2003 REPORT OF THE JOINT COMMISSION ON HEALTH CARE



REVIEW OF THE PERSONAL MAINTENANCE ALLOWANCE WITHIN THE MEDICAID ELDERLY AND DISABLED WAIVER

(Item 11, 2002-2004 Appropriations Act)

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Preface

Item 11 of the 2002-2004 Appropriations Act requires a Joint Commission on Health Care (JCHC) evaluation of the personal maintenance allowance (PMA) within the Medicaid Elderly and Disabled Waiver.

When the Medicaid program was established in 1965, it was expected to provide health and nursing home care for low-income Americans; it is unlikely that the scope of Medicaid's current role in long-term care (LTC) was anticipated.

"Today, more than one-third of all Medicaid spending pays for long-term care (Kaiser 1997)....It is the largest source of financing for nursing home care, constituting 48% of payments (Levit et al. 1997). Medicaid is also a significant, though less dominant, source of funding for home care, paying for 14% of such services in 1996 (Levit et al. 1997)" from AARP *Medicaid Financial Eligibility for Older People*.

To qualify for Medicaid payment for LTC services a person must:

- Be aged, blind or disabled
- Comply with income and resource limitations
- Meet level of functioning criteria.

Special income and resource requirements are applied in determining eligibility for LTC services. Thus, persons with incomes above the levels usually allowed for Medicaid may be eligible due to the cost of care. In Virginia, the income level is set at 300% of SSI ($$545 \times 3 = $1,635$) and "countable" resources are in general \$2,000 for an individual and \$3,000 for a couple.

Medicaid waivers must be designed to allow individuals who would otherwise qualify for institutional placement (in a NF, ICF/MR or hospital) to remain in the community. The personal maintenance allowance is the amount the waiver recipient is allowed to deduct from income to account for the basic expenses related to living in the community. Additional deductions are allowed if the waiver recipient has un-reimbursed medical

or remedial care expenses or a spouse or dependent children are living in the home.

An AARP survey of the PMA allowed in the elder care waivers in 50 states in 1998 showed:

- PMAs varied from \$242 in North Carolina to \$1,482 in 14 states (North Carolina increased its PMA to 100% SSI in 1999)
- the average PMA was \$881 (178% SSI) and median PMA was \$671 (136% SSI)
- 31 states allowed higher PMAs than Virginia.

Virginia has 6 Medicaid home- and community-based services (HCBS) waivers:

- Acquired Immunodeficiency Syndrome (AIDS); 417 individuals
- Elderly and Disabled (E&D); 9,567 individuals
- Consumer-Directed Personal Attendant Services (CD-PAS); 151 individuals
- Individual and Family Developmental Disabilities Support (DD); 323 individuals
- Mental Retardation (MR); 5,056 individuals
- Technology Assistance; 280 individuals

While income eligibility for each of the waivers is set at 300% of SSI, PMAs are set at 100% SSI except for the AIDS waiver.

Advocates indicate that the PMA is not high enough for individuals who receive the Medicaid waivers (other than AIDS waiver). Three Centers for Independent Living provided cost of living estimates for one disabled person:

- \$1,914 per month in Northern Virginia
- \$1,247 per month in Norfolk
- \$1,154 per month in far Southwest Virginia.

DMAS cost estimates to the Centers for Medicare and Medicaid Services showed waiver is less costly than NF care (FY 2001):

E&D Waiver - \$14,856/individual; \$141 million NFs - \$22,749/individual; \$596 million

Actions Taken by JCHC

A number of policy options were offered by the Joint Commission on Health Care regarding the issues discussed in this report. These policy options are listed on pages 21-22. A summary of public comments received regarding the proposed Options are included in Appendix B.

JCHC took the following action with regard to the study Options:

• Introduce budget amendments to increase the allowance from 100 percent (\$552 per month) to 150 percent (\$828 per month) of Supplemental Security Income.

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TABLE OF CONTENTS

I.	AUTHORITY FOR THE STUDY ORGANIZATION OF REPORT	1
II.	BACKGROUND	3
III.	REVIEW OF THE PERSONAL MAINTENANCE ALLOWANCE WITHIN THE VIRGINIA MEDICAID E&D WAIVER	7
IV.	POLICY OPTIONS	21
V.	APPENDICES	
	Appendix A: Item 11 of the 2002-2004 Appropriations Act	
	Appendix B: Summary of Public Comments	

I. Authority for the Study/Organization of Report

Item 11 of the 2002-2004 Appropriations Act requires an evaluation of the personal maintenance allowance within the Medicaid Elderly and Disabled (E&D) waiver. Item 11 reads:

The Joint Commission on Health Care, with the cooperation of the Department of Medical Assistance Services, shall evaluate the personal maintenance allowance of the Medicaid Elderly and Disabled Waiver Program. Such evaluation shall consider the adequacy of such allowance, the effect of the allowance on the selection or continuation of community-based services as compared to institutional services, whether individuals unnecessarily receive institutional care because of the allowance, whether adjustments in the allowance are warranted, and the estimated costs of any changes.

