>United States</i>	<i>19.88</i>	<i>21.7</i>
Maryland	16.29	13.2
Virginia	15.07	16.8

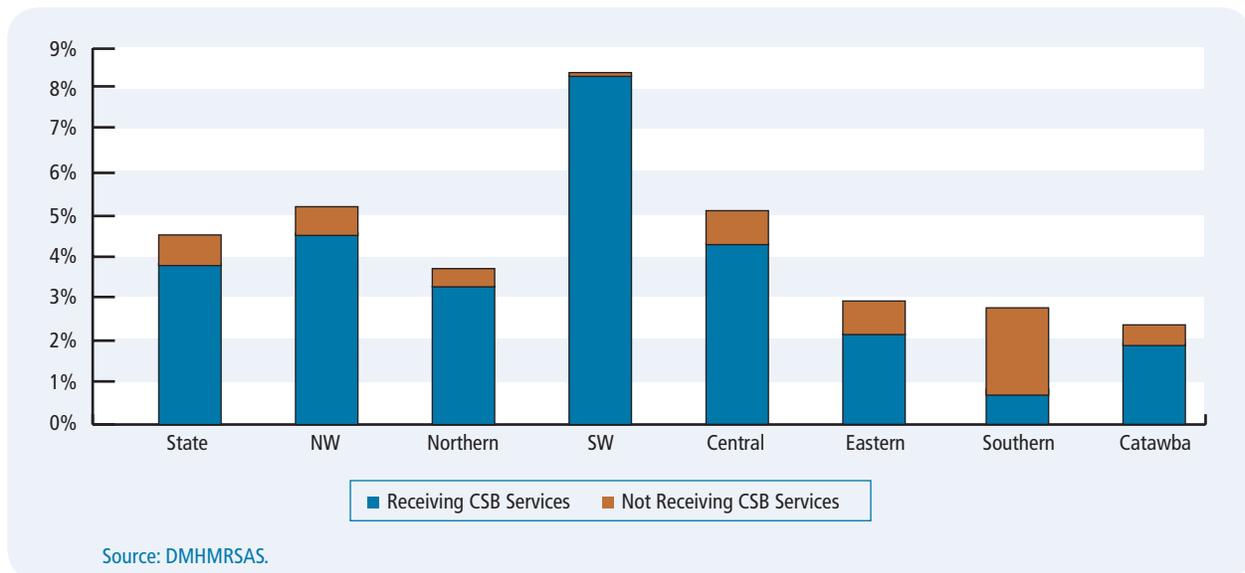
Source: SAMHSA, 2006 CMHS Uniform Reporting System (URS) Tables, August 20, 2007. Persons served refers to number of mental health consumers across both community and hospital services in the state. Client counts are duplicated in West Virginia between community and hospital and between community programs.

CSBs maintain databases on the service needs and demographic characteristics of individuals on waiting lists; the availability of this information can be an important advocacy tool. The CSB waiting lists include individuals who have sought but are not receiving CSB services, as well as current recipients of CSB services who are not receiving the amounts or types that staff have determined they need. Waiting lists are a function of both physical and financial resources, although stakeholders consider the extent of local funding of CSBs to be a key driver. As a result, even mandatory CSB services may not be available if funding is not sufficient.

The number of adults on CSB waiting lists for mental health services decreased from 4,365 in January through April 2005 to 4,029 in January through April 2007.¹⁵³ Mental health services for which the most adults were waitlisted in early 2007 were psychiatric services (1,759 adults), counseling and psychotherapy (1,681), medication management (1,519) and case management (1,226). The average wait times for adults to access these mental health services ranged from five to seven weeks.

As shown in Figure 7.5, the size and composition of the CSB waiting lists for mental health services vary by Health Planning Region. The regional rates also reflect underlying variation at the individual CSB level, e.g. three CSBs had mental health waiting lists in early 2007 equal to over 10 percent of persons served.¹⁵⁴

Figure 7.5 Number of Adults on CSB Waiting Lists for MH Services as Percentage of Adults Served: By Health Planning Region, 2007



System Components Associated with Rebalancing

Consolidated State Agency

As stated previously, DMHMRSAS is Virginia's state authority for mental health services. However, responsibility for planning and delivering mental health services is primarily divided between DMHMRSAS and DMAS (the Medicaid agency); there is an active Interagency Agreement and extensive collaboration between the two agencies. A variety of other agencies are also involved in providing mental health services and supports, including DRS (employment), Department of Housing and Community Development (subsidized housing), DSS (income security and AGs), VDH (certificate of need) and Department of Corrections.

¹⁵³ DMHMRSAS, December 6, 2007; and DMHMRSAS, *Comprehensive State Plan 2006-2012*, December 7, 2005.

¹⁵⁴ Thomson Reuters analysis of Appendix E in DMHMRSAS, December 6, 2007.

Single Access Point

Virginia policymakers and advocates desire for the services system to have a “wide front door” for individuals who seek publicly funded mental health services. CSBs serve as the door through which referrals are designed to go, functioning as a single point of entry into publicly funded mental health services, including access to state mental health facility services. CSBs also work with individuals to identify those eligible for Medicaid and assist them with the application process. Individuals using mental health services commented that there was not always good access to information about the CSB system and available services. They also stressed that it was imperative to be a self-advocate in order to find out about the full range of services CSBs offer and to receive those for which they qualify.

“All of the agencies that are supposed to support mental illness, there’s no connection. You can come from the hospitals, to the CSBs, to the group home, . . .and there’s no real connection. They need a central computer to log everybody in and where we are. I think it would make a difference if people actually knew what was going to happen to them in the next 90 days, in the next six months . . .” - Individual with mental illness

Institutional Supply Controls

Stakeholders acknowledged the challenge of assessing the adequacy of psychiatric bed capacity. State mental health facilities serve individuals with SMI who are in crisis, present with acute and/or complex conditions or require a highly structured environment. Furthermore, co-occurring substance abuse is believed to affect rehospitalization rates to the extent that individuals self-medicate instead of taking prescribed medications.¹⁵⁵ Finally, Virginia has seen hospital bed use reductions for civil bed days, primarily linked to new or expanded community services funded through the System Transformation Initiative, offset by forensic (i.e., jail transfer) admissions which have increased over time.¹⁵⁶

Virginia is currently in the process of downsizing a few state mental health facilities. The Commonwealth is replacing an older state psychiatric hospital (Eastern State Hospital) with a newer, smaller facility, and has received an appropriation and bond funding to replace a second psychiatric hospital (Western State Hospital) with a slightly smaller facility.

The Virginia Certificate of Public Need (COPN) program requires owners and sponsors of identified medical care facility projects to secure a COPN from the State Health Commissioner prior to initiating projects that include psychiatric/substance abuse services. VDH has taken an incremental approach to reviewing COPN regulation in response to legislative initiatives, by de-emphasizing regulation of replacement and smaller, nonclinically related expenditures, and focusing COPN regulation on new facilities development, new services development and expansion of service capacity.¹⁵⁷ In 2009, the

¹⁵⁵ DMHMRSAS personal communication, February 24, 2009.

¹⁵⁶ DMHMRSAS, *Report on System Transformation Initiative (STI)*, September 19, 2008.

¹⁵⁷ VDH, *Annual Report on the Status of Virginia’s Medical Care Facilities Certificate of Public Need Program*, 2007.

General Assembly changed the law to require a COPN for conversion of existing psychiatric inpatient treatment beds to nonpsychiatric beds and to create an expedited COPN process for psychiatric hospital projects. The statutory change also establishes eight instead of 21 criterion for determining public need, including the availability of reasonable alternatives that would meet population needs in a less costly, more efficient, or more effective manner.¹⁵⁸

Transition from Institutions

DMHMRSAS has articulated a strategy of improving state hospital bed utilization by providing aggressive treatment and discharge efforts that reduce length of stay and encourage quicker community integration.¹⁵⁹ Key to this strategy is that the CSBs:

- serve a gate-keeping function over entry to state psychiatric hospitals by conducting pre-admission screening for both voluntary and involuntary clients;
- rigorously screen and continuously review acuity and level of functioning of state hospital patients to ensure continued need for inpatient services;
- work with hospital staff to prepare discharge plans for individuals being discharged from state hospitals and
- provide case management (monitoring, coordinating support services) to state hospital patients when discharged into the community.

CSBs describe the Discharge Assistance Project (DAP) as “critical in effecting successful long-term discharges from state facilities” and successful in reducing state facility beds and achieving individual outcomes.¹⁶⁰ DAP is one of several mechanisms established with dedicated funds as a strategy to reduce facility census following Department of Justice investigations during the 1990s. The program began in 1998 to provide community resources to support the discharge and placement of state psychiatric hospital consumers age 18 and older whose special needs had prevented community placement and who did not have benefits, such as the MR/ID waiver, that could help make community placement successful. It has grown to a statewide program serving over 900 people for \$22.3 million today. Approved Individualized Service Plans for discharged individuals range from \$516 to \$123,400 with a median cost of \$59,156, not including Medicaid, third party insurers or other government funds that contribute to the total plan cost.¹⁶¹ About 80 percent of funds are spent on full-time supportive supervised housing.¹⁶² Under a regionalized organization, CSBs maintain lists of people served by DAP and some choose to track annual rehospitalization rates.

¹⁵⁸ Code of Virginia, Chapter 175, 32.1-102.1 through 32.1-102.3.

¹⁵⁹ DMHMRSAS, *Service Area Strategic Plan*, Community Mental Health Services, accessed February 2, 2009.

¹⁶⁰ Letter and report from Virginia Association of Community Services Board, Inc. to Chairman of Virginia Health, Welfare and Institutions Committee, August 21, 2007.

¹⁶¹ DMHMRSAS, Discharge Assistance Project Fact Sheet.

¹⁶² DMHMRSAS personal communication, February 24, 2009.

Individuals with MI expressed an interest in peer liaisons for people in psychiatric hospitals, as a complement to CSB staff members who serve as liaisons to other types of hospitals. *On Our Own* of Charlottesville was specifically identified as an example of a successful peer liaison program (see below).

FOCUS: *On Our Own* Programs Provide Critical Peer Support to People with Mental Illness to Assist with Community Integration

On Our Own programs in Charlottesville, Fairfax County, and Roanoke provide a range of consumer-operated supports varying by location to people with mental illness including: drop-in centers with showers, phones, and computers; liaison programs with local psychiatric facilities to assist with transition; transitional housing; social/recreational activities; and mental health advocacy. There are similar peer-operated drop-in centers in other localities.

Continuum of Residential Options

As noted above and reinforced by stakeholders, affordable housing is a very significant concern – maybe even at the top of the list, in some cases -- for hospitalized individuals ready to be discharged into the community. Stakeholders noted that some housing providers are perceived to be reluctant to serving individuals because of their MI. Stakeholders also observed that financial housing supports seemed to only one option -- group homes – which are inconsistently available across the state and in high demand where they do exist. For these reasons, stakeholders advocated for Housing First-type programs: those that focus on providing transitional or permanent housing before addressing other needs. As noted in Section 2, the Commonwealth is piloting a portable AG for people with MI starting the summer of 2009.

“I’m in an adult home. Social Security pays for a certain amount and then there’s a grant that pays for the rest of it. Even in Congress they were talking about those in adult homes to encourage them to get out to get their own apartment, to let us have the grant along with their check. And, that would be very beneficial.” --Individual with mental illness

Adults with MI in Virginia were more likely than those in the rest of the country to live in a private residence (70 vs. 65 percent), residential care (seven vs. four percent), or a jail/correctional facility (five vs. two percent) in FY 2006. They were somewhat less likely to live in an institutional setting (one vs. three percent) or to be homeless (two vs. three percent).¹⁶³ The longest waiting times for CSB mental health services in early 2007 were for residential services, for which the average wait times were 24

163 U.S. Substance Abuse and Mental Health Services Administration, 2006 CMHS Uniform Reporting System (URS) Tables, August 20, 2007.

weeks for adult supervised and supportive residential services.¹⁶⁴ Despite their length, these times are a substantial improvement over four years earlier, when average waits were 53 and 34 weeks, respectively, for adult supervised and supportive residential services.¹⁶⁵

HCBS Infrastructure

DMHMRSAS' Integrated Strategic Plan, "Envision the Possibilities: An Integrated Strategic Plan for Virginia's Mental Health, Mental Retardation, and Substance Abuse Services System" (2005) acknowledged many of the shortcomings of the current mental health system and provided the framework for transitioning the state's publicly funded mental health system to one that relies more on community-based services. The Transformation Initiative provided roughly \$187.5 million in state general and Medicaid funds for the 2006-2008 biennium to invest in community mental health services. In addition, changes in the civil commitment process and standard resulting from mental health law reforms of 2008 are expected to have an impact on CSB services, as DMHMRSAS anticipates an increase in the number of individuals receiving court-ordered outpatient services.

A report on expanded community-based services funded by the System Transformation Initiative (STI) indicates that the continuum of crisis services available at individual CSBs has expanded between 2005 and 2007, particularly for the service areas of residential crisis stabilization, mobile outreach crisis team, psychiatric crisis consultation, and after-hours psychiatric evaluation and medication administration.¹⁶⁶ However, the number of individuals served with STI funds in FY 2008 was sometimes less than the number proposed by the CSBs.

Other strategies being used by Virginia to strengthen the community-based infrastructure for mental health care include using telepsychiatry to provide mental health services in rural areas or areas without full-time psychiatrists. Also, in cooperation with the Department of Veterans Services, CSBs will be increasing their ability to address growing demand for mental health services among veterans of post-9/11 deployment and current National Guard members and Reservists who do not have military support systems.¹⁶⁷ Many soldiers reside in rural areas where there are no VA service centers and CSB resources are already stretched. DMHMRSAS also sponsors a web-based training for direct support personnel through the College of Direct Support VA Partnership Program (described in Section 2).

¹⁶⁴ DMHMRSAS, December 6, 2007. Supervised residential services offer overnight care with supervision and services typically for no more than 30 days and include supervised apartments, domiciliary care, residential respite, and sponsored placements. Supportive residential services are unstructured services that support people in their own housing arrangements.

¹⁶⁵ DMHMRSAS, December 12, 2003.

¹⁶⁶ DMHMRSAS, *Report on System Transformation Initiative (STI)*, September 19, 2008.

¹⁶⁷ Department of Mental Health, Mental Retardation, and Substance Abuse Services, *Service Area Strategic Plan, Community Mental Health Services*, accessed February 2, 2009.

FOCUS: Pathfinders Program Educates and Empowers Veterans with Mental Health Needs

The Pathfinders program, run by Mental Health America of Virginia, is a four-day leadership program targeted to Veterans to educate them on self-care, system reform, and advocacy for self and others. Pathfinders creates a team-building environment in which Veterans can learn from each other and become empowered to effect change in their lives. The program was created in recognition of the unique challenges Veterans with mental health issues face as they reintegrate back into the community after military service. In Phase I of the program, 18 Veterans attended the leadership program. In Phase II, the program hopes to expand to run five leadership academies with 15 participants each.

In addition to being an important part of recovery for adults with MI, meaningful employment may make alternative housing options more feasible. The DMHMRSAS Office of Mental Health -- in collaboration with DRS, DMAS, individuals, and employment providers -- seeks to align Virginia's existing financial infrastructure (i.e., Medicaid plan, DRS) with evidence-based practice of supported employment.¹⁶⁸ Using resources from a Real Choice Systems Change Grant for Mental Health System Transformation, a supported employment pilot was conducted in FY 2008 with the Fairfax CSB in northern Virginia, where 30 individuals received Medicaid mental health support services as a complement to DRS-funded services. The initiative produced a manual for CSBs on how to use funding streams to enhance employment services and supports. Evidence-based supported employment continues to be pursued as a key strategy in the Cross-Governmental Strategic Plan to ensure community integration of Virginians with disabilities.

Participant Direction

Section 2 provides an overview on Virginia's efforts related to person-centered planning and participant direction. The State Mental Health, Mental Retardation and Substance Abuse Services Board adopted policy in 2006 on the importance of consumer and family member participation in the design, operation and evaluation of the system. Individuals and family members as a share of CSB Board members increased from a low of 11 percent in 1991 to a high of 40 percent in 2007; in 2008, nine percent were individuals and 28 percent were family members, for a total composition of 37 percent.¹⁶⁹ Some CSBs also have mental health Consumer Advisory Boards.

In addition, DMHMRSAS uses federal block grant funds to contract with mental health organizations in the state to educate individuals and their families about mental illnesses and treatments. Consumer-oriented activities supported by these funds include Consumer Empowerment Leadership Training, peer counselor training, technical assistance for education and support groups, and peer-operated programs. In particular, between FY 2007 and FY 2008, the dollar value of contracts to peer-run programs nearly

¹⁶⁸ *Virginia's Comprehensive Cross-Governmental Strategic Plan to Assure Continued Community Integration of Virginians with Disabilities, 2008 Update and Progress Report*, by the Community Integration Implementation Team and the Community Integration Advisory Commission.

¹⁶⁹ DMHMRSAS, *2008 Overview of Community Services Delivery in Virginia*, July 22, 2008.

quadrupled.¹⁷⁰ DMHMRSAS' most recent Strategic Plan continues the strategy of establishing and expanding peer-provided community mental health services across the state.

"[What I really needed was] the education part of it, of the sickness I have, because no one understood what I was going through. So I kind of hid it from people. And then later, when I had my episode that got me into the hospital, that's what really changed my life, was the education. I'm hoping that education will continue when I get out [of the mental health facility], hoping to learn more about what I'm going through and why I'm going through it."

- Hospitalized individual with mental illness

CSBs are described as advocates for individuals and other individuals in need of services. At a minimum, CSB performance contracts contain Mental Health and Substance Abuse Case Management Service Performance Goals, which state that a copy of an advance directive, a Wellness Recovery Action Plan (WRAP) or a similar expression of a consumer's treatment preferences, if available, shall be included in the clinical record of a new case management client who has been discharged from a psychiatric unit or released from a commitment hearing.¹⁷¹ WRAP is "an individualized system for monitoring and responding to symptoms to achieve the highest possible levels of wellness."¹⁷² Stakeholders generally view the recent investment by CSBs in 15 WRAP facilitators as positive, but note that there is great variation across the state in whether CSBs use WRAP.

Quality Assurance

DMHMRSAS has identified consumer perceptions of CSB services as an annual performance measure.¹⁷³ In its 11th annual statewide survey of adults who presented for non-emergency outpatient services, Virginia individuals reported similar levels of satisfaction as did individuals nationally on all domains. Within the state, results vary dramatically by CSB, e.g., ranging from 60 to 88 percent on social connectedness, a national outcome measure for SAMHSA's Uniform Reporting System.¹⁷⁴

In developing the FY 2009 Community Services Performance Contract for CSBs, DMHMRSAS added a new emphasis on continuous quality improvement (CQI) and performance goals and expectations for emergency services, case management services, and data quality. As the CQI process evolves, opportunities for performance evaluation across all program areas will be identified. CSB funding will not be based on or associated with Board performance in achieving these expectations and goals.

¹⁷⁰ DMHMRSAS, December 6, 2007.

¹⁷¹ FY2009 Community Services Performance Contract, May 6, 2008.

¹⁷² Mary Ellen Copeland, www.mentalhealthrecovery.com, *About Mental Health Recovery and WRAP*.

¹⁷³ The CSBs also agree to participate in the conduct of an Annual Youth Services Survey for Families (i.e., Child MH survey) and a MR Family Survey (done at the time of the consumer's annual planning meeting).

¹⁷⁴ DMHMRSAS, *Consumer Satisfaction Survey, FY2007*. This was administered in October 2007 using a 33-item version of the consumer survey developed for the Mental Health Statistics Improvement Program's (MHSIP) Consumer-Oriented Mental Health Report Card.

As part of the CQI process, DMHMRSAS is working with CSBs to implement the Recovery-Oriented System Indicators. This activity is in accordance with the Partnership Agreement and recommendations in the Services System Transformation Initiative Data/Outcomes Measures Workgroup Report (September 1, 2006), which calls for the development and implementation of a plan by June 30, 2009 to assess and increase CSBs' recovery orientation over time, initially for adults with SMI. CSBs are to involve individuals in developing and implementing the plan, such as by training and hiring them to administer the instrument, compile the data, or analyze the results.¹⁷⁵

Summary of Strengths and Gaps

"I wish that I could have more places to be other than here at the [psychosocial rehab] center. This area has so few places you can go to talk to other people, to hang out."

"We feel very isolated, even though we have this place [psychosocial rehab program]."

- Individuals with mental illness living in a rural area.

The State's efforts to date to transform the mental health system are generally recognized as significant, such that the National Alliance on Mental Illness recently upgraded the state's system compared to where it was three years ago.¹⁷⁶ Among the priorities for action has been expansion of community mental health services, particularly crisis stabilization and response services that can reduce the number of admissions to state psychiatric hospitals. Regional consortia of CSBs are actively engaged in better managing hospital utilization using resources such as DAP. Advocate stakeholders were unanimous about DMHMRSAS' support of the recovery model for mental health and felt that the challenge was in changing others' perspectives. (However, they noted that DMHMRSAS doesn't consistently require CSBs to use state funds received for recovery even if that was the plan.) Due to Virginia's focus on ACT, several geographic areas benefit from having teams to serve individuals whose illnesses are not effectively remedied by available treatments or the individual resists involvement with services. In addition, knowledge from a supported employment pilot with Medicaid financing will soon be shared more broadly.

Nevertheless, stakeholders consistently expressed concern about the lack of greater access to community-based mental health services. Outpatient services such as case management, psychiatrists and other clinical counseling staff were identified as a gap area that should be the "bread and butter" of community care but currently is not. Pervasive workforce shortages are a factor in some of these gaps, as are reimbursement rates and funding limits (over 90 percent of mental health case managers have case loads of over 25 patients).¹⁷⁷ A major piece of the delivery system that is not fully realized is effective crisis

¹⁷⁵ FY 2009 Community Services Performance Contract, May 6, 2008.

¹⁷⁶ National Alliance on Mental Illness, *Grading the States 2009, A Report on American's Health Care System for Adults with Serious Mental Illness*, March 2009.

¹⁷⁷ DMHMRSAS Budget Proposal, Presentation of James Reinhard, Commissioner, to HHR Subcommittee of Virginia Senate Finance Committee, January 21, 2008.

stabilization and intervention programs that support people without hospitalization or incarceration and return them to the community. There was also a desire for community-based services to include peer-run recovery programs such as drop-in centers or wellness centers that expand the continuum of care options under a psychosocial model. Individuals residing in rural areas were particularly concerned about lack of workforce (psychiatrists), transportation, and peer education program availability. In fact, the lack of a consistent level of service availability across the state was another theme. As already noted, affordable housing is a very significant concern for Virginians ready to be discharged into the community. Limits on DAP funding mean new enrollment is contingent on deaths, attrition, or less intensive service needs among existing enrollees.

“The biggest part of it for me has been peer support. That’s really what helped me with getting into recovery was peer support and education about my illness. . . I can look back now and say that the system always only took me halfway.” - Individual with mental illness

Section 8. Services for Children with Disabilities

Entitlements to a broad array of Medicaid and public education services create a comprehensive services continuum for children with disabilities that changes dramatically when youth transition to the adult services world. Through the EPSDT program, Medicaid-eligible children are able to receive any medically-necessary service, including services outside Virginia's Medicaid State Plan. Part B of the Federal Individuals with Disabilities Education Act (IDEA) requires local school districts to offer educational services to children with disabilities ages three to 22; Virginia also makes Part B services available to two year-olds. For children under age three, the Infant and Toddler Connection of Virginia program offers support and services to eligible infants and toddlers and their families. In addition, the state's Comprehensive Services Act (CSA) Program provides services to children with serious emotional and behavioral problems as mandated by federal laws, including those pertaining to foster care.

However, entitlements are not a guarantee of community services. By several measures, wait lists for mental health services were of great concern for children in Virginia. Stakeholders reported an inadequate supply of non-institutional behavioral health services as well as a shortage of waiver and other resources for children with intellectual and developmental disabilities and autism. Families are particularly concerned about the lack of supports for children outside of school hours and days of operation, and the impact this has on parents' ability to maintain their jobs. Virginia parents of children ages 12 to 17 with special health care needs were less likely than parents across the country (38 vs. 41 percent) to report their youth receiving services necessary to make the appropriate transitions to adult health care, work and independence.¹⁷⁸ The state has acknowledged many of these shortcomings through its actions on both DMHMRSAS' STI and the Children's Services System Transformation, which aims to strengthen permanent family connections.

"We're worried about the protection of our special needs kids." – Parent of a child with a developmental disability

Programs and Services

Table 8.1 shows public LTC spending for children with disabilities in SFY 2004 and SFY 2008, unless noted otherwise. The definition of a child is specific to each program's eligibility criteria, i.e., ages zero to 17 for CSB services and under age 21 for Medicaid. Based on available data, there were approximately \$2.7 billion in public expenditures for supports to children with disabilities in FY 2008, an increase of 49 percent since FY 2004. Medicaid expenditures contributed \$406 million to the FY 2008 total, 15 percent. Special education data includes federal grants, state appropriations, and spending by local school districts. Expenditure totals include both acute and long-term mental health services given the difficulty in distinguishing between acute and LTC in the available data (as described in the Section 7).

¹⁷⁸ Child and Adolescent Health Measurement Initiative. *2005/2006 National Survey of Children with Special Health Care Needs*, Data Resource Center for Child and Adolescent Health website. Retrieved March 16, 2009 from www.cshcndata.org. Children with special health care needs (CSHCN) are defined as "...those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally."

Table 8.1 Public LTC Expenditures for Children in Virginia: SFYs 2004 and 2008

	2004	2008	Average Annual Percent Change
Mental Health Services			
CSB Mental Health Services	Not available	Not available	N/A
Medicaid Mental Health Facilities	\$55,483,328	\$96,498,971	15%
Medicaid Community Mental Health Services	\$51,058,815	\$216,613,278	44%
Medicaid Treatment Foster Care Case Management	\$13,563,438	\$4,260,911	-15%
Intellectual and Developmental Disability Services			
CSB ID Services	Not available	Not available	N/A
Medicaid ICF/MR - Public	\$1,949,242	\$1,378,750	-7%
Medicaid ICF-MR - Private	\$10,684,150	\$1,378,750	8%
Medicaid MR/ID Case Management	\$3,906,754	\$3,170,968	1%
Medicaid DD Case Management	\$421,135	\$643,635	14%
Medicaid MR/ID Waiver	\$15,904,734	\$25,151,356	12%
Medicaid DD Waiver	\$1,311,008	\$2,706,301	20%
Medicaid Day Support Waiver	N/A	\$216,759	N/A
Physical Disability Services			
Medicaid Nursing Facility	\$12,159,334	\$12,364,815	1%
Medicaid Home Health	\$506,375	\$750,218	11%
Medicaid Hospice	\$81,526	\$180,828	29%
Medicaid EDCD Waiver	\$1,544,680	\$8,407,561	53%
Medicaid Tech Waiver	\$14,890,958	\$18,744,335	6%
Medicaid HIV/AIDS Waiver	\$14,174	\$22,247	101%
Other Targeted Care Management	\$135,506	\$721,445	80%
Special Education and Related Services			
Part C funded (Early Intervention) ¹⁷⁹	\$11,044,704	\$28,281,113	36.8%
Other special education (includes Part B) ¹⁸⁰	\$1,333,567,176	\$1,841,148,559	8.4%
Comprehensive Services Act Program ¹⁸¹	\$259,513,411	\$380,536,394	10.0%
Total Medicaid	\$183,615,157	\$406,382,656	N/A
Total Other Public	\$1,604,125,291	\$2,249,966,066	N/A
Total Public Expenditures	\$1,787,740,448	\$2,656,348,722	N/A

Notes: Medicaid Day Support waiver started in FY 2006. The EDCD waiver also serves individuals with autism. CSB expenditures are not available by age. Part C funded data represent direct service expenses for federal fiscal years 2004 and 2007. Other special education funding data are for federal fiscal years. CSA represents CSA pool expenditures only. Medicaid and Title IV-E funds are not included.

¹⁷⁹ DMHMRSAS, *A Report on Virginia's Part C Intervention System (Budget Item 312 K.2, 2006 Appropriations Act)*, July 1, 2006-June 30, 2007, October 2007; and DMHMRSAS, *A Report on Virginia's Part C Intervention System (Budget Item 334K, 2004 Appropriations Act)*, July 1, 2004-June 30, 2005, October 2005.

¹⁸⁰ Virginia Department of Education, *Report of Federal, State, and Local Funds Expended for Special Education and Related Services, Fiscal Years 2004 and 2008*, provided March 16, 2009.

¹⁸¹ Office of Comprehensive Services Act, *Program Years 1994-2008 Summary: Statewide*.

Table 8.2 presents data for SFY 2004 and SFY 2008 (unless noted otherwise) on the number of children with disabilities who received public LTC services. As many children use more than one service within and among the disability categories shown below, we could not calculate totals.

Table 8.2 Number of Children in Virginia Receiving Public LTC: SFYs 2004 and 2008

	2004	2008	Average Annual Percent Change
Mental Health Services			
CSB Mental Health Services	24,177	30,082	8%
Medicaid Mental Health Facilities	1,742	2,160	6%
Medicaid Community Mental Health Services	16,001	32,434	6%
Medicaid Treatment Foster Care Case Management	1,187	1,446	5%
Intellectual and Developmental Disability Services			
CSB ID Services	10,913	13,052	6%
Medicaid ICF/MR - Public	23	14	-11%
Medicaid ICF-MR - Private	131	116	-3%
Medicaid MR/ID Case Management	2,264	935	-13%
Medicaid DD Case Management	277	427	12%
Medicaid MR/ID Waiver	683	958	9%
Medicaid DD Waiver	205	390	17%
Medicaid Day Support Waiver	N/A	39	N/A
Physical Disability Services			
Medicaid Nursing Facility	89	67	-2%
Medicaid Home Health	751	735	<1%
Medicaid Hospice	13	18	18%
Medicaid EDCD Waiver	241	1,684	64%
Medicaid Tech Waiver	284	306	29%
Medicaid HIV/AIDS Waiver	11	1	-33%
Other Targeted Care Management	952	1,502	19%
Special Education and Related Services			
Part C funded (Early Intervention) ¹⁸²	8,540	10,330	6.5%
Other special education (includes Part B) ¹⁸³	173,871	169,538	-0.6%
Comprehensive Services Act Program ¹⁸⁴	14,505	18,195	5.8%

Notes: CSB counts include children receiving Medicaid services. CSB services data are from FY 2004 and FY 2007. Medicaid community mental health services include group homes (922 persons under age 21 in 2008, of which 707 were CSA), targeted case management (10,906 persons under age 21 in 2008), rehabilitation option, and services of other licensed mental health professionals. Part C funded Early Intervention program data are for 2003-2004 (December) and 2006-2007 (July). Other special education data are as of December 2003 and December 2007.

¹⁸² DMHMRSAS, *A Report on Virginia's Part C Intervention System (Budget Item 312 K.2, 2006 Appropriations Act)*, July 1, 2006-June 30, 2007, October 2007; and DMHMRSAS, *A Report on Virginia's Part C Intervention System (Budget Item 334K, 2004 Appropriations Act)*, July 1, 2004-June 30, 2005, October 2005.

¹⁸³ Virginia Department of Education, *Totals for Students with Disabilities by Disability and Age*, February 2, 2005 and October 10, 2008.

¹⁸⁴ Office of Comprehensive Services Act, *CSA Data Set--Statewide Profile, FY08-QTR4 and FY04-QTR4*.

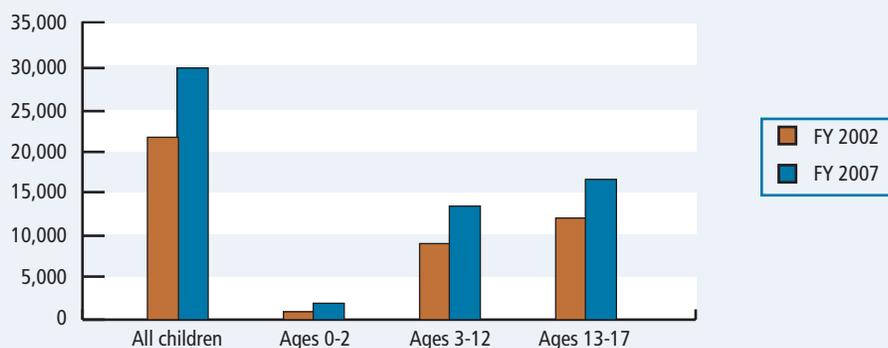
Most services for children with disabilities have been described in previous sections of this report. This section identifies available LTC services and programs, and provides additional information related to children's utilization of these services.

Mental Health Services

Mental Health Services through CSBs. As described in Section 7, publicly funded, community-based mental health services in Virginia are either directly delivered by community services boards (CSBs), or they are coordinated by CSBs and delivered through licensed private and public providers. As the information in Section 7 about publicly-funded mental health services for adults also applies to children, it will not be repeated here.

In FY 2007, 24 percent of persons served by CSBs for mental health services were under age 18; this age group increased nearly 40 percent between FYs 2002 and 2007, the fastest of all age groups. As shown in Figure 8.1, adolescents were the largest subgroup of children, but those age two and under more than tripled in number over the time period.¹⁸⁵

**Figure 8.1 Unduplicated Number of Children Receiving CSB MH Services:
FY 2002 and FY 2007**



Source: DMHMRSAS.

Recently, CSBs in certain parts of the state have been involved in new approaches to serving children with mental health problems. Under one approach, four communities that had developed a system of care for children added an evidence-based practice to their existing array of services. Their target populations include children involved with the juvenile justice system, children returned from residential care, and children with co-occurring substance abuse problems. In addition, DMHMRSAS and the Department of Juvenile Justice – which estimates that at least 50 percent of Virginia's juvenile detention population needs behavioral health services -- have collaborated to support mental health case

¹⁸⁵ DMHMRSAS, 2008 Overview of Community Services Delivery in Virginia, July 22, 2008, and Table 4: FY2002 Unduplicated Numbers of Consumers Served by Program Area by Age and Gender provided through personal contact with DMHMRSAS staff, February 23, 2009.

management services in regional juvenile detention centers. CSB staff now provide short-term behavioral health services to more than 2,500 children annually in 23 of 25 centers.¹⁸⁶

In 2008, the General Assembly approved \$5.8 million in the biennium budget to hire one clinician specializing in children's mental health at each of the 40 CSBs in order to help serve children who are not eligible for services through the Comprehensive Services Act.¹⁸⁷ Stakeholders considered this an important step in increasing system capacity for children, especially in localities where it would be the only position dedicated to serving children's mental health needs.