A copy of Item 11 is included in Appendix A.

Organization of Report

This report is presented in four major sections. This section discussed the authority for this study of the personal maintenance allowance provided for within Virginia's Medicaid E&D waiver. Section II provides an overview of the federal Medicaid program and of Virginia's Medicaid waivers. The adequacy of the personal maintenance allowance is considered in Section III. Section IV provides a series of policy options the Joint Commission on Health Care may wish to consider in addressing the issues raised in this study.

II. Background

Medicaid is the Primary Payer of Long-Term Care Services in the United States

When the Medicaid program was established in 1965, it was expected to provide health and nursing home care for low-income Americans. It is unlikely that the scope of Medicaid's current role in funding long-term care was anticipated. An AARP study, *Medicaid Financial Eligibility for Older People*, published in April 2000, described how Medicaid's role has changed in the last 37 years:

The original purpose of the Medicaid program was to provide health care and nursing home services to the poor. Developed in 1965, before the enormous expansion and increased longevity of our nation's aging population, few could have anticipated just how large a role Medicaid would come to play in providing long-term care. Today, more than one-third of all Medicaid spending pays for long-term care (Kaiser 1997), making it the primary source of public financing for long-term care services in the U.S. It is the largest source of financing for nursing home care, constituting 48 percent of payments (Levit et al., 1997). Medicaid also is a significant, though less dominant, source of funding for home care, paying for 14 percent of such services in 1996 (Levit et al., 1997).

When the Medicaid program was developed, there were few, if any, alternatives to institutions for people needing long-term care. Over the past 20 years, however, there has been a growing movement to develop home and community-based services (HCBS). People with disabilities [as well as many elderly persons] have voiced an overwhelming preference for receiving services outside of an institution, yet public programs, such as Medicaid, have been somewhat slow to respond. It is important to note that Medicaid law *requires* states to offer nursing home services to the eligible population age 21 and older as a condition of Medicaid participation. The provision of HCBS is optional. Moreover, states that elect to offer HCBS waivers must demonstrate that these services do not increase Medicaid expenditures. While people who meet the

functional and financial eligibility criteria are entitled to receive Medicaid nursing home services, waiver services are subject to enrollment caps. As a result, many waiver programs have waiting lists. In 1998, 75 percent of total Medicaid spending on long-term care paid for services received in institutions, while non-institutional care accounted for 25 percent (Burwell 1999)....Today, the effort to reduce or eliminate Medicaid's institutional bias is a key issue on the policy agenda of many consumers, advocates and policymakers.

Medicaid Provides Funding for Long-Term Care for Individuals who Meet Categorical, Income/Resource, and Functioning Requirements

The Department of Medical Assistance Services (DMAS) Statistical Report for FY 2001 describes basic Medicaid eligibility in the following manner:

Medicaid is a means-tested program. Applicants' income and other resources must be within program financial standards....The [Medicaid] Program does not cover everyone who is poor, but rather is available only to members of families with children, pregnant women, and to persons who are aged, blind, or disabled. Persons not falling into these categories – such as single adults and childless couples – cannot qualify for Medicaid, no matter how low their income.

To qualify for Medicaid payment for <u>long-term care services</u>, an individual must be aged, blind, or disabled; comply with income and resource limitations; and meet level of functioning criteria. (It should be noted that institutional care for the mentally ill who are between the ages of 21 and 65 is the responsibility of each state. Consequently, Medicaid funding is not available to provide institutional care for mentally ill individuals who do not qualify as aged.)

Virginia Medicaid Income and Resource Rules. DMAS indicates that "special [income and resource] eligibility rules apply to persons receiving care" provided in nursing facilities, in intermediate care facilities for the mentally retarded (ICF/MRs), and in certain "alternative community care programs for the aged and disabled. Many of these persons may have incomes well above the poverty level but qualify for Medicaid because of the very high cost of their care." In Virginia, the income level is set at 300 percent of the Supplemental Security Income (SSI) benefit rate. SSI is the

federal program, administered by the Social Security Administration, which provides monthly benefits to qualifying individuals who are aged (defined as 65 years of age or older), blind, or disabled. The basic SSI benefit rate was increased to \$545 as of January 1, 2002. Thus, the current income limit is 300 percent of the SSI benefit rate of \$545 or \$1,635 for an individual to qualify for Medicaid-funded nursing facility or community-based care.