Medicaid Mental Health Services. In addition to the mental health services described in Section 7, the following are provided to children through Medicaid:

- Inpatient stays in a psychiatric hospital if identified as necessary by EPSDT screening and pre-authorized by DMAS. State-operated facilities currently consist of a 15-bed adolescent unit at Southwestern Mental Health Institute and the 48-bed Commonwealth Center for Children and Adolescents. Also, inpatient psychiatric services in an acute hospital are covered for individuals under age 21 beyond the 21-day limit that applies to individuals over age 21.
- Intensive in-home services
- Case management for children with or at risk of serious emotional disturbance (SED)
- Treatment Foster Care case management (TFC-CM) for children under age 21 in TFC with SED or behavioral disorders who would be at risk for placement into more restrictive residential settings.
- Residential treatment
- Community based residential treatment (group homes)

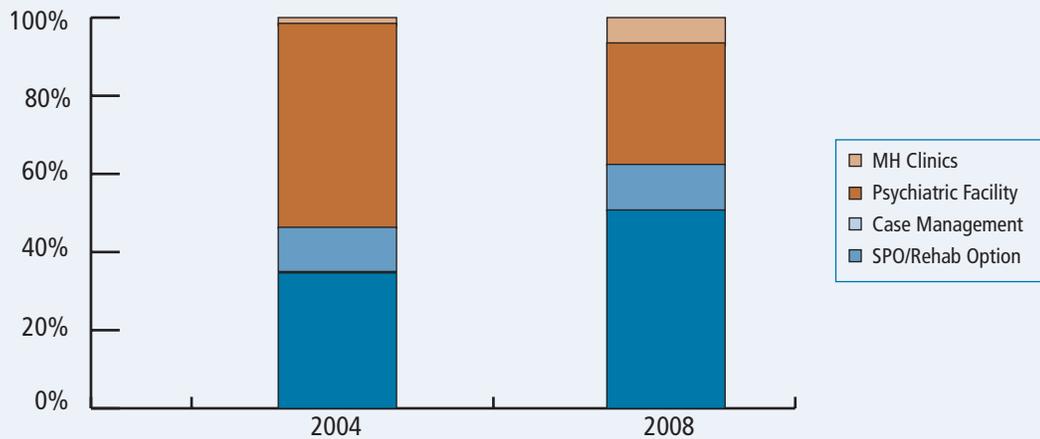
Figure 8.2 shows the important role of mental health services provided to children under the Rehabilitation Option, as well as a dramatic decrease in spending on care in facilities.¹⁸⁸ As share of total Medicaid MH spending for children, the Rehabilitation Option increased from 35 in FY 2004 percent to 53 percent in FY 2008, and mental health facility services decreased from 52 percent in FY 2004 to 31 percent in FY 2008.

¹⁸⁶ DMHMRSAS, *An Integrated Policy and Plan to Provide and Improve Access to Mental Health, Mental Retardation, and Substance Abuse Services for Children, Adolescents and Their Families (Budget Item 311-E, 2007 Appropriations Act)*, July 1, 2007-June 30, 2008.

¹⁸⁷ Voices for Virginia's Children, *2009 Legislative Agenda*.

¹⁸⁸ Thomson Reuters analysis of VAMMIS custom data runs. Case management includes targeted case management and treatment foster care case management.

**Figure 8.2 Distribution of Medicaid MH Spending for Children by Service:
FY 2004 Compared to FY 2008**



Source: Thomson Reuters analysis of VAMMIS.

In late 2007, Virginia started a five-year demonstration to offer children community-based alternatives to psychiatric residential treatment facilities (PRTFs) that are critical to enabling them to reside at home. Children under age 21 who have been in a PRTF for at least 90 days, have a psychiatric diagnosis, and remain eligible for Medicaid after they leave the PRTF are eligible for the Children's Mental Health (CMH) Program. Services offered include transition coordination; companion (agency and consumer-directed); respite (agency and consumer-directed); services facilitation for consumer-directed services; environmental modifications; family/caregiver training; in-home residential support; and therapeutic consultation.¹⁸⁹ During the first year of the program (FY2008), 11 children participated.¹⁹⁰

As described in Section 7, some mental health services are not covered under Medicaid managed care plans for enrollees of any age. Coverage carve-outs relevant to children include state psychiatric hospital services, treatment foster care, residential treatment services for children, community mental health rehabilitative services, and the CMH Program.¹⁹¹

¹⁸⁹ DMAS, *Medicaid Manual, Children's Mental Health Program Manual*, May 21, 2008.

¹⁹⁰ DMAS personal communication.

¹⁹¹ DMAS, *Attachment II—Summary of Covered Medallion II and Medicaid/FAMIS Plus Services*.

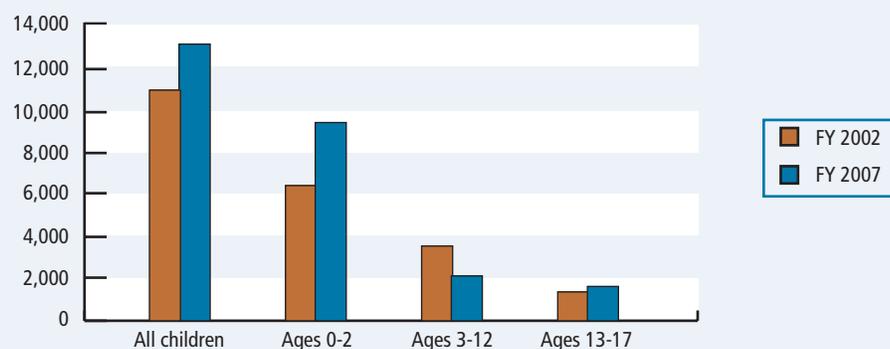
Intellectual and Developmental Disability Services

“There’s no money left for people who are not waiver-eligible.” – Parent of a child with a developmental disability

Intellectual Disability Services through CSBs. As the local entity responsible for the delivery of publicly-funded ID services, CSBs provide programs aimed at infants from birth to toddlers age three who have or are at risk of DD and children and youth with ID who want to remain in their homes, schools and communities. CSBs are the single point of entry to these services, including the Medicaid MR/ID waiver.

In FY 2007, nearly half of persons served by CSBs for ID services were under age 18; this subgroup of individuals with ID also increased the fastest of all age groups at 21 percent between FYs 2002 and 2007.¹⁹² As shown in Figure 8.3, toddlers age two and under were the largest subgroup of children and grew the fastest during the time period; this pattern is due to the role of CSBs in providing Part C Early Intervention services and, in part, to greater efforts at outreach and case finding.

**Figure 8.3 Unduplicated Number of Children Receiving CSB ID Services:
FY 2002 and FY 2007**



Source: DMHMRSAS.

Given the limited slots for Medicaid MR/ID waivers, CSBs have a potentially valuable role to play in providing services to children with ID if funding is available; however, advocates generally describe these services as insufficient. Although no information was available about which ID services had the most children and adolescents waitlisted, the average wait times in April 2007 were longest for children waitlisted for day support services (65 to 66 weeks), residential services (44 to 59 weeks), employment services (31 to 52 weeks), and behavior management (33 weeks). Among MR/ID waiver services, children were waitlisted the longest, on average, for assistive technology (21 weeks).¹⁹³

¹⁹² DMHMRSAS, 2008 Overview of Community Services Delivery in Virginia, July 22, 2008, and Table 4: FY2002 Unduplicated Numbers of Consumers Served by Program Area by Age and Gender.

¹⁹³ DMHMRSAS, Comprehensive State Plan 2008-2014, December 6, 2007.

Medicaid ID/DD Services. Medicaid provides the same services as are available for adults and described in Section 6: ICF/MR; targeted case management; and the MR, DD, and Day Support waivers. In 2008, children under age 21 accounted for eight percent of the ICF/MR population. This age group also comprised 13 percent of the MR/ID Waiver population, 65 percent of the DD Waiver population, and 14 percent of the Day Support Waiver population.¹⁹⁴ Children who do not have a diagnosis of ID become ineligible for the MR/ID Waiver when they reach the age of six, at which point children can be screened for eligibility for the DD Waiver. DMAS is currently exploring solutions to an inconsistency in how regulations handle these individuals with regard to the waiting list. The DD Waiver is one of two waivers for which Virginia children with autism are eligible.

Physical Disability Services

Medicaid Services Related to Physical Disabilities. Medicaid provides the same general services as are available for adults and described in Sections 4 and 5: NF care; home health; and the EDCD and Technology Assisted (Tech) waivers. In 2008, children accounted for less than one percent of the NF population and 20 percent of the home health population. Children comprised 10 percent of the EDCD Waiver population and over three quarters of the small Tech Waiver population.¹⁹⁵ Children under the age of 21 are eligible for the Tech Waiver if they are dependent on technology to substitute for a vital body function (e.g., ventilator, feeding tube) and have exhausted available third-party insurance benefits for private-duty nursing. This waiver provides personal care only for adults, but does not limit private duty nursing hours for the first 30 days of the waiver for children. Also, parental income and resources are not considered when making a financial eligibility determination for a child under the age of 18 who is enrolling in the Tech Waiver.¹⁹⁶

Brain Injury/Spinal Cord Injury Services. As noted in Section 5, case management comprises the largest share of the DRS allocation for BI services. Less than one percent of the 812 individuals served by the Community Rehabilitation Case Management Services program in FY 2008 were children.¹⁹⁷ By comparison, nationally, the two age groups at highest risk for traumatic brain injury are zero to four year olds and 15 to 19 year olds.¹⁹⁸ Children under 18 are not eligible for DRS' three Personal Assistance Service (PAS) programs.

Other Key Health and LTC Services

Medicaid EPSDT Services. Medicaid's EPSDT benefit provides comprehensive coverage to identify and treat problems as soon as possible, including assessment/diagnosis and medically necessary services required to correct an identified condition, reduce its effects, prevent them from worsening, or prevent development of secondary conditions. Any treatment service which is not already covered

¹⁹⁴ DMAS, VAMMIS custom data run.

¹⁹⁵ DMAS, VAMMIS custom data run.

¹⁹⁶ VBPD, 2008.

¹⁹⁷ DRS personal communication.

¹⁹⁸ CDC, *Traumatic Brain Injury in the United States: Emergency Department Visits, Hospitalizations, and Deaths*, 2004.

under Virginia's State Plan can be covered for a child through EPSDT as long as the service is allowable under the Social Security Act Section 1905(a) and the service is determined by DMAS to be medically necessary.¹⁹⁹ Recipients of EPSDT personal care services must be functionally limited in performing three or more activities of daily living.²⁰⁰ EPSDT is available to all Medicaid enrollees under the age of 21 in MEDALLION, Medallion II, or FFS Medicaid.

Children with Special Health Care Needs. The Children with Special Health Care Needs (CSHCN) Program, administered by the Office of Family Health Services, Department of Health, promotes the optimal health and development of Virginia's children with special health care needs through multiple service networks. In FY 2007, nearly 7,000 children received care coordination services through the program.²⁰¹

Within the CSHCN Program, Care Connection for Children is a statewide network of centers of excellence for CSHCN that provides leadership in the enhancement of specialty medical services; care coordination; medical insurance benefits evaluation and coordination; information and referral to CSHCN resources; family-to-family support; and training and consultation with community providers on CSHCN issues. Children through age 21 with medical disorders having a physical basis expected to last at least one year are eligible. A CSHCN Pool of Funds provides limited assistance in paying for certain services to uninsured or underinsured CSHCN whose gross family income does not exceed 300 percent of the federal poverty level. Care Connection is funded by Title V of the Maternal and Child Health Block Grant program and state General Funds.

Also within the CSHCN Program and a companion to Care Connection, Child Development Services focuses on children and adolescents through age 21 who are suspected of having or diagnosed with developmental, learning, and behavioral disorders. Core services include diagnostic assessment and care planning, follow-up care coordination and referral; consultations from other pediatric specialists are available as needed. A sliding scale fee is based on the income level and size of the family. Child Development Services is financed by state funds, Title V (MCH block grant) funds, and Medicaid.

Special Education and Related Services

Special Education. Part B of the IDEA requires local school districts to provide services and supports to help children ages three to 21 learn in the least restrictive environment.²⁰² Preschoolers ages two to five who are eligible in Virginia under one or more of 14 disability categories receive Early Childhood Special Education (ECSE) services. In addition, Early Intervention (EI) services are provided to children under

¹⁹⁹ Virginia DMAS, *Medicaid Manual, EPSDT Nursing*.

²⁰⁰ Virginia DMAS, *Medicaid Manual, Supplement B—EPSDT—Personal Care Services*, December 1, 2007.

²⁰¹ Virginia Board for People with Disabilities, April 2008.

²⁰² Individuals with Disabilities Education Improvement Act of 2004, Public Law 108-446, 108th Congress. Virginia Department of Education data include information for children age 22+ because those who turn 2 after September 30 are allowed to remain in special education throughout the school year or because hearing officers may request that services be continued for older children.

age three²⁰³ with developmental delays or disabilities through the Infant and Toddler Connection of Virginia program, which is funded in part by Federal grants under Part C of IDEA.

As shown in Table 8.2, the number of children served by Part C-funded programs has increased substantially over the past several years, while those receiving other special education services (including Part B funded services) has declined slightly. It was not possible to determine how many of these children also receive LTC. However, about 15 percent of non-Part C funded children had ID, emotional disturbance, severe disability, multiple disabilities, or traumatic brain injury as of December 2007. Less than one percent of special education children received services from state-operated programs such as training centers or psychiatric facilities.²⁰⁴

There are 40 Infant and Toddler Connection entities, 33 of which are CSBs, in Virginia (one in each CSB jurisdiction). Services are provided by both public and private agencies/providers. Families are eligible to receive a multidisciplinary evaluation and assessment, the development of an Individualized Family Services Plan (IFSP), and service coordination free of charge. The specific early intervention supports and services that are necessary and appropriate are determined on an individual child and family basis by the IFSP team, which includes the family as an equal member. A key component of IFSP addresses the transition from Part C (EI) to Part B special education portion of IDEA, including the transition between the infant/toddler and preschool programs, or to other community services, if needed.

According to federal regulations, children are age-eligible for Part C EI services until their third birthday. Virginia is the only state that makes Part B special education services available to two-year olds (i.e., both EI service providers and public school divisions have responsibility for serving eligible children ages 24 to 36 months) so families have the option to transition these children from EI services to Part B special education services. Because a child may not receive Part C and Part B services concurrently, parents must choose. Differences between EI and ECSE services in terms of scope, cost and setting can influence a family's decision about when their child will transition from Part C services.²⁰⁵

Each of Virginia's 132 public school divisions, which are accountable to their local school boards, offers a range of Part B ECSE programs. When the child transitions to Part B services at age three, s/he moves into a child-centered system with the Individualized Education Program (IEP) serving as the child's educational blueprint. An IEP must be developed for each child prior to the initiation of Part B services, including before the third birthday if a Part C child requires special education under Part B. In Virginia, planning for the child's adult life is required to begin at age 16 with formal transition planning to discuss learning, living and working in the community.²⁰⁶ Transition planning includes preparing the individual and family for the reduced benefit set available for adults. The number of children age 18 and older receiving special education services increased over three percent annually from 2003, totaling roughly 9,500 by December 2007.²⁰⁷

²⁰³ A child is age-eligible for Early Intervention services from birth through two, inclusive, if the birthday falls on or before September 30, or when eligible to receive Part C services up to age three.

²⁰⁴ Virginia Department of Education, *Totals for Students with Disabilities by Disability and Age*, October 10, 2008.

²⁰⁵ DMHMRSAS and Virginia Department of Education, *Early Childhood Transition From Part C Early Intervention to Part B Special Education and Other Services for Young Children With Disabilities*, Technical Assistance Document, August 2003.

²⁰⁶ 8 Virginia Administrative Code 20-80-62 F.10. Transition planning can begin earlier, if needed.

²⁰⁷ Virginia Department of Education, *Totals for Students with Disabilities by Disability and Age*, February 2, 2005 and October 10, 2008.

In addition to federal Part B and C funds, special education services in Virginia are financed by state funds, local revenues and Medicaid reimbursement for services in Virginia's State Plan provided to eligible children when the school division is a Medicaid provider. While Virginia's EI system emphasizes local decision-making in service implementation, it does not require that localities provide funding. However, the state mandates that certain insurance plans pay for EI therapy services for which fees are charged, often up to \$5,000 annually per insured child.²⁰⁸ Children placed in private special education by a local public agency are funded through the interagency pool established by Virginia's CSA.

Comprehensive Services Act. The CSA program is a system unique to Virginia that was created in 1993 by pooling eight funding streams related to mental health, juvenile justice, education, and foster care, in an attempt to better serve emotionally/behaviorally troubled and at-risk children whose needs spanned multiple agencies. Four state agencies – the Departments of Social Services; Education; Juvenile Justice; and Mental Health, Mental Retardation, and Substance Abuse Services – work with different local entities that are primarily responsible for administering the program. Substantial additional funding comes from a local match to the CSA pool, as well as supplemental funds from Medicaid and Title IV-E.²⁰⁹ Effective July, 2009, pool funds are not to be used if Medicaid funds are available and appropriate for meeting the needs of the child.²¹⁰

Federal law requires that children in mandated eligibility categories be provided services, while children in non-mandated categories receive services only if local programs choose to serve this population and funding is available. A recent Virginia Attorney General opinion clarified that parents are not required to relinquish custody in order for their children to access mental health services through CSA.²¹¹ Although disability alone is not the basis for eligibility, children with disabilities are mandated if placed by the state in private residential facilities or private special education day schools because they also have more severe behavioral problems than public schools can accommodate.²¹² In addition, mental health issues are common, even if they are not an explicit reason for receiving services: in FY 2008, 40 percent of all children served by CSA had a mental health diagnosis, and 30 percent took psychotropic medications.²¹³

At the local level, an interagency Family Assessment and Planning Team (FAPT) that includes parents focuses on eligibility screening and service planning, and a case manager from the referring agency monitors progress. A broad array of services is available to meet the tailored needs of each child within statutory and policy guidelines that are intended to promote child- and family-centeredness and service delivery in the least restrictive setting possible. As a financial incentive to localities to provide community-based services, the local CSA match for community-based services was reduced by 50

²⁰⁸ Infant and Toddler Connection of Virginia, *Virginia's Private Insurance Early Intervention Mandated Benefit, Early Intervention Provider Information Guide*, October 1999. See Code of Virginia §2.1-20.1 for state employee coverage and Code of Virginia §38.2-3418.5 for private insurers.

²⁰⁹ JLARC, *Evaluation of Children's Residential Services Delivered through the Comprehensive Services Act*, House Document No. 12, 2007.

²¹⁰ Memorandum from Office of Comprehensive Services, *Maximizing Medicaid Funding for Children Served through the Comprehensive Services Act*, October 8, 2008.

²¹¹ Memorandum from CSA State Executive Council, *Proposed interagency guidelines on specific foster care services for children in need of services funded through the Comprehensive Services Act*, May 18, 2007.

²¹² Code of Virginia Section 2.2-5211.

²¹³ Office of Comprehensive Services, *CSA Data Set--Statewide Profile, FY08-QTR4*.

percent in FY 2009, and the match for residential services was increased by 15 percent in FY 2009 and 25 percent in FY 2010.²¹⁴

In FY 2008, 28 percent of CSA children received services in residential settings, such as group homes, residential treatment facilities, or psychiatric facilities.²¹⁵ Based in part on the experience of CSA Innovative Community Service Grantees of the past, intensive care coordination (ICC) was recently added for children at risk of entering or already in residential care. The state expects each CSB to offer ICC, even if it means working with other localities due to resource constraints.²¹⁶

Demographic and Utilization Trends

A national survey estimates 16 percent of Virginia's children have special health care needs, compared to the national average of 14 percent.²¹⁷ The number of children in Virginia has been increasing by less than one percent per year since 2000 and is expected to continue to grow -- at slightly over one percent per year -- over the next 20 years. If disability rates remain constant, the need for services among this population is likely to increase gradually. In Virginia, children from the lowest-income families have the highest prevalence of special health care needs: 22 percent of children whose family income is below the poverty level have special health care needs compared to 16 percent of those whose family income is 400 percent of poverty or higher.²¹⁸ This differs from the national trend in which prevalence is the same across income levels.

DMHMRSAS estimates that between 85,000 and 104,000 Virginia children and adolescents have an SED, with between 47,000 and 66,000 exhibiting extreme impairment.²¹⁹ SED is defined by the state authority as "a serious mental health problem that affects a child, age birth through 17, and can be diagnosed under the current edition of the DSM-MD or meets specific functional criteria."²²⁰ At risk of SED means a condition experienced by a child, age birth through seven, that meets at least one of three criteria pertaining to behavior, psychological or physical stressors, or predisposing factors of parents or guardians.

The number of children on CSB waiting lists for mental health services decreased from 2,002 in January through April 2005 to 1,680 in January through April 2007. Mental health services for which the most children were waitlisted in early 2007 were counseling and psychotherapy (973 children), psychiatric

²¹⁴ Community Integration Implementation Team and the Community Integration Advisory Commission, *Virginia's Comprehensive Cross-Governmental Strategic Plan to Assure Continued Community Integration of Virginians with Disabilities, 2008 Update and Progress Report*, August 28, 2008. The increased local match for residential services occurs after the first \$200,000 in annual residential care expenditures.

²¹⁵ Office of Comprehensive Services, *CSA FY08 Data Set Gross Expenditures Report*.

²¹⁶ Office of Comprehensive Services, *Guidelines for Intensive Care Coordination*; and Office of Comprehensive Services, *Intensive Care Coordination Frequently Asked Questions*.

²¹⁷ Child and Adolescent Health Measurement Initiative, *2005/2006 National Survey of Children with Special Health Care Needs*, Virginia Chartbook Page, Data Resource Center for Child and Adolescent Health.

²¹⁸ Ibid.

²¹⁹ Based on applying prevalence rates from national epidemiological studies and the 2004 and 2005 National Household Surveys on Drug Use and Health to 2005 Final Estimated Population data.

²²⁰ State Mental Health, Mental Retardation, and Substance Abuse Services Board, *Definitions of Serious Mental Illness, Serious Emotional Disturbance, and At Risk of Serious Emotional Disturbance, Policy 1029 (SYS) 90-3*. Note that this definition is more narrow than the federal definition.

services (561), case management (556), and medication management (527). The average wait times for children to access these mental health services ranged from four to five weeks.²²¹

As with adults, the size and composition of the CSB waiting lists for child mental health services vary by region (see Figure 8.4), which also reflects underlying variation at the individual CSB level.²²² Compared to CSB waiting lists for adult mental health services, the portion of individuals represented by the waiting lists was larger for children, and more of the children's waiting list was made up of persons not already receiving CSB services.

Figure 8.4 Number of Children on CSB Waiting Lists for MH Services as Percentage of Children Served: By Health Planning Region 2007

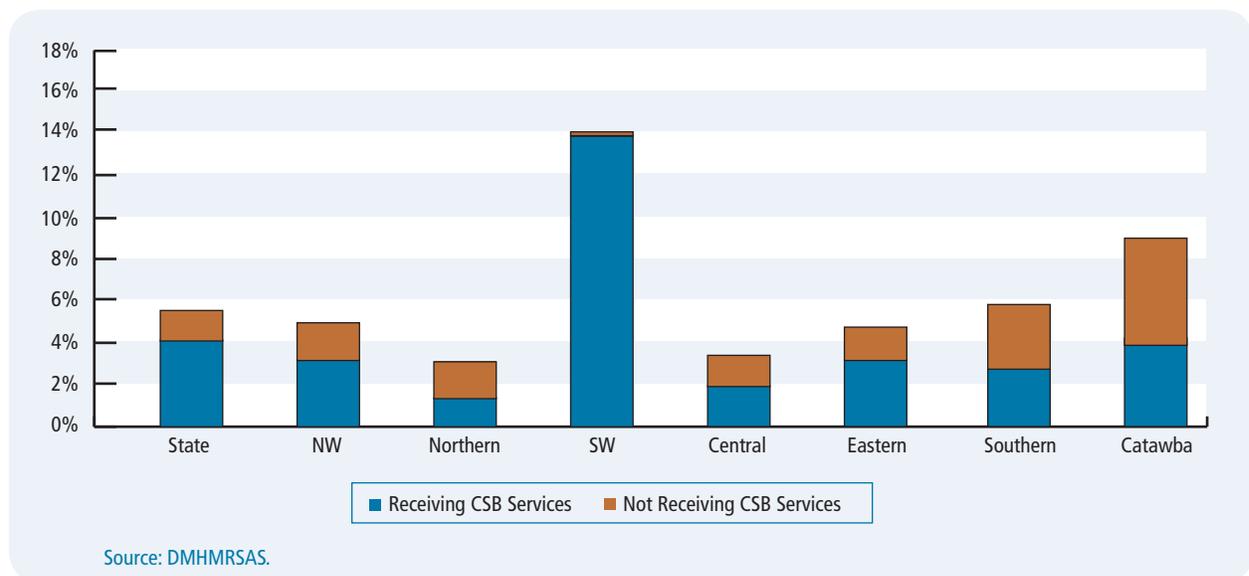


Table 8.3 compares Virginia's institutional utilization to the national average on measures where state comparison data are available. Virginia has a relatively low proportion of children in state institutions for people with ID/DD and in NFs. Data comparing Virginia to most states regarding children in other institutions, such as private ICF/MR and psychiatric treatment facilities, are not available. Similarly, data sources for community supports for children that include a majority of states also are not available.

Table 8.3 Institutional Utilization Data Regarding Children under Age 21, per 100,000 Population under 21

	State Developmental Disabilities Institutions, Residents on June 30, 2006	Nursing Facilities, Medicaid-funded beneficiaries, Oct. 2005 - Sept. 2006	Nursing Facilities, Medicaid-funded days, Oct. 2005 - Sept. 2006
Virginia	1.1	6.7	384
United States	1.7	5.8	909

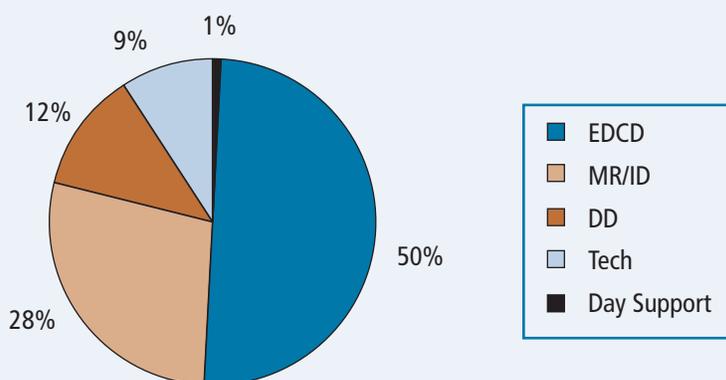
Sources: Prouty, et al (eds.) University of Minnesota for DD institution data. Thomson Reuters analysis of data from the CMS, Medicaid Statistical Information System (MSIS) State Summary Datamart, *Annual Estimates of the Resident Population by Single-Year of Age and Sex for the United States and States: April 1, 2000 to July 1, 2007, May 1, 2008, for population data.*

²²¹ DMHMRSAS, December 6, 2007; and DMHMRSAS, *Comprehensive State Plan 2006-2012*, December 7, 2005.

²²² Thomson Reuters analysis of Appendix E in DMHMRSAS. December 6, 2007.

Figure 8.5 shows the types of Medicaid waivers most prevalent among children and adolescents in 2008, accounting for roughly one in eight waiver participants among people of all ages. Children comprise a larger share of ID/DD waivers compared to those serving people with physical disabilities (as shown in Figure 2.6 in Section 2).

Figure 8.5 Distribution of Waiver Participants Under Age 21 by Waiver Type: FY 2008



Source: Thomson Reuters analysis of DMAS VAMMIS custom data run.

Note: There was one person under age 21 in the HIV/AIDS waiver in FY 2008.

System Components Associated with Rebalancing

Consolidated State Agency

Multiple agencies support children with disabilities, in part reflecting the complex needs of this population. However, even within a single service area, administrative leadership in Virginia is frequently divided among different agencies. For example, within special education, DMHMRSAS (Office of Child and Family Services) is the lead for Part C Early Intervention services while the DOE is the lead agency for Early Childhood Special Education services under Part B. In addition, although the CSA consolidated eight categorical funding streams directed to a common population of children and families, many consider the resulting administrative structure to have increased bureaucracy at the state and local levels.²²³ In 2007, a Special Advisor on Children's Services Reform was created within the office of the Health and Human Resources Secretary to lead Virginia's efforts to improve services for at-risk children and families.

²²³ National Health Policy Forum, *Tending to Richmond's Children: Community Strategies to Bridge Service Gaps*, January 22, 2009.

Single Access Point

When it comes to the practical task of seeking publicly funded services for children with disabilities in Virginia, many of the service systems have “single points of entry,” e.g., the local lead agency for EI services designates a single point of entry (usually itself), and the CSB serves as a single point of entry for publicly-funded mental health services and ID services. Yet, the number of separate access points with which a child with disabilities needs to interact makes for a system that is fragmented overall. The process of accessing Medicaid waivers can be particularly cumbersome for children, given that the MR/ID Waiver is administered by a different entity than the DD Waiver.

Ironically, stakeholders also identified the case management system as a potential source of administrative complexity, rather than a coordination aid, for children with disabilities. The complexity derives from the likelihood that children with disabilities in school have a special education case manager, may have other case managers provided through CSBs and Medicaid (e.g., mental health, ID), plus may have Title V case managers performing care coordination under the CSHCN program; the CSA program also has case managers. According to parents, not only does this create silos instead of linkages, but parents gravitate to the case manager(s) that accomplish the most for the child and the family.

Stakeholders identified several alternative or supplemental sources of information and referral that are unique to children with disabilities. First, there is a lot of formal and informal sharing of information and subject matter expertise among parents who have first-hand experience with and in-depth knowledge about the service delivery systems. The Parent-to-Parent organization says 40 percent of calls received are about special education and 25 percent about Medicaid. Second, information, resource referrals, and assistance in obtaining services are available free of charge to Virginia children with disabilities and special health care needs through Medical Home Plus: a coalition of 13 pediatric practices in central Virginia that are implementing the Medical Home concept using funds from a variety of sources, including grant funds passed through by DMHMRSAS (see below). Third, stakeholders mentioned a “waiver mentor” program as a very important information network, especially to military families moving among states that have different types of waivers for children. This program is no longer funded, but does still exist.

FOCUS: Medical Home Plus Promotes Coordination of Medical and Non-Medical Services for Special Needs Children and Provides Resources to Families and Practitioners

Medical Home Plus is a private, non-profit organization based in Richmond which promotes a “medical home” model of care for children with special health care needs and provides resources to their families and healthcare practitioners. “Medical home” is a holistic approach to providing care in which the individuals using services, their families/caregivers, and healthcare providers work as a team to identify and access needed medical and non-medical services to maximize outcomes. The Medical Home Plus program was founded and is staffed by licensed healthcare professionals, many of whom are also parents of special needs children. One of its main goals is to help families navigate the complex service system by providing education and referral to resources throughout Virginia.

Institutional Supply Controls

The supply control mechanisms for ICFs-MR, NFs, and psychiatric hospitals were described in previous sections. With regard to inpatient psychiatric services for children, stakeholders have called for maintaining current capacity to assure needs of children for emergency and intensive inpatient services can be met. Consistent with this concern, the 2009 General Assembly rejected the Government's proposal to close the Commonwealth Center for Children and Adolescents and the adolescent unit at the Southwestern Virginia Mental Health Institute. DMHMRSAS is required to develop a plan to "understand the needs of the individuals served at these facilities, the capacity of the community to serve them, and the appropriate role of the state in providing treatment services."²²⁴

Children's residential facilities are a special category of institutional care encompassing community-based residential facilities that serve children and adolescents (excluding psychiatric hospitals providing acute care to youth, or providers offering residential care in their own homes, e.g., foster homes). Included in this broad category are facilities such as group homes, residential treatment facilities, emergency shelters, intensive residential treatment, wilderness programs, and diagnostic facilities. The number of licensed children's residential facilities increased by more than 80 percent between 1992 and 2006.²²⁵ The largest increase occurred in 2004 with the addition of 49 new facilities, more than half of which were group homes. Licensing standards for children's residential facilities require that a certificate of occupancy from the locality where the facility would be located be submitted with the application for licensure/certification.²²⁶ There is currently no state-wide moratorium from the General Assembly on children's residential facilities.²²⁷

Transition from Institutions

Initiatives to help people move from institutions have been described in other sections of this report (e.g., MFP), and the authors are not aware of additional initiatives specific to children beyond the CMH program described earlier in this section. Under the leadership of the First Lady, Anne Holton, the Commonwealth has focused within recent years on increasing permanent family placements for children in Virginia's foster care system. The Council on Reform, a partnership between the Commonwealth and 13 localities accounting for nearly 50 percent of the state's foster care caseload, piloted promising strategies and best practices in funding, foster parent recruitment/retention, and worker training. This pilot resulted in reduced use of group/congregate care settings, mostly through a return to home, regular foster home or therapeutic foster home.²²⁸

It is a difficult decision for families to make when selecting how best to meet their child's care needs, as institutional care may be the only option available or feasible when care demands are too overwhelming for family members to provide what is needed. In some cases, families that choose institutional

²²⁴ DMHMRSAS, 2009 Legislative Report.

²²⁵ JLARC, House Document No. 12, 2007.

²²⁶ DMHMRSAS, Office of Licensing, *Siting of Children's Residential Facilities*, July 1, 2006.

²²⁷ DMHMRSAS, Office of Licensing personal communication.

²²⁸ Health and Human Resources personal communication.

placements for children under 21 are not aware of community-living options and supports such as waivers. In addition, stakeholders note that Medicaid eligibility policy creates an incentive for children to stay in residential treatment for 30 or more days because eligibility is determined only by the child's income, compared to children in the community where eligibility is determined by family income.

Continuum of Residential Options

In-home services and family supports are essential elements of the continuum for children with disabilities and their families. However, when these supports are not sufficient, community residential options can provide important opportunities to serve children and youth in the least restrictive setting possible. Residential options for children include facilities such as those noted above (group homes, residential treatment facilities, emergency shelters, intensive residential treatment, wilderness programs, and diagnostic facilities) as well as specialized/therapeutic foster care. Despite the less restrictive setting of these residential facilities compared to nursing facilities, ICFs-MR, and hospitals, parent stakeholders, and other child advocates interviewed voiced concerns about the overuse of congregate care settings in Virginia.

The authors did not have information to assess the distribution of care settings for children with specific types of needs. The available data indicate that Medicaid paid for residential treatment of 922 children under age 21 in group homes in SFY 2008; roughly three-quarters of these children were in the CSA program.²²⁹

Therapeutic foster care is recognized as an evidence-based practice that can avoid hospitalization for some children. In fact, SAMHSA includes the number of children receiving therapeutic foster care as a national outcome measure for comprehensive community-based mental health system for Mental Health block grant applicants. Comparative statistics for Virginia are not provided because the measure incorporates the estimate of SED, which is defined differently by Virginia. Virginia has been collaborating with local Social Services departments to provide therapeutic foster care for at least a decade; however, the need exceeds the availability of therapeutic foster families.²³⁰

HCBS Infrastructure

"This is an underfunded system with underfunded and undervalued people." - Parent of a child with a developmental disability

The HCBS infrastructure in Virginia and initiatives to improve it for persons needing LTC have been discussed in other sections. For children with disabilities, who interact not only with the CSBs but also with special education system and the CSA program, the locally administered aspect of each system

²²⁹ DMAS, unpublished data.

²³⁰ DMHMRSAS, *Community Mental Health Services Block Grant Application, FY2009*, August 2008.

means access is highly variable across all services. Stakeholders described this local variation among CSB programming for children with disabilities as a function of both strategy (e.g., degree to which they apply for grants or use Medicaid to the fullest potential) and orientation toward various target populations (e.g., age, health need). Similarly, although flexibility was described as one of the strengths of the CSA program, it was also noted that some localities are better than others at bringing children back to the community and supporting them with wraparound services. Localities often find it easier to provide CSA services that already exist than to use resources to develop new ones because start-up costs are a barrier. Other localities have joined forces to create economies of scale and are developing community-based services for intensive needs at the regional level.

Parent stakeholders indicated that many parents want their disabled children to be able to live at home with them, but they need to be supported so that parents don't have to stop working or experiencing some aspects of a normal life. This means having services after school and when school is not in session; programs such as summer camps also provide important socialization and companionship for children with disabilities. Stakeholders also said that children with disabilities in Virginia needed access to more evidence-based care and more mid-level (i.e., less than residential) services such as in-home care or day treatment. Respite care was identified as a type of Medicaid-covered community-based service that is currently underused by parents but would be less disruptive to families. Finally, stakeholders raised concerns about the system's ability to meet the growing need for case management services, including the positive addition of intensive care coordination.