In terms of eligibility rules for allowable resources, Virginia is one of 12 states which chose to establish more restrictive resource criteria as provided by Section 209(b) of P.L. 92-603 (currently Section 1902(f) of the *Social Security Act*). As noted in the DMAS Statistical Report for FY 2001:

Resource methodologies are ways in which various types of real and personal property are evaluated to determine whether an applicant owns "countable" resources equal to the resource standard....States may choose to evaluate resources in the same way as the federal programs or differently....

Section 209(b) of P.L. 92-603...[gave] states the option of imposing more restrictive eligibility criteria on the aged, blind and disabled than the criteria imposed by the Supplemental Security Income (SSI) program....

The 209(b) option has been used in Virginia to contain Medicaid expenditures in selected areas of eligibility criteria when changes in the criteria for SSI would have caused large expenditures for Medicaid. The more restrictive criteria...discussed most often [as] being the limit on the amount of exempted property contiguous to the applicant's home....Virginia Medicaid exempts the home, the lot on which it sits regardless of value, and up to \$5,000 in additional contiguous property.

A detailed discussion of Virginia Medicaid's eligibility rules regarding resources is beyond the scope of this study. In general, "countable" resources are limited to \$2,000 for an individual and \$3,000 for a couple.

Virginia Medicaid Functional Criteria for Nursing Home Care. In addition, individuals must meet functional criteria that indicate nursing facility care is appropriate in order to qualify for Medicaid payments for long-term care. A preadmission screening assessment is completed to

determine whether an individual meets the functional criteria. These criteria, as described by DMAS, are shown in Figure 1. Activities of daily living (ADLs) refer to the seven activities of bathing, dressing, toileting, transferring (moving from bed to chair for example), bowel function, bladder function, and eating/feeding. Virginia's requirements for nursing facility admission are generally agreed to be among the most stringent of the 50 states.

Figure 1 Virginia's Nursing Facility Admission Criteria

1. Dependent in 2-4 ADLs, plus semi-dependent or dependent in behavior and orientation, plus semi-dependent in joint motion or semi-dependent in medication administration,

,

AND
Have
Medical
Nursing
Needs

OR

2. Dependent in 5-7 ADLs plus dependent in mobility

OR

3. Dependent in 2-7 ADLs, plus dependent in mobility, plus dependent in behavior and orientation.

Source: Department of Medical Assistance Services.

Equivalent Income, Resource, and Functional Requirements Apply to Eligibility for Medicaid Waivers. Medicaid waivers must be designed to allow individuals who would otherwise qualify for institutional placement (in a nursing facility, ICF/MR, or less commonly a hospital) to remain in the community. For reasons noted previously, the alternative institutional placement cannot be an institution for mental disease. Medicaid Home and Community-Based Services (HCBS) waivers are required by the Centers for Medicare and Medicaid Services(CMS) to be cost-neutral, that is, the waiver cannot be more costly than the alternate institutional placement. In addition, Medicaid waivers cannot pay for the cost of room and board.

III.

Review of the Personal Maintenance Allowance within the Virginia Medicaid E&D Waiver

Item 11 of the 2002-2004 Appropriations Act addresses the adequacy of the personal maintenance allowance within the E&D waiver. The personal maintenance allowance is designed to account for the waiver recipient's expenses related to living in the community. These expenses include such costs as rent or mortgage payments, food, transportation, and so forth. Thus the personal maintenance allowance is very important because it is the amount that the waiver recipient is allowed to deduct from his or her income to account for the basic expenses related to living in the community. The personal maintenance allowance and certain other allowable expenses (generally costs related to a spouse, dependent children, and non-reimbursed medical and remedial expenses) are deducted from the waiver recipient's "post-eligibility" income to determine his/her patient pay share.

Federal Regulations Require States to Determine and Assess Patient Pay Amounts for Waiver Services

Code of Federal Regulations Title 42, Section 435.726 requires states to reduce the payment made for HCBS waivers by whatever amount of "countable" income that remains after the personal maintenance allowance and all allowable deductions have been made. In general, the formula for determining the waiver recipient's patient pay share is:

WAIVER RECIPIENT'S "QUALIFYING" INCOME — (PERSONAL MAINTENANCE ALLOWANCE + DEDUCTION BASED ON MAINTENANCE NEEDS OF A SPOUSE IF LIVING IN THE HOME + DEDUCTION BASED ON MAINTENANCE NEEDS OF DEPENDENT CHILDREN LIVING IN THE HOME + DEDUCTION BASED ON ANY UNREIMBURSED MEDICAL OR REMEDIAL CARE EXPENSES FOR THE WAIVER RECIPIENT) = PATIENT PAY SHARE

It should be noted that a waiver recipient's patient pay share may equal zero.