Participant Direction

Section 2 provides an overview on Virginia's efforts related to person-centered planning and participant direction. Stakeholders indicated that parents care about whether (1) the service delivery system understands what is important to parents and children, (2) those issues are reflected in the child's individualized plan, (3) the system is integrated, and (4) the system is capable of responding to changing needs. Parents and child advocates involved with mental health services unanimously felt that Virginia was doing well in increasing self-determination – through both its commitment to person-centered planning and positive behavior supports – and this was starting to spill over onto other disabilities. However, compared to state mental health systems across the country, primary caregivers of children who received public mental health services in Virginia were less likely to report positively about participation in treatment planning (80 percent in Virginia vs. 87 percent nationally).²³¹

As described in other sections, several Medicaid home and community-based services waivers have consumer-directed service components (typically personal care and/or respite). For children enrolled in a waiver, consumer-directed means parents or guardians can hire, train, supervise and fire direct support workers. The ability of children to participate in consumer-directed services had an additional benefit: according to stakeholders, a lot of children moved out of MR/ID and DD waivers a few years ago – freeing up slots for others -- when the EDCD waiver was created in 2005. This new waiver was the result of merging the former Elderly and Disabled waiver and the Consumer Directed Personal Attendant

²³¹ DMHMRSAS, *Parent Perceptions of Services at Community Service Boards, Outpatient Mental Health Services Provided to Children and Adolescents, Youth Services Survey for Families Results, FY 2007*.

Services (CD-PAS) waiver. The new merged waiver did not retain the CD-PAS requirement of being able to self-direct services.

The Medical Home concept also incorporates participant direction. As described earlier in this section, the Medical Home Plus program based in Richmond includes parents in the practice team.

The DOE's "I'm Determined" program within the special education system uses person-centered practices in the development of the student's Individualized Education Program (IEP). By June 2011, this pilot program aims to provide students with disabilities with tools for using self-determination skills, increase student self-determination and engagement, and engage schools and communities in systems change that promotes self-determination. Core components of self-determination that are being developed include choice-making, decision-making, problem-solving, goal-setting, self-regulation, self-advocacy, and self-awareness skills.²³²

Quality Management

Many services for children with disabilities are also provided to adults. For these services, quality management processes have been discussed in previous sections of this report. Given the number of separate agencies responsible for services for children with disabilities across the state and the reliance on local entities to administer each program, the ability to aggregate and share data that will inform quality management and decision making as needed is likely to be an issue.

The Virginia Department of Education monitors its performance on a variety of goals related to the special education program. It recently reported an improvement in transitions from Part C to Part B for eligible children, yet only 70 percent of youth age 16 and above had an IEP supportive of post-secondary goals and transition services. In both cases, the state failed to meet its 2006-2007 targets in these specific transition areas.²³³

The Office of Comprehensive Services conducts both routine and special compliance reviews of local CSA operations. Localities must have a system in place for review of CSA program information regarding service delivery, quality and cost yet, within guidelines, they retain latitude in designing a utilization management system to fit their situations.²³⁴ In addition, the performance of the CSA program has been the subject of special attention by the General Assembly, which directed the Joint Legislative Audit and Review Commission (JLARC) to evaluate children's residential services funded by CSA. The study found problems with the adequacy of minimum licensing standards, use of enforcement actions, and frequency and thoroughness of monitoring to ensure the quality of children's residential services.²³⁵

The 2008 General Assembly quickly revised state law such that, effective July 2008, the Office of Interdepartmental Regulation within DSS was abolished and the functions were assumed by the Office

²³² www.imdetermined.org

²³³ Virginia Department of Education, *Special Education Performance Report*, July 25, 2008.

²³⁴ VBPD, 2008.

²³⁵ JLARC, House Document No. 12, 2007.

of Licensing, DMHMRSAS. This office now serves as the sole agency responsible for licensing residential programs that serve children and adolescents who have serious emotional disturbance, intellectual disabilities (MR), substance abuse disorders, and/or brain injuries and deliver treatment/services on site. The standards remain the same but the protocols, procedures, practices and forms have been modified. New regulations to reflect the 2008 Code change will be promulgated by October 31, 2009.²³⁶ In addition to licensure, these facilities must meet additional standards regarding staff qualifications and ratios to be certified by DMAS to receive Medicaid reimbursement. Certain facilities must be accredited by private organizations.

Summary of Strengths and Gaps

Virginia has put in place a variety of special efforts to address the needs of Virginia's children who currently require or are at risk of requiring LTS. These efforts involve several agencies and programs, particularly Medicaid and DMHMRSAS. Parents and child advocates involved with mental health services unanimously felt that Virginia was doing well in increasing self-determination – through both its commitment to person-centered planning and positive behavior supports – and this was starting to spillover onto other disabilities. Stakeholders highlighted community-based mental health services under Medicaid, the CMH Program, CSB budgeting for clinicians specializing in children's mental health, Medicaid waivers available to children and adolescents, and the introduction of intensive care coordination for children in or at risk of entering residential care. Stakeholders believe that even recent "systems of care" progress within the foster care and child welfare systems have some spillover benefit to the LTC system.

At the same time, it is clear that the system that serves children and adolescents with LTC needs is complex. The number of separate access points with which a child with disabilities must interact makes for a fragmented system. And, as noted, the case management system was identified as a potential source of additional complexity, rather than simplification. For children with disabilities, the locally administered aspect of each system (e.g., CSB, special education, CSA) means access is highly variable across services. Parent stakeholders indicated a need for additional supports to keep their children with disabilities living at home. Finally, stakeholders pointed to the need for more evidence-based care and mid-level (i.e., less than residential) services.

²³⁶ Memorandum to children's residential services providers from Office of Licensing, DMHMRSAS, regarding *Changes Effective July 1, 2008 in the Licensing Process*, June 19, 2008.

List of Abbreviations

Abbreviation	Meaning
AAA	Area Agency on Aging
ACT	Assertive Community Treatment
AG	Auxiliary Grant
ALF	Assisted Living Facility
CCRC	Continuing Care Retirement Community
CDC	Centers for Disease Control and Prevention
CIL	Centers for Independent Living
CMH	Children's Mental Health (Program)
CMS	Centers for Medicare & Medicaid Services
COPN	Certification of Public Need
CQI	Continuous Quality Improvement
CRCMS	Community Rehabilitation Case Management Services
CSA	Virginia Office of the Comprehensive Services Act
CSB	Community Services Board
DAP	Discharge Assistance Project
DCW	Direct Care Worker
DD	Developmental Disability
DMAS	Virginia Department of Medical Assistance Services
DMHMRSAS	Virginia Department of Mental Health, Mental Retardation and Substance Abuse Services
DHP	Virginia Department of Health Professions
DOD	Department of Defense
DRS	Virginia Department of Rehabilitative Services
DSB	Disability Services Board
DSS	Virginia Department of Social Services
EBP	Evidence Based Practice
ECSE	Early Childhood and Special Education
EDCD	Elderly or Disabled with Consumer Direction (waiver)
EI	Early Intervention
EPSDT	Early and Periodic Screening, Diagnosis, and Treatment
FFS	Fee-for-service
HCBS	Home and Community-Based Services
HHA	Home health agency
HHR	Virginia Health and Human Resources
ICF-MR	Intermediate Care Facilities for the Mentally Retarded

List of Abbreviations, cont.

Abbreviation	Meaning
ID	Intellectual Disability
IDEA	Individuals with Disabilities Education Act
IEP	Individualized Education Program
IFSP	Individualized Family Services Plan
IMD	Institutions for Mental Diseases
JLARC	Virginia Joint Legislative Audit and Review Commission
LTC	Long-term care
LTCI	Long-Term Care Insurance
LTCP	Long-Term Care Partnership
LTS	Long-term supports
MCO	Managed Care Organization
MEOC	Mountain Empire Older Citizens, Inc.
MFP	Money Follows the Person (Demonstration
MI	Mental Illness
MR/ID	Mental Retardaion /Intellectual Disability
PACE	Program of All-Inclusive Care for the Elderly
PAS	Personal Assistance Services
N/A	Not applicable
NF	Nursing facility
NWD	No Wrong Door
OCI	Office of Community Integration
OYF	Own Your Future (Campaign)
PCCM	Primary Care Case Management
PD	Physical Disability
PRTF	Psychiatric Residential Treatment Facility
RFA	Request for Application
SAMHSA	Substance Abuse and Mental Health Services Administration
SED	Serious emotional disturbance
SEVTC	Southeastern Virginia Training Center
SMI	Serious mental illness
SPT	State Profile Tool
STEPS	Southside Training, Employment, and Placement Services, Inc.
STG	Systems Transformation Grant
STI	System Transformation Initiative

List of Abbreviations, cont.

Abbreviation	Meaning
VA	Veterans Administration
VBPD	Virginia Board for People with Disabilities
VDA	Virginia Department for the Aging
VDH	Virginia Department of Health
VR	Vocational Rehabilitation
WRAP	Wellness Recovery Action Plan

Bibliography

AARP.org. *Continuing Care Retirement Communities*. Accessed at http://www.aarp.org/families/housing_choices/other_options/a2004-02-26-retirementcommunity.html.

American Health Care Association. *2001 Facts and Trends: The Nursing Facility Source Book*. Accessed at http://www.ahcancal.org/research_data/trends_statistics/Documents/Nursing_Facility_Sourcebook_2001.pdf.

American Health Care Association. *Nursing Facility Beds by Certification Type, CMS OSCAR Data Current Surveys, December 2008*. Accessed at http://www.ahcancal.org/research_data/oscar_data/Nursing%20Facility%20Operational%20Characteristics/NF_Beds_Certification_TypeDec2008.pdf.

American Health Care Association. *Medical Condition – Mental Status, CMS OSCAR Current Surveys*. Accessed at http://www.ahcancal.org/research_data/oscar_data/NursingFacilityPatientCharacteristics/MC_mental_status_Dec2008.pdf.

Brain Injury Association of America Web Site. *About Brain Injury*. Accessed at <http://www.biausa.org/aboutbi.htm>.

Burwell B, Sredl K, Eiken S. Thomson Reuters (September 26, 2008). *Medicaid Long-Term Care Expenditures in FY 2007*. Accessed at http://www.hcbs.org/moreInfo.php/nb/doc/2374/Medicaid_Long_Term_Care_Expenditures_FY_2007.

Child and Adolescent Health Measurement Initiative. *2005/2006 National Survey of Children with Special Health Care Needs*. Data Resource Center for Child and Adolescent Health website (www.cshcndata.org).

Code of Virginia, Sections 2.2-5211, 20-80-62 F.10, 37.2-509, and Chapter 303.

Commonwealth of Virginia. (December 17, 2008). *Executive Amendments to the 2008-2010 Biennial Budget, Part D: 2008-2010 Budget Reduction Plan*.

Commonwealth of Virginia. *Governor Kaine Announces Revenue Reforecast, Plan to Address Shortfall*. Accessed at <http://www.governor.virginia.gov/MediaRelations/NewsReleases/viewRelease.cfm?id=838>.

Commonwealth of Virginia. *Money Follows the Person Program Operational Protocol/Program Guidebook, A.2. Benchmarks*. Accessed at <http://www.olmsteadva.com/mfp/OpProtocol.htm>.

Commonwealth of Virginia. *Roadmap for Virginia's Health: a Report of the Governor's Health Reform Commission*. (September 2007). Accessed at http://www.hhrvirginia.gov/Initiatives/HealthReform/MeetingMats/FullCouncil/Health_reform_Comm_Final_Report.pdf.

Commonwealth of Virginia. *Virginia State Rehabilitation Council 2008 Annual Report*. Accessed at <http://www.drsvirginia.gov/downloads/srcannualreport.pdf>.

Commonwealth of Virginia. Community Integration Implementation Team and the Community Integration Advisory Commission. (August 28, 2008). *Virginia's Comprehensive Cross-Governmental Strategic Plan to Assure Continued Community Integration of Virginians with Disabilities. 2008 Update and Progress Report*.

Commonwealth of Virginia. Joint Legislative Audit and Review Commission. (2007). *House Document No. 12*.

Commonwealth of Virginia. Joint Legislative Audit and Review Commission. *Access to State-Funded Brain Injury Services In Virginia*. Senate Document No. 15, 2007.

Commonwealth of Virginia. Joint Legislative Audit and Review Commission. *Evaluation of Children's Residential Services Delivered through the Comprehensive services Act*. House Document No. 12. 2007.

Commonwealth of Virginia. Department of Medical Assistance and Department of Mental Health, Mental Retardation and Substance Abuse Services. (April 7, 2005). *Letter to Prescribers from Directors of Virginia*.

Commonwealth of Virginia. Department of Medical Assistance Services. FY 2006 Statistical Record. *Annual Expenditures for Medical Services by Type of Medical Service and Age Group*. Accessed at http://www.dmas.virginia.gov/downloads/Stats_06/8_28-EXPSVCAG-06.pdf.

Commonwealth of Virginia. Department of Medical Assistance Services. *Attachment II--Summary of Covered Medicaid II and Medicaid/FAMIS Plus Services*.

Commonwealth of Virginia. Department of Medical Assistance Services. (May 21, 2008). *Medicaid Manual Children's Mental Health Program Manual*.

Commonwealth of Virginia. Department of Medical Assistance Services. *Medicaid Manual EPSDT Nursing*.

Commonwealth of Virginia. Department of Medical Assistance Services. (December 1, 2007). *Medicaid Manual, Supplement B--EPSDT--Personal Care Services*.

Commonwealth of Virginia. Department of Medical Assistance Services. (January 2009). *The Virginia Medicaid Program At a Glance*.

Commonwealth of Virginia. Department of Medical Assistance Services. *Consumer Recipient Satisfaction Survey: 2007 Executive Summary*. (September 2007).
Public Partnerships, LLC.

Commonwealth of Virginia. Department of Mental Health, Mental Retardation and Substance Abuse Services. *2008 Overview of Community Services Delivery in Virginia*. Accessed at <http://www.dmhmrzas.virginia.gov/documents/reports/OCC-CSB-Overview2008.pdf>.

Commonwealth of Virginia. Department of Mental Health, Mental Retardation and Substance Abuse Services. *FY 2008 Community Services Boards - Original Performance Contract*.

Commonwealth of Virginia. Department of Mental Health, Mental Retardation and Substance Abuse Services. (May 6, 2008). *FY 2009 Community Services Boards – Original Performance Contract*.

Commonwealth of Virginia. Department of Mental Health, Mental Retardation and Substance Abuse Services. (October 17, 2007). *Report of the Study of Mental Retardation System in Virginia*. Accessed at [http://leg2.state.va.us/dls/h&Sdocs.nsf/By+Year/RD2572007/\\$file/RD257.pdf](http://leg2.state.va.us/dls/h&Sdocs.nsf/By+Year/RD2572007/$file/RD257.pdf).

Commonwealth of Virginia. Department of Mental Health, Mental Retardation and Substance Abuse Services (December 6, 2007). *Comprehensive State Plan: 2008-2014*. Accessed at <http://www.dmhmrzas.virginia.gov/documents/reports/opd-StatePlan2008thru2014.doc>.

Commonwealth of Virginia. Department of Mental Health, Mental Retardation and Substance Abuse Services (December 6, 2007). *Chapter 105. Rules and Regulations for the Licensing of Providers of Mental Health, Mental Retardation and Substance Abuse Services*. Accessed at <http://www.dmhmrzas.virginia.gov/documents/OL-RulesandRegulations.pdf>.

Commonwealth of Virginia. Department of Mental Health, Mental Retardation and Substance Abuse Services. (July 1, 2006). *Siting of Children's Residential Facilities*.

Commonwealth of Virginia. Department of Mental Health, Mental Retardation and Substance Abuse Services. *Discharge Assistance Project Fact Sheet* (provided by the Department).

Commonwealth of Virginia. Department of Mental Health, Mental Retardation and Substance Abuse Services. Office of Licensing. (June 19, 2008). *Memorandum - Changes Effective July 1, 2008 in the Licensing Process*.

Commonwealth of Virginia. Department of Mental Health, Mental Retardation and Substance Abuse Services. Office of Mental Health Services. *Parent Perceptions of Services at Community Service Boards, Outpatient Mental Health Services Provided to Children and Adolescents, Youth Services Survey for Families Results, FY 2007*.

Commonwealth of Virginia. Department of Mental Health, Mental Retardation and Substance Abuse Services. (October 2005). *A Report on Virginia's Part C intervention system (Budget Item 334K, 2004 Appropriates Act), July 1, 2004 - June 30, 2005*.

Commonwealth of Virginia. Department of Mental Health, Mental Retardation and Substance Abuse Services. (August 2008). *Community Mental Health Services Block Grant Application, FY 2009*.

Commonwealth of Virginia. Department of Mental Health, Mental Retardation and Substance Abuse Services. (March 3, 2009). *Comparative Cost Analysis and Collection Summary for 2004 and 2008*.

Commonwealth of Virginia. Department of Mental Health, Mental Retardation and Substance Abuse Services. (October 2007). *A Report on Virginia's Part C Intervention System (Budget Item 312K.2, 2006 Appropriations Act), July 1, 2006 - June 30, 2007*.

Commonwealth of Virginia. Department of Mental Health, Mental Retardation and Substance Abuse Services. *An Integrated Policy and Plan to Provide and Improve Access to Mental Health, Mental Retardation, and Substance Abuse Services for Children, Adolescents and Their Families (Budget Item 311-E, 2007 Appropriations Act), July 1, 2007-June 30, 2008*.

Commonwealth of Virginia. Department of Mental Health, Mental Retardation and Substance Abuse Services. (August 2006). *Community Mental Health Services Block Grant Application, FY 2007*.

Commonwealth of Virginia. Department of Mental Health, Mental Retardation and Substance Abuse Services. (December 7, 2005). *Comprehensive State Plan 2006-2012*.

Commonwealth of Virginia. Department of Mental Health, Mental Retardation and Substance Abuse Services. (December 6, 2007). *Comprehensive State Plan 2008-2014*.

Commonwealth of Virginia. Department of Mental Health, Mental Retardation and Substance Abuse Services. *Consumer Satisfaction Survey FY 2007*.

Commonwealth of Virginia. Department of Mental Health, Mental Retardation and Substance Abuse Services. (August 2003). *Early Childhood Transition from Part C Early Intervention to Part B Special Education and Other Services for Young Children with Disabilities*.

Commonwealth of Virginia. Department of Mental Health, Mental Retardation and Substance Abuse Services. (September 19, 2008). *Report on System Transformation Initiative (STI)*.

Commonwealth of Virginia. Department of Mental Health, Mental Retardation and Substance Abuse Services. *Service Area Strategic Plan - Community Mental Health Services*.

Commonwealth of Virginia. Department of Rehabilitative Services. *2008 Agency Strategic Plan*. Accessed at <http://www.drs.virginia.gov/strategicplan08.htm>.

Commonwealth of Virginia. Department of Rehabilitative Services. *Community Rehabilitation Case Management Services Overview*. Accessed at <http://www.drs.virginia.gov/cbs/ltrcm.htm>.

Commonwealth of Virginia. Department of Rehabilitative Services. *Supported Employment in Virginia*. Accessed at <http://www.drs.virginia.gov/essp/se.htm>.

Commonwealth of Virginia. Department of Rehabilitative Services. (2007). Education Services Unit. *Transition Services Guide: A Roadmap to Successful Employment for Virginia's Youth*.

Commonwealth of Virginia. Office of Community Integration. *Money Follows the Person Demonstration Annual Housing and Transportation Action Plan*. Submitted to the Honorable Marilyn B. Tavenner, Secretary of Health and Human Resources, and the Honorable Patrick O. Gottschalk, Secretary of Commerce and Trade. October 15, 2008. Accessed at <http://www.olmsteadva.com/mfp/downloads/AnnualHousingTransportationActionPlan.doc>.

Commonwealth of Virginia. Office of Comprehensive Services. *Intensive Care Coordination Frequently Asked Questions*. Accessed at <http://www.csa.state.va.us/html/Intensive%20Care%20Coordination%20FAQs.pdf>

Commonwealth of Virginia. Office of Comprehensive Services. *CSA Data Set -- Statewide Profile FY08-QTR4 and FY04-QTR4*.

Commonwealth of Virginia. Office of Comprehensive Services. *CSA FY08 Data Set Gross Expenditures Report*.

Commonwealth of Virginia. Office of Comprehensive Services. *Guidelines for Intensive Care Coordination*.

Commonwealth of Virginia. Office of Comprehensive Services. (October 8, 2008). *Memorandum - Maximizing Medicaid Funding for Children served through the Comprehensive Services Act*.

Commonwealth of Virginia. Office of Comprehensive Services. *Program Years 1994-2008 Summary: Statewide*.

Commonwealth of Virginia. Office of the Secretary for Health and Human Resources. (October 16, 2008). *Report on "Home" for Autism Spectrum Disorders and Developmental Disabilities*. Accessed at http://www.hhr.virginia.gov/Autism/AutismDD_Report_101608.pdf.

Commonwealth of Virginia. State Mental Health, Mental Retardation and Substance Abuse Services Board. *Definitions of Serious Mental Illness, Serious Emotional Disturbance and At Risk of Serious Emotion Disturbance*. Policy 1029 (SYS) 90-3.

Commonwealth of Virginia. University of Virginia. Weldon Cooper Center for Public Service. Demographics & Workforce. 2007 Final and 2008 Provisional Population Estimates. Accessed at <http://www.coopercenter.org/demographics/POPULATION%20ESTIMATES/>.

Commonwealth of Virginia. University of Virginia. (January 2009). Weldon Cooper Center for Public Service, Demographics & Workforce, *Older Virginians*. Stat Chat. Accessed at http://www.coopercenter.org/demographics/sitefiles/documents/pdfs/statchat/coopercenter_aging_jan-09.pdf.

Commonwealth of Virginia. Virginia Board for People with Disabilities. *2008 Biennial Assessment of the Disability Services System in Virginia. Section IV Community Living Supports*. Accessed at <http://www.vgpd.virginia.gov/downloads/biennial/2008/IVVBPDCCommunityLiving.pdf>.

Commonwealth of Virginia. Virginia Department for the Aging. (November 18, 2008). *Memorandum to Directors of Area Agencies on Aging*.

Commonwealth of Virginia. Virginia Department for the Aging. *Agency Strategic Plan*. Accessed at <http://www.vda.virginia.gov/pdfdocs/stratplan.pdf>.

Commonwealth of Virginia. Virginia Department of Education. *Totals for Students With Disabilities By Disability and Age, Ages 0 – 22+, State Totals and Individual Division Totals, As of December 1, 2007*. Accessed at http://www.doe.virginia.gov/VDOE/Publications/SPED_child_count/total07.pdf.

Commonwealth of Virginia. Virginia Department of Education. (March 16, 2009). *Report of Federal, State, and Local Funds Expended for special Education and Related Services, Fiscal Years 2004 and 2008*.

Commonwealth of Virginia. Virginia Department of Education. (July 25, 2008). *Special Education Performance Report*.

Commonwealth of Virginia. Virginia Department of Education. (February 2, 2005 and October 10, 2008). *Totals for Students with Disabilities by Disability and Age*.

Commonwealth of Virginia. Virginia Department of Health. *Home Health and Hospice Leading Indicators 2007*.

Commonwealth of Virginia. Virginia Department of Health (undated). *Directory of Long Term Care Facilities*. Accessed at <http://www.vdh.virginia.gov/OLC/Facilities/documents/2009/pdfs/2009%20LTC%20directory.pdf>.

Commonwealth of Virginia. Virginia Department of Health (2008). *Virginia Rural Health Plan*.

Commonwealth of Virginia. Virginia Department of Health. *Unpublished Construction and Development Listing* (provided by the Office of Licensure and Certification, Division of Long Term Care). (February 19, 2009).

Commonwealth of Virginia. Virginia Department of Health. (2007). *Annual Report on the Status of Virginia's Medical Care Facilities Certificate of Public Need Program*.

Commonwealth of Virginia. Virginia Department of Health, Office of Licensure and Certification. *Extract for Section 32.1-102.3 of the Code of Virginia*.

Commonwealth of Virginia. Virginia Employment Commission. *Virginia's December 2008 Unemployment Rate Rises 0.6 Percentage points to 5.2 Percent As the Recession Catches Up to Virginia*. Accessed at <http://www.wvec.com/news/downloads/vajobless.pdf>.

Commonwealth of Virginia. Virginia State Corporation Commission. *Long-Term Care Policies, Part II. Companies with Approved Long-Term Care Partnership Policies in Virginia, Revised 3/23/09*. Accessed at <http://www.scc.virginia.gov/division/boi/webpages/inspagedocs/ltclist.pdf>.

Commonwealth of Virginia. Virginia Workforce Connection. Labor Force Employment and Unemployment. Accessed at <http://www.vawc.virginia.gov>.

Congressional Budget Office. (April 2004). *Financing Long-Term Care for the Elderly*. Accessed at <http://www.cbo.gov/ftpdocs/54xx/doc5400/04-26-LongTermCare.pdf>.

CSA State Executive Council. (May 18, 2007). *Memorandum - Proposed interagency guidelines on specific foster care services for children in need of services funded through the Comprehensive Services Act*.

Doty P (October 2004). *Consumer-Directed Home Care: Effects on Family Caregivers*. Policy Brief. Family Caregiver Alliance.

Doty P, Flanagan S (2002). *Highlights: Inventory of Consumer-Directed Support Programs*. U.S. Department of Health and Human Services, Assistant Secretary for Planning and Evaluation. Accessed at <http://aspe.hhs.gov/daltcp/reports/highlight.htm>.

Eiken S (December 2006). *Technical Assistance Guide to Assessing a Long-Term Care System*. Thomson Medstat. Accessed at http://www.cms.hhs.gov/NewFreedomInitiative/Downloads/TA_Guide.pdf.

Ellis D. *Tax-Friendly Places 2007*. CNNMoney.com. Accessed at http://money.cnn.com/galleries/2007/pf/0704/gallery.tax_friendliest/8.html.

Genworth Financial 2008 *Cost of Care Survey: Home Care Providers, Adult Day Health Care Facilities, Assisted Living Facilities and Nursing Homes*. Genworth Financial. Accessed at http://www.aapr.org/families/housing_choices/other_options/a2004-02-26-retirementcommunity.html.

Grabowski D, Aschbrenner KA, Feng Z, Mor V (2009). *Mental Illness in Nursing Homes: Variations Across States*. Health Affairs. Volume 28, Number 3.

Houser A, Gibson MJ (November 2008). *Valuing the Invaluable: The Economic Value of Family Caregiving, 2008 Update*. Insight on the Issues 13. AARP Public Policy Institute. Retrieved at http://www.aarp.org/research/housing-mobility/caregiving/i13_caregiving.html on June 3, 2009.

Individuals with Disabilities Education Improvement Act of 2004, Public Law 108-446, 108th Congress.

Infant and Toddler Connection of Virginia. (October 1999). *Virginia's Private Insurance Early Intervention Mandated Benefit, Early Intervention and Provider Information Guide*.

Kaiser Family Foundation. *Long-Term Care Insurance Tax Incentives Offered by States, 2008*. Retrieved at <http://www.statehealthfacts.org/comparetable.jsp?ind=381&cat=7>.

Kaiser Family Foundation, statehealthfacts.org. (2005). *Medicaid 1915(c) Home and Community-Based Service Waiver Participants, by Type of Waiver, 2005*. Accessed at <http://www.statehealthfacts.org/comparetable.jsp?ind=241&cat=4>.

Kronick R, Bella M, Gilmer T, Somers S (October 2007). *The Faces of Medicaid II: Recognizing the Care Needs of People with Multiple Chronic Conditions*. Center for Health Care Strategies, Inc.

Long Term Care Group. (2005). *Index of the Uninsured*.

MDS Active Resident Information Report, Question Q1A. (4th Quarter 2008). Accessed at http://www.cms.hhs.gov/MDSPubQIandResRep/04_activeresreport.asp?isSubmitted=res3&var=Q1a&date=25

MetLife Mature Market Institute. (July 2006.) *The MetLife Caregiving Cost Study: Productivity Losses to U.S. Business*.

National Alliance of Direct Support Professionals web site. Accessed at <http://www.nadsp.org/credentialing/index.asp>.

National Alliance on Mental Illness. (March 2009). *Grading the States 2009, A Report of American's Health Care System for Adults with Serious Mental Illness*.

National Association of Insurance Commissioners. *2007 Long-Term Care Insurance Experience Reports - Form C*.

National Association of State Mental Health Program Directors Research Institute, Inc. (October 2008). *State Mental Health Agency Profiling System: System 2007*.

National Association of State Mental Health Program Directors Research Institute, Inc. (November 21, 2006). *State Psychiatric Hospitals: 2006*. State Profile Highlights, No. 06-4.

National Association of State Mental Health Program Directors Research Institute, Inc. (October 2008). *Virginia 2007*.

National Caregiver Alliance. (undated). *Women and Caregiving: Facts and Figures*. Accessed at http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=892.

National Health Policy Forum. (January 22, 2009). *Tending to Richmond's Children: Community Strategies to Bridge Service Gaps*.

Paraprofessional Healthcare Institute. (Number 3, Spring 2004). *Direct Care Worker Associations: Empowering Workers to Improve the Quality of Home- and Community-Based Care*. Workforce Tools.

Prouty RW, Albar K, Lakin KC, editors (July 2008). *Residential Services for Persons with Developmental Disabilities: Status and Trends through 2007*. University of Minnesota. Accessed at <http://www.rtc.umn.edu/docs/risp2007.pdf>.

Prouty RW, Smith G, Lakin KC, editors (August 2007). *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2006*. University of Minnesota: August 2007.

Reinhard J (January 21, 2008). *DMHMRSAS Budget Proposal*. Department of Mental Health, Mental Retardation and Substance Abuse Services.

Reinhard J (June 30, 2008). *Memorandum to CBS on Allocations of FY 2009 Mental Health Law Reform, Mental Health Child and Adolescent Services and Jail Diversion Funds*. Department of Mental Health, Mental Retardation and Substance Abuse Services.

Rogers S, Komisar H. (May 2003). *Who Needs Long-Term Care*. Georgetown University.

Sommers A, Cohen M, O'Malley M (November 2006). *Medicaid's Long-Term Care Beneficiaries: An Analysis of Spending Patterns*. Kaiser Commission on Medicaid and the Uninsured. The Henry J. Kaiser Family Foundation. Accessed at <http://www.kff.org/medicaid/upload/7576.pdf>.

Tritz K (2006). *Long-Term Care: Trends in Public and Private Spending. Report for Congress*. Congressional Research Service. Library of Congress. April 11, 2006.

U.S. Census. 2007 American Community Survey. *Table C19037, Age of Householder by Household Income in the Past 12 Months*.

U.S. Census, Population Division. (May 1, 2008 for 2000 and 2005 data). *Annual Estimates of the Resident Population by Single-Year of Age and Sex for the United States and States: April 1, 2000 to July 1, 2007*.

U.S. Census, Population Division. (April 21, 2005 for 2010-2030 data). *Interim Projections for the Population by Selected Age Groups for the United States and States: April 1, 2000 to July 1, 2030*.

U.S. Census. (2007). *Current Population Survey, Table HI05 Health Insurance Coverage Status and Type of Coverage by State and Age for All People*. Accessed at http://pubdb3.census.gov/macro/032008/health/h05_000.htm.

U.S. Census. (2000). *Table P12. Sex by Age*. Decennial Census 2000 Summary File.

U.S. Census, 2007 American Community Survey. *Table B.18032: Physical Disability by Sex By Age by Poverty Status for the Civilian Noninstitutionalized Population 5 Years and Over*.

U.S. Census, 2007 American Community Survey. *Table B18022: Physical Disability by Sex By Age by Employment Status for the Civilian Noninstitutionalized Population 16-64 Years*.

U.S. Department of Health and Human Services. Administration on Aging (January 2009). *Statistical Profiles of Black, Asian, and Hispanic Older Americans Aged 65+*. Accessed at http://www.aoa.gov/AoARoot/Aging_Statistics/minority_aging/Index.aspx.

U.S. Department of Health and Human Services. Administration on Aging. (September 29, 2008). *HHS Announces \$36 Million to Help Older Americans and Veterans Remain Independent*. Accessed at http://www.aoa.gov/AoARoot/Press_Room/For_The_Press/pr/archive/2008/September/9_29_08.aspx.

U.S. Department of Health and Human Services. Centers for Disease Control and Prevention. *2007 Behavioral Risk Factor Surveillance Survey*.

U.S. Department of Health and Human Services. Centers for Disease Control and Prevention. *Summary Health Statistics for U.S. Adults: National Health Interview Survey, 2007*. Vital and Health Statistics. Series 10, Number 240 (May 2009). Tables 21 and 23.

U.S. Department of Health and Human Services. Centers for Disease Control and Prevention. *Traumatic Brain Injury in Prisons and Jails: An Unrecognized Problem*. Undated. Accessed at http://www.cdc.gov/ncipc/tbi/FactSheets/Prisoner_TBI_Prof.pdf.

U.S. Department of Health and Human Services. Centers for Disease Control and Prevention. Nation Center for Injury Prevention and Control. *Traumatic Brain Injury in the United States: Emergency Department Visits, Hospitalizations, and Deaths*. Atlanta (GA): 2004.

U.S. Department of Health and Human Services. Centers for Medicare & Medicaid Services. *2008 Nursing Home Data Compendium*.

U.S. Department of Health and Human Services. Centers for Medicare & Medicaid Services. *Minimum Data Set Active Resident Report*. Accessed at http://www.cms.hhs.gov/MDSPubQIandResRep/04_activeresreport.asp#TopOfPage.

U.S. Department of Health and Human Services. Centers for Medicare & Medicaid Services, *MSIS State Summary Datamart*. Accessed at <http://msis.cms.hhs.gov/>.

U.S. Department of Labor. Bureau of Labor Statistics. *Labor Force Statistics from the Current Population Survey*. Table 1. Employment status of the civilian noninstitutional population by sex, age, and disability status, not seasonally adjusted. Accessed at <http://www.bls.gov/cps/cpsdisability.htm>.

U.S. Department of Labor. (May 2007). Bureau of Labor Statistics. Occupational Employment Statistics.

U.S. Department of Veterans Affairs. (February 29, 2008). *OIF/OEF Table*.

U.S. Substance Abuse and Mental Health Services Administration. (August 20, 2007). *2006 CMHS Uniform Reporting System (URS) Tables*.

Virginia Association of Community Services Board Inc. (August 21, 2007). *Letter to Chairman of Virginia Health, Welfare and Institutions Committee*.

Voices for Virginia's Children. *2009 Legislative Agenda*.

Wagner DL. (September 21, 2007). "Paid Work and Care Work: Employed Caregivers in the U.S." Towson University, Towson, Maryland. Presented at *Informal Care of the Frail Elderly: Policy and Practices to Support Family Caregivers*, National Health Policy Forum.

Appendix A. Additional Tables and Charts

Table A.1 FFY 2007 Medicaid LTC Expenditures, Per Capita Expenditures, and Rank: VA Compared to Border States and the U.S.