The amount of the personal maintenance allowance is set by the state but is required by the *Code of Federal Regulations* Title 42 to be "based on a reasonable assessment of need." Further, Title 42 requires the

maintenance needs of a spouse or dependent children living in the home to be considered in calculating allowable deductions.

In Virginia, the personal maintenance allowance for the E&D waiver is 100 percent of the SSI benefit rate for an individual. Thus, while the eligibility income for the E&D waiver is \$1,635 (or 300 percent of the SSI benefit rate), a waiver recipient with no spouse, no dependent children, and no allowable expenses would have a patient pay of any amount of income above \$545 in order to receive waiver services. The following example illustrates how this might work:

Mr. Smith, an elderly individual receives \$845 in Social Security benefits each month and meets the functional criteria for nursing facility admission. Mr. Smith lives alone and has no medical or therapeutic expenses that would not be covered by Medicaid. Mr. Smith requires adult health day care services because he cannot be left at home alone while his children work during the day. Mr. Smith would be allowed to deduct \$545 under the personal maintenance allowance and consequently would have a co-pay of \$300 per month for adult health day care.

The specific calculations to determine the maintenance needs of the spouse are quite complicated. However, in general Virginia Medicaid determines the maintenance needs of the spouse by looking at the spouse's income in comparison to the minimum monthly maintenance needs allowance needs allowance. The minimum monthly maintenance needs allowance is determined using the maintenance needs standard (which will increase on July 1st to \$1,492.50 and is based on 150 percent of the federal poverty level for two) plus an excess shelter expense (which will increase on July 1st to \$447.75 and is determined by state policy). At this time, the maximum amount that may be allowed as a deduction for the monthly maintenance needs allowance for a spouse is \$2,232.

To determine the deduction for the maintenance needs of dependent children, the appropriate medically needy income level (MNIL) is subtracted from any income the children have. (In Virginia, the "appropriate" MNIL is based on the locality in which the waiver recipient lives. Three MNILs have been established with corresponding monthly income limits of \$224.25, \$258.75, or \$336.37 for one child.)

A final deduction is allowed for "incurred expenses for medical or remedial care that are not subject to payment by a third party including – (i) Medicare or other health insurance premiums, deductibles, or coinsurance charges; and (ii) Necessary medical or remedial care recognized under State law but not covered under the State's Medicaid plan, subject to reasonable limits the [State] agency may establish on amounts of these expenses."

AARP Found Substantial Variation in the Personal Maintenance Allowances Provided within the Medicaid Elderly Waiver Established by Each of the 50 States

Within a larger study of Medicaid financing, AARP examined the personal maintenance allowance for the Medicaid waiver that each state had established to serve elderly individuals. States have substantial latitude in setting the amount of the personal maintenance allowance for living expenses although it must be based on a "reasonable assessment of need."

Figure 2 shows the personal maintenance allowance that each state's Medicaid elderly waiver allowed in 1998. As Figure 2 shows, the personal maintenance allowances varied substantially ranging from \$242 in North Carolina to \$1,482 (or 300 percent of SSI) in 14 states. In 1998, 31 states allowed higher personal maintenance allowances within their Medicaid elderly waivers than Virginia allowed.

Virginia Has Six Medicaid Home and Community-Based Services Waivers

Virginia's six Medicaid HCBS waivers are:

- Acquired Immunodeficiency Syndrome (AIDS) Waiver
- Elderly and Disabled (E&D) Waiver
- Consumer-Directed Personal Attendant Services (CD-PAS)
 Waiver
- Individual and Family Developmental Disabilities Support (DD)
 Waiver
- Mental Retardation (MR) Waiver
- Technology Assisted Waiver.