State	Expenditure Type																	
	Nursing Home			HCBS-Waiver			ICF-MR			Home Health			Personal Care			Total LTC		
	Total (\$m)	Per Cap	State Rank	Total (\$m)	Per Cap	State Rank	Total (\$m)	Per Cap	State Rank	Total (\$m)	Per Cap	State Rank	Total (\$m)	Per Cap	State Rank	Total (\$m)	Per Cap	State Rank
VA	\$720	\$93	43	\$631	\$82	31	\$251	\$33	25	\$5	\$1	47	n/a	n/a	49	\$1,607	\$208	46
KY	\$759	\$179	20	\$282	\$67	41	\$150	\$35	22	\$111	\$26	5	n/a	n/a	44	\$1,303	\$307	28
MD	\$955	\$170	24	\$619	\$110	24	\$60	\$11	39	\$57	\$10	17	\$32	\$6	26	\$1,724	\$307	29
NC	\$1,126	\$124	36	\$725	\$80	33	\$469	\$52	13	\$126	\$14	10	\$449	\$50	8	\$2,895	\$320	25
TN	\$1,183	\$192	13	\$605	\$98	26	\$234	\$38	19	\$0	\$0	51	n/a	n/a	48	\$2,021	\$328	23
WV	\$421	\$232	10	\$269	\$148	12	\$58	\$32	29	\$28	\$15	7	\$42	\$23	19	\$816	\$451	11
U.S.	\$46,980	\$156	n/a	\$27,455	\$91	n/a	\$12,012	\$40	n/a	\$3,966	\$13	n/a	\$10,396	\$34	n/a	\$101,262	\$336	n/a

Source: Thomson Reuters analysis of CMS-64.

Note: Per capita is defined as expenditures per state (or national) resident.

Table A.2 LTC and Related Workforce in Virginia, Neighboring States, and the U.S.

Occupation	KY	MD	NC	TN	VA	WV	U.S.
Geriatrician - number	68	233	188	88	165	41	7,590
# per 100,000 65+	12.5	35.2	17.0	11.1	18.2	14.6	20.1
Geriatric Psychiatrist - number	13	50	38	35	42	9	1,657
# per 100,000 65+	5.5	7.6	3.4	4.4	4.6	3.2	4.4
Psychiatrist - number	250	*	370	280	550	140	21,790
# per 100,000	5.9	n/a	4.1	4.5	7.1	7.7	7.2
Psychologist - number	920	1,990	2,260	1,620	2,200	400	95,120
# per 100,000	21.7	35.4	24.9	26.3	28.5	22.1	31.5
Registered nurse - number	39,120	48,840	80,090	54,960	57,740	16,970	2,468,340
# per 100,000	922.3	869.3	883.9	892.7	748.7	936.5	818.4
LPN/LVN	10,930	10,380	16,250	23,080	19,270	6,300	719,240
# per 100,000	257.7	184.8	179.3	374.9	249.9	347.7	238.5
Home health aide - number	3,710	11,280	73,770	10,720	12,250	5,130	834,580
# per 100,000 65+	679.5	1,705.7	6,687.9	1,356.0	1,352.3	1,827.9	2,205.5
Nursing aide - number	24,220	28,180	21,610	30,790	31,950	8,940	1,390,260
# per 100,000 65+	4,435.8	4,261.3	1,959.1	3,894.7	3,527.1	3,185.4	3,674.0
Personal and home care aide - number	3,730	4,570	17,170	8,900	9,100	4,770	595,350
# per 100,000 65+	683.1	691.1	1,556.6	1,125.8	1,004.6	1,699.6	1,573.3

*Estimates not released

Table A.3 Virginia State Agencies with a Major Role in Providing or Delivering Long-Term Care Services by Target Group

STATE AGENCY AND ROLE	TARGET GROUP				
	Older Adults	Adults with Severe Mental Illness	People with Intellectual Disabilities/Developmental Disabilities	People with Physical Disabilities (including people with brain injury & spinal cord injury)	Children with Disabilities
Department of Medical Assistance Services					
Finances services	X	X	X	X	X
Arranges screening for the DD waiver through local child development clinics			X		X
Conducts level of care assessment for Tech and DD waivers			X	X	X
Enrolls all waiver providers	X	X	X	X	X
Conducts level of care reviews for all HCBS waivers	X	X	X	X	X
Conducts Quality Management Review for all HCBS waivers, Medicaid-funded institutions and State Plan Services	X		X	X	X
Coordinates all out-of-state Medicaid placements	X	X	X	X	X
Department of Mental Health, Mental Retardation and Substance Abuse Services					
Finances and provides services through contracts with 40 local Community Services Boards	X	X	X	X (if person also has mental health needs or is intellectually or developmentally disabled)	X
Licenses over 25 facilities, residential settings, and services	X	X	X	X	X
Conducts screening for the ID waiver and Day Support waiver			X		X
Virginia Department for the Aging					
25 local Area Agencies on Aging	X			(transit provider)	
Participation in transition from State Psychiatric Hospitals		X			
Department of Rehabilitative Services					
Provides employment and rehabilitative services and training	X	X	X	X	N/A
Conducts disability determination for Social Security claims	X	X	X	X	N/A
Department of Social Services					
Through 120 local departments of social services:					Limited role, provides some home-based supports to children on waiver lists
Determines financial eligibility for Medicaid, Auxiliary Grant, and other programs	X	X	X	X	

Source: Stakeholder interviews, Virginia Board for People with Disabilities 2008 Biennial Assessment, DMAS, and state agency background reports.

Table A.3, Continued

STATE AGENCY AND ROLE	TARGET GROUP				
	Older Adults	Adults with Severe Mental Illness	People with Intellectual Disabilities/Developmental Disabilities	People with Physical Disabilities (including people with brain injury & spinal cord injury)	Children with Disabilities
Department of Social Services, cont.					
Conducts initial level of care assessment for nursing home and some waiver services; Conducts level of care assessments for assisted living/adult foster care	X	X		X	
Licenses assisted living facilities and adult day care centers, and approves adult foster care homes	X	X		X	
Provides and funds adult home-based LTC services and Auxiliary Grant	X	X		X	
Provides adult protective services and child protective services	X	X	X	X	X
Virginia Department of Health					
Through 35 local health districts:					
nursing home and some waiver services	X			X	X
<u>Through Central office:</u> Licenses and inspects all Medicaid and Medicare-certified nursing home facilities, home health agencies and hospice providers	X			X	X
Virginia Office for Protection and Advocacy					
Protects rights of people with disabilities through legal representation, training, and investigation	X	X	X	X	X
Office of the Comprehensive Services Act					
Pools funding streams to finance services in localities for high-risk youth (mainly with behavioral and/or emotional problems)					X
Governor's Office – Director of Community Integration for People with Disabilities, Implementation Team and Oversight Advisory Board					
Develops and annually updates a cross-disability community integration strategic plan and reports progress to Governor; promotes community integration through numerous means	X	X	X	X	X
Virginia Board for People with Disabilities					
Produces biennial assessment	X	X (though doesn't address specific needs of this group)	X	X	X
Developmental Disabilities Planning Council			X		

Figure A.1 Timeline of Key Events in Supporting the Provision of Community-Based Long-Term Care Services in Virginia

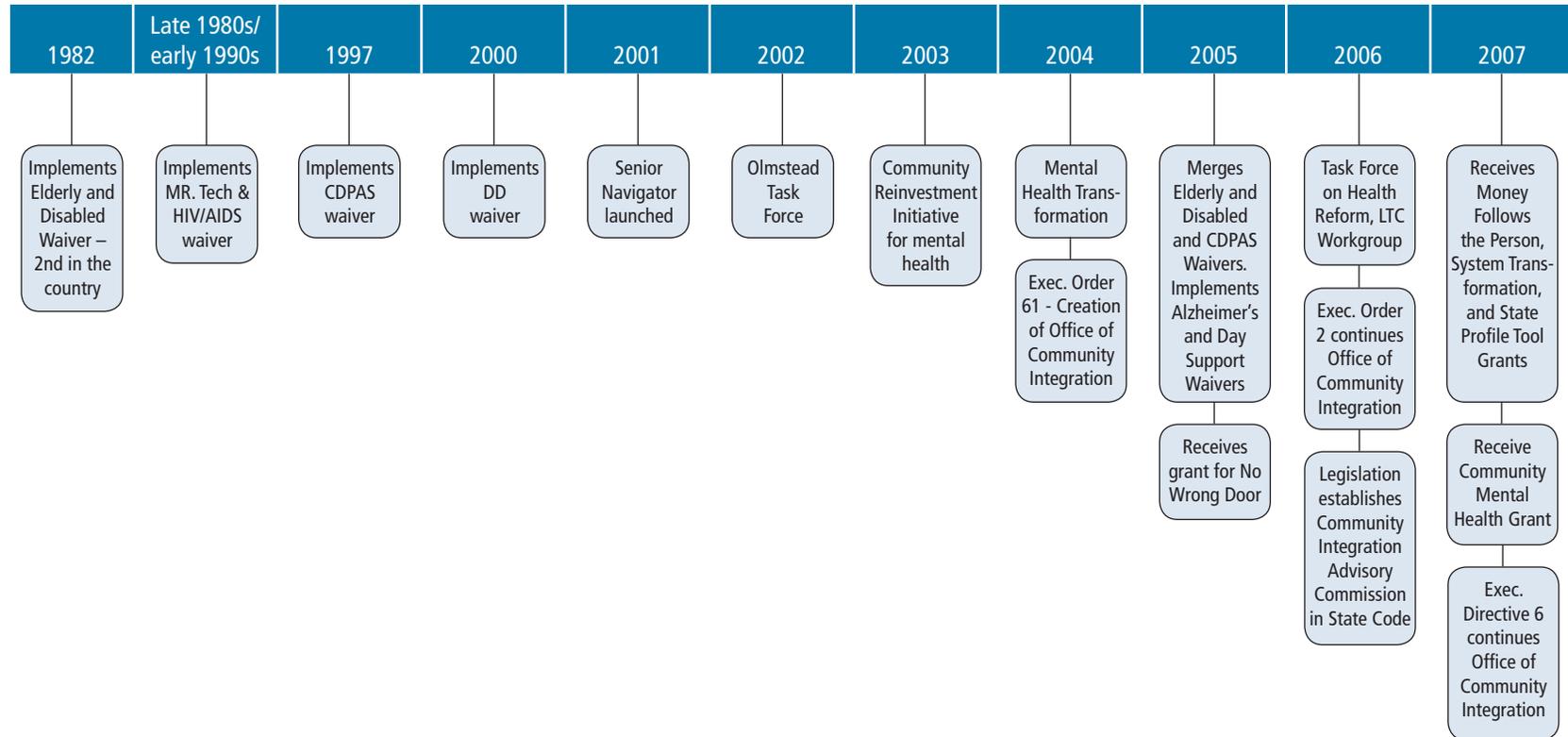
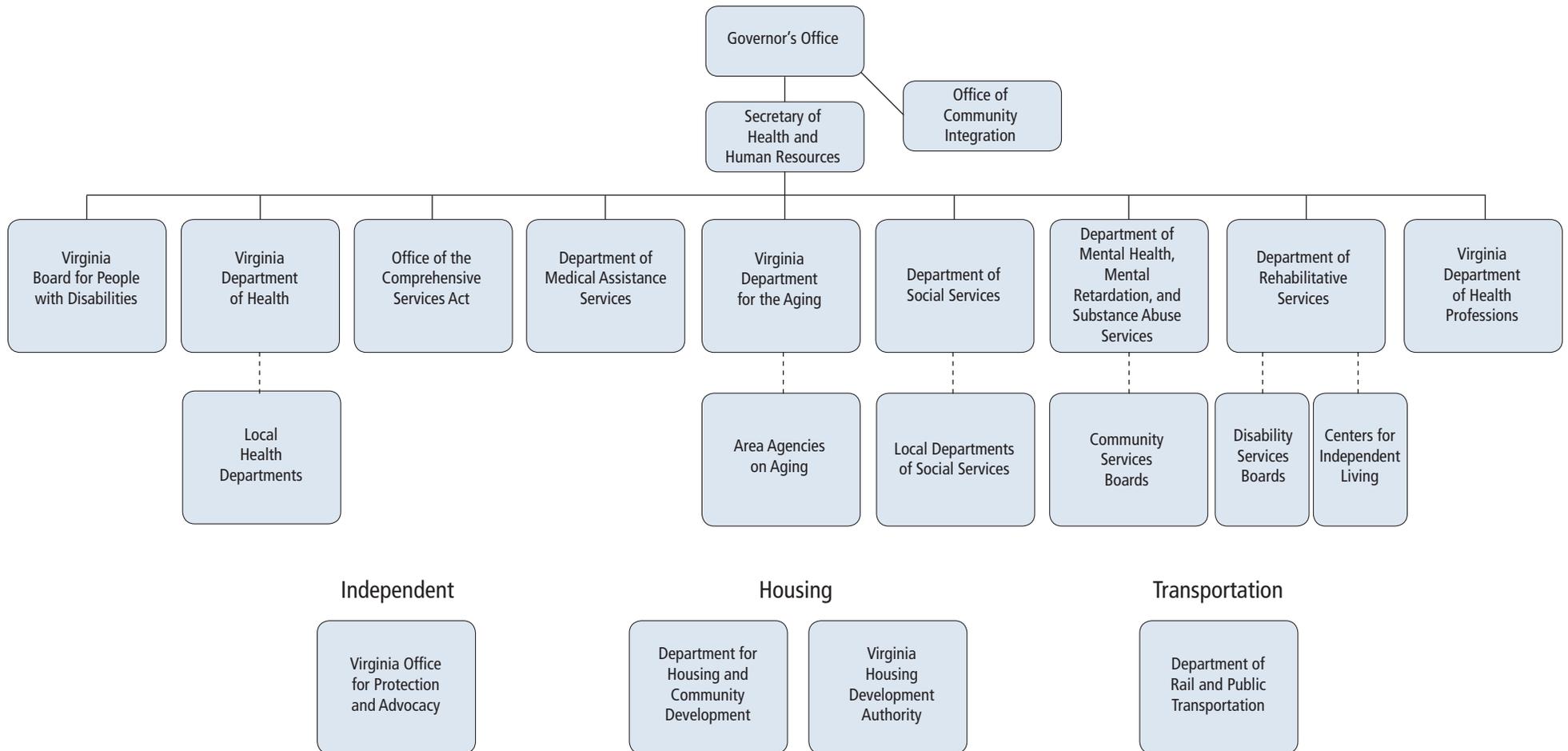


Figure A.2 Virginia State Agencies and Local Partners with Key Roles in the LTC System



Appendix B. Stakeholders Interviewed for the Virginia State Profile Tool

State Profile Tool Constituent Listing		
Last Name	First Name	Representing
AGENCIES WITHIN SECRETARIAT OF HEALTH AND HUMAN RESOURCES AND GOVERNOR'S OFFICE		
Tavener	Marilyn	Secretary of Health and Human Resources
Finnerty	Patrick	Department of Medical Assistance Services
Jones	Cindi	Department of Medical Assistance Services
Smith	Terry	Department of Medical Assistance Services
Lawson	Karen	Department of Medical Assistance Services
Ford	Steve	Department of Medical Assistance Services
Gore	Suzanne	Department of Medical Assistance Services
Tetrick	Frank	Department of Mental Health, Mental Retardation and Substance Abuse Services
Martinez, Jr.	James	Department of Mental Health, Mental Retardation and Substance Abuse Services
Price	Lee	Department of Mental Health, Mental Retardation and Substance Abuse Services
Scherger	Priscilla	Department of Mental Health, Mental Retardation and Substance Abuse Services
Stokes	Teja	Department of Mental Health, Mental Retardation and Substance Abuse Services
Rothrock	James	Department of Rehabilitative Services
Nablo	Linda	Virginia Department for the Aging
Burcham	Debbie	Virginia Department for the Aging
Steinhauser	Tom	Virginia Department of Social Services
Lawyer	Heidi	Virginia Board for People with Disabilities
Driscoll	Tom	Virginia Board for People with Disabilities
Stanley	Julie	Office of Community Integration for Persons with Disabilities
Dix	Heidi	Governor's Office
Ratke	Ray	Governor's Office
Harms	Steve	Governor's Office
VIRGINIA GENERAL ASSEMBLY		
Hamilton	Phillip	House of Delegates
Howell	Janet	State Senator
OTHER		
Cole	Mary	Virginia Association of Community Services Boards
Webster	Carol	Virginia Association of Community Services Boards
Lynch	Dean	Virginia Association of Counties
Fidura	Jennifer	Virginia Network of Private Providers

State Profile Tool Constituent Listing		
Last Name	First Name	Representing
Levin	Sandee	Virginia Association of Non-Profit Homes for the Aging
Carsons	Dana	Virginia Association of Non-Profit Homes for the Aging
Bailey	Mary Lynne	Virginia Health Care Association
Harvey	Hobart	Virginia Health Care Association
Jackson	Rick	Hampton-Newport News Community Services Board
McCormick	Amy	Administrator, Chase City Nursing & Rehab
Bailey	Christopher	Virginia Health Care and Hospital Assn
Bush	Madge	AARP – Virginia Chapter
Michalski-Karney	Karen	Centers for Independent Living
Cullum	Howard	ARC of Virginia
Trosclar	Jamie	ARC of Virginia
PARTICIPANTS OF TRANSFORMATION LEADERSHIP TEAM MEETING ON 5/12/08		
PARTICIPANTS OF SYSTEMS TRANSFORMATION GRANT MEETING ON 5/13/08		
Roeper	Katie	Senior Navigator
Hollowell	Maureen	Waiver Mentor Network
Lukhard	Bill	AARP
Toscano	John	Commonwealth Autism Service
Wooten	Alan	Fairfax County Community Services Board
Edes	Tom	U.S. Veterans Administration
Day	Kristin	U.S. Veterans Administration
Pace Maxwell	Marilyn	Mountain Empire Older Citizens
Miller	Judy	Mountain Empire Older Citizens
Dillon	Julia	Mountain Empire Older Citizens
Lawson	Tony	Mountain Empire Older Citizens
Davis	Linda	U.S. Dept of Defense
Owens	Chris	Mental Health America
Dunn Stewart	Mary	Voices for Virginia's Children
May	Cathy	Voices for Virginia's Children
Yarbrough	Dana	Parent to Parent of Virginia
Hardy-Murrell	Vicki	Medical Home Plus
Benner	Ann	VOCAL Network Virginia
Signer	Mira	NAMI (Virginia Chapter)
Fisher	Stacie	Office of Comprehensive Services Act

State Profile Tool Constituent Listing		
Last Name	First Name	Representing
SITE VISITS		
Gleeson	Thomas	RAFT Program Director
Trumball	Lyanne	Fairfax-Falls Church Community Services Board
James	Jayne	Fairfax-Falls Church Community Services Board
Mercer	Nancy	ARC of Northern Virginia
Koshatka	Cynthia	Fairfax-Falls Church Community Services Board
Nelson	Davene	Fairfax-Falls Church Community Services Board (and adult mental health services case managers)
Staff for Mark Diorio		Northern Virginia Training Center
Mosher	Allyson	Stevenson Place
Gilbertson	Patty	Hampton-Newport News Community Services Board
DeHaven	Cheryl	Hampton-Newport News Community Services Board
Connors	Craig	Riverside PACE
Lazier	Jay	Virginia Beach Community Services Board
Laidlaw	Tom	Virginia Beach Community Services Board
Traverse-Charlton	Paula	Hope House Foundation
Murray	Dave	Peninsula Agency on Aging
Massey	Bill	Peninsula Agency on Aging
Brandau	Sharon	Peninsula Agency on Aging
Shrewsbury, M.D.	Robert	Southeastern Virginia Training Center
Davis	Sherwin	Southeastern Virginia Training Center
Hinzman	Gwen	Lake Country Area Agency on Aging
Gage	Linda	Lake Country Area Agency on Aging
Herrick	Steven	Executive Director, Piedmont Geriatric Hospital
Willis	Joyce	Southside Community Services Board
Walker	Wanda	Southside Community Services Board
Edwards	Joseph	Executive Director, Southside Community Services Board

Also, we gratefully acknowledge the following additional individuals for their guidance and assistance with obtaining information for this report: Karen Lawson, Scott Cannady, Molly Huffstetler, Jeffrey Nelson, Rhonda Newsome, Jason Rachel, William Lessard, Debra Pegram, Mendy Meeks, Melissa Fritzman, Helen Leonard and Linda Struck from the Department of Medical Assistance Services; Kristin Burhop of the Governor's Office; Joel Rothenberg, Paul Gilding, Russell Payne, John Jackson, Leslie Anderson, Deborah Stephen-Mapp, Cherie Stierer and Susan Elmore from the Department of Mental Health, Mental Retardation and Substance Abuse Services; Linda Richmond from the Virginia Board for People with Disabilities; Leonard Eshmont, Charlene Cole, William Peterson and Kathy Miller from the Virginia Department for the Aging; Connie Kane, Erik Bodin, Carrie Eddy and Kathy Wibberly from the Virginia Department of Health; Bill Rhodenhiser and Patricia Goodall from the Department of Rehabilitative Services; Gail Nardi from the Department of Social Services; Paul Raskopf, Brian Logwood, Gene Adkins and Jerry Mathews from Virginia Department of Education; Neil Sherman from the Department of Rail and Public Transportation; Patti Smith from the Virginia Department of Veterans Services; Chuck Savage from the Office of the Comprehensive Services Act; and Kim Tarantino from SeniorNavigator. We apologize for any inadvertent omissions from this list.

Appendix C. Sites Visited and Consumer Focus Groups

Name	Type of Site/Provider
<u>FAIRFAX COUNTY</u>	
Wilburdale Group Home	Group home for people with intellectual disabilities
Twinbrook Group Home	Group home for people with intellectual disabilities
Stevenson Place	Assisted living facility providing mental health, health care, and long-term support services to adults with severe and persistent mental illness
Northern Virginia Training Center	Large State ICF-MR
Central Fairfax Services	Day support/employment program for people with developmental disabilities and related disabilities
<u>TIDEWATER</u>	
West Neck Residence	24-bed ICF-MR
Kentucky Avenue	5-bed ICF-MR
Sugar Plum Bakery	Non-profit business certified as an employment program for people with disabilities
Hope House Foundation residences	Non-profit organization that provides individualized supported living services for and with people with developmental disabilities
Riverside PACE	Program for All-inclusive Care for the Elderly site
Southeastern Virginia Training Center	Large State ICF-MR
<u>BURKEVILLE</u>	
Piedmont Geriatric Hospital	State mental health facility for people age 65 and older
<u>SOUTHERN VIRGINIA</u>	
STEPS, Inc.	An integrated manufacturing and job training organization for people with and without disabilities
Marc Manor	Semi-independent living for people with intellectual disabilities operated by Southside Community Services Board
Mecklenburg Co. Community Support Services Center	Community support services day program for people with severe and persistent mental illness
Hazelwood House Adult Day Care	Adult day care
Mecklenburg Senior Citizens Center	Senior center

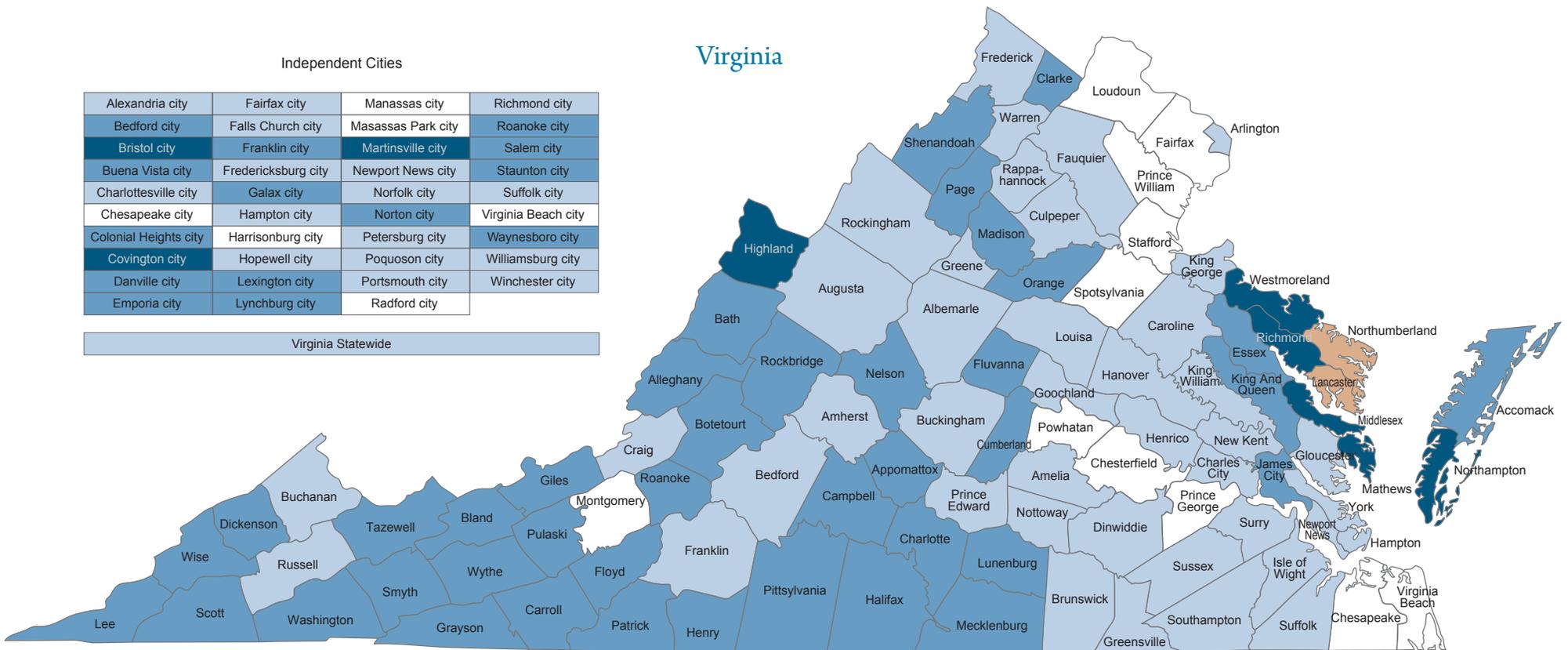
Thomson Reuters attempted to conduct a site visit to the Southwestern part of Virginia, but had to cancel the visit due to scheduling difficulties.

CONSUMER FOCUS GROUPS AND HOME VISITS

- Two focus groups with individuals with severe and persistent mental illness (Southern Virginia and Hampton-Newport News)
- Three focus groups with older adults using long-term care services (Southern Virginia and Newport News)
- One focus group with individuals with intellectual disabilities and related disabilities and their families (Northern Virginia)
- Home visits to three clients in Southern Virginia using Medicaid Personal Care or Area Agency on Aging home health

Appendix D. Maps

Exhibit 1. People Age 65 and Older as Share of Population by Locality: 2007



Source: University of Virginia Weldon Cooper Center for Public Affairs (2007).

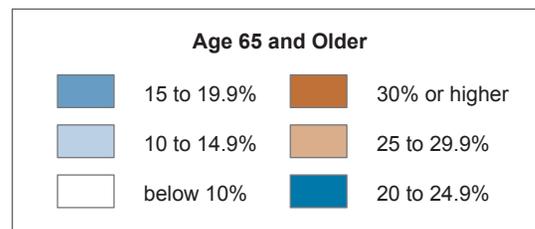
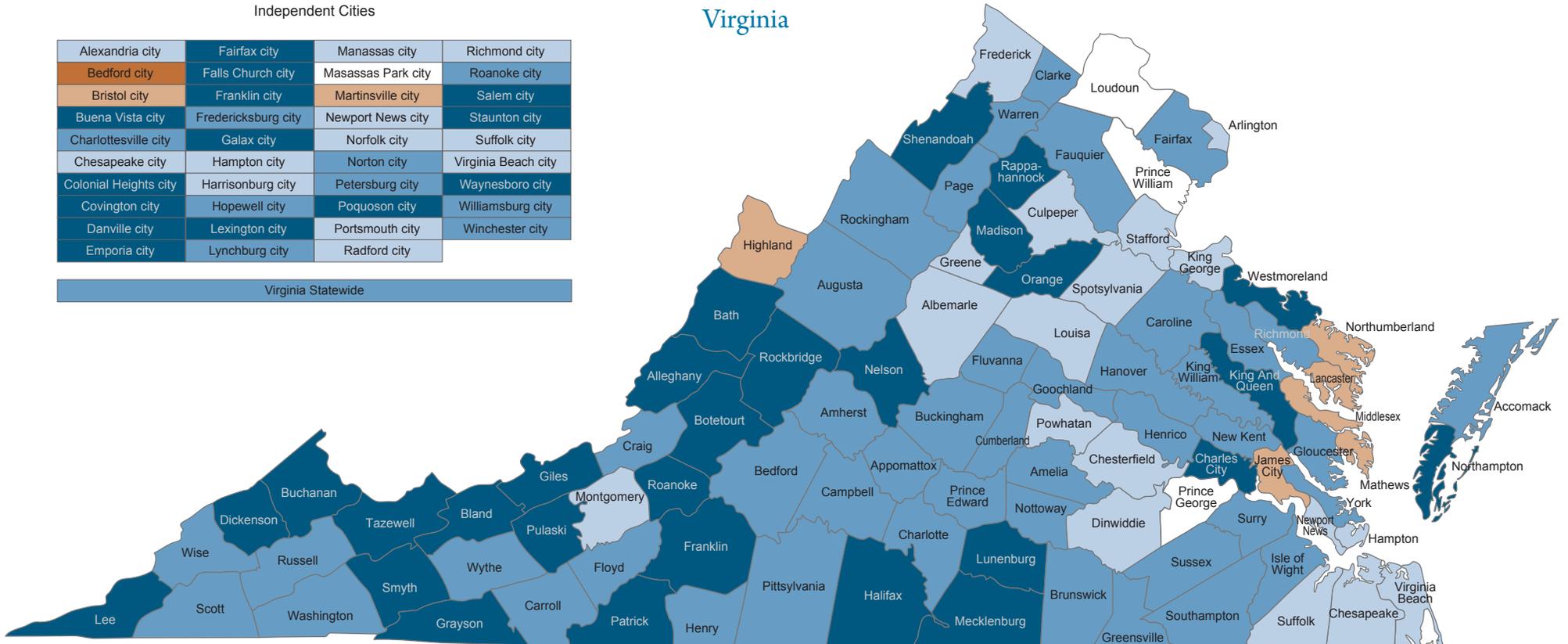


Exhibit 2. People Age 65 and Older as Share of Population by Locality: Projections for Year 2020

Independent Cities

Alexandria city	Fairfax city	Manassas city	Richmond city
Bedford city	Falls Church city	Masassas Park city	Roanoke city
Bristol city	Franklin city	Martinsville city	Salem city
Buena Vista city	Fredericksburg city	Newport News city	Staunton city
Charlottesville city	Galax city	Norfolk city	Suffolk city
Chesapeake city	Hampton city	Norton city	Virginia Beach city
Colonial Heights city	Harrisonburg city	Petersburg city	Waynesboro city
Covington city	Hopewell city	Poquoson city	Williamsburg city
Danville city	Lexington city	Portsmouth city	Winchester city
Emporia city	Lynchburg city	Radford city	
Virginia Statewide			



Source: Virginia Workforce Connections (revised 2007).

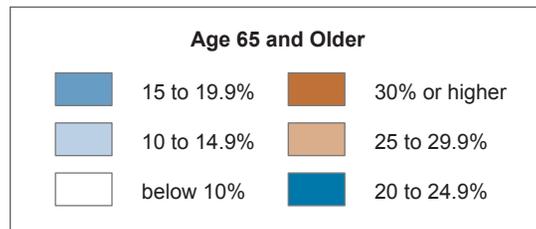


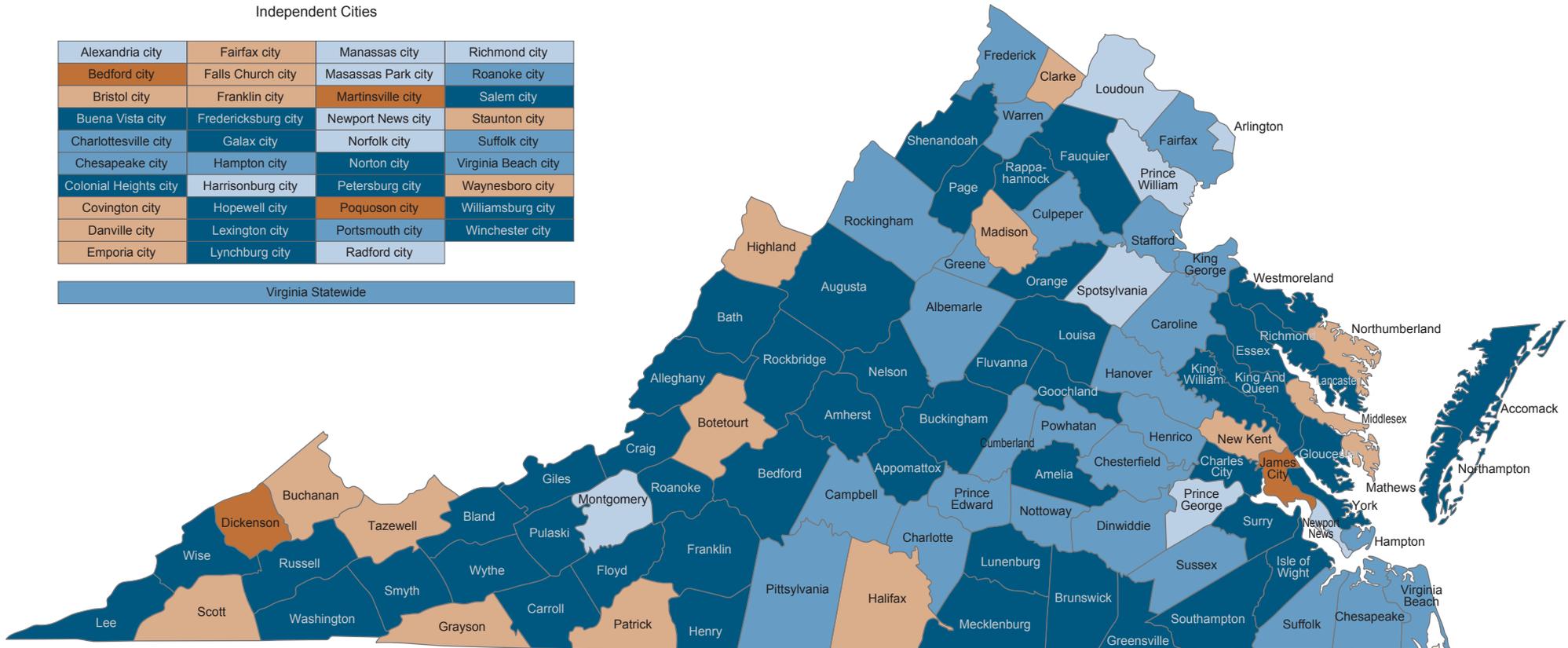
Exhibit 3. People Age 65 and Older as Share of Population by Locality: Projections for Year 2030

Virginia

Independent Cities

Alexandria city	Fairfax city	Manassas city	Richmond city
Bedford city	Falls Church city	Masassas Park city	Roanoke city
Bristol city	Franklin city	Martinsville city	Salem city
Buena Vista city	Fredericksburg city	Newport News city	Staunton city
Charlottesville city	Galax city	Norfolk city	Suffolk city
Chesapeake city	Hampton city	Norton city	Virginia Beach city
Colonial Heights city	Harrisonburg city	Petersburg city	Waynesboro city
Covington city	Hopewell city	Poquoson city	Williamsburg city
Danville city	Lexington city	Portsmouth city	Winchester city
Emporia city	Lynchburg city	Radford city	

Virginia Statewide



Source: Virginia Workforce Connections (revised 2007).