Figure 2
Personal Maintenance Allowances for HCBS-Waivers in the 50 States

General Rule Setting Personal	Amount in	
Maintenance Allowance Limits	1998	States
Variety of state-specific rules	\$ 242	North Carolina
including medically-needy	\$ 283	Illinois
income levels and cost-of living	\$ 350	Maryland
considerations	\$ 392	Nebraska
(15 states)	\$ 405	North Dakota
,	\$ 467	Minnesota
	\$ 491	Montana
	\$ 508	New Hampshire
	\$ 534	Idaho
	\$ 558.33	Rhode Island
	\$ 556.55	New York
	1	California
	\$ 600	Vermont
	\$ 741	Missouri
	\$ 863	Ohio
1000/ (00)	\$ 964	
100% of SSI	\$ 494	Georgia, Indiana, Mississippi, <i>Virginia</i>
100% of SSI + state supplement	\$ 495.70	Oregon
100% of SSI + \$20 disregard	\$ 514	Alabama, Kentucky, South Dakota
100% of SSI + state supplement	\$ 521.40	Pennsylvania
(9 states)		
100% of FPL	\$ 671	Kansas, Massachusetts, Utah, Washington
(5 states)	\$ 772	Hawaii
SSI expense rate plus housing,	\$ 674 \$1,028	Wisconsin
utilities, share of earned income		
(1 state)		
125% of FPL	\$ 839	Maine
(1 state)		
200% of SSI	\$ 988	Tennessee
(1 state)		
200% 300% SSI	\$ 988 \$1,482	Nevada ²
(1 state)		
250% of SSI	\$1,235	Delaware
(1 state)		
257% of SSI	\$1,268	New Mexico
(1 state)		
200% of FPL	\$1,342	Connecticut
(1 state)		
300% of SSI	\$1,482	Alaska, Arizona, Arkansas, Colorado,
(14 states)		Florida, Iowa, Louisiana, Michigan, New
-		Jersey, Oklahoma, South Carolina, Texas,
		West Virginia, Wyoming

¹North Carolina increased its personal maintenance allowance to 100% of FPL January 1, 1999. ²Nevada's personal maintenance allowance was 200% of SSI for elderly recipients and 300% of SSI for disabled recipients.

Source: AARP study, Medicaid Financial Eligibility for Older People, April 2000.

Each of Virginia's six Medicaid HCBS waivers has its <u>income</u> <u>eligibility</u> set at 300 percent of SSI. The personal maintenance allowance for the waivers is set at 100 percent of SSI for all of the waivers except the AIDS waiver. The allowance for the AIDS waiver is 300 percent of SSI.

Figure 3 provides a brief description of each of Virginia's HCBS waivers. Although the E&D waiver is the largest of Virginia's waivers in terms of recipients, it is not the most costly waiver on a per-recipient (\$14,856/person) or total cost basis (\$141 million). The most costly waiver on a per-person basis (\$88,750/person) is the technology assisted waiver which receives \$17.4 million in direct funding and has \$7.5 million in associated "other" costs. "Other" costs incorporate costs that are not related to the waiver services but are covered under Medicaid such as pharmacy, hospital, and medical transportation costs. The MR waiver is the most costly waiver in terms of total costs at \$211.9 million.

Advocates Indicate that the Personal Maintenance Allowance Provided within Virginia's Medicaid E&D Waiver Is Not High Enough to Allow Some Individuals to Remain in the Community

Advocates of increasing Virginia's personal maintenance allowance for individuals submitted a number of examples of individuals who were unable to live in the community because of the inadequacy of the allowance.

Steve, a 45 year old quadriplegic resides in Chesterfield County. After he became disabled in 1986, he continued to live in his own home with his wife and two children. Substantial modifications and renovations, such as ramps, expanded doorways, and a mechanical lift for transferring, were completed on the house to make it safe and fully accessible. After his wife provided most of his personal care for six years, the couple separated. Steve applied for and was found eligible for Medicaid community based care. His personal maintenance allowance was calculated using the formula for married people, which provides a generous allowance for spouses and children. Steve was allowed to keep all of his Social Security Income of about \$1100 to support himself, his wife and children. Two years later the couple divorced. As a single person, his personal

Figure 3
Characteristics of Virginia's Six HCBS Waivers

Type of Waiver	Targeted Recipient Population	Available Waiver Services
AIDS 417 recipients	Individuals with AIDS or AIDS- related condition having associated "medical or functional symptomswhich would require nursing facility or hospital care."	Case management Nutritional supplements Private duty nursing Personal care Respite care
Elderly & Disabled 9,567 recipients	Individuals 65 or older or disabled who meet NF criteria and are at "imminent risk" of placement.	Adult day health care Personal care Respite care
CD-PAS 151 recipients	Same as for E&D BUT must have "no cognitive impairments."	Personal attendant services
Developmentally Disabled 323 recipient slots	"Individuals 6 years of age and older with a condition related to mental retardation but who do not have a diagnosis of mental retardation who have been determined to require the level of care provided in an Intermediate Care Facility for the Mentally Retarded" (Conditions related to MR include "cerebral palsy, epilepsy or autism; or[a]ny other condition, other than mental illness, found to be closely related to mental retardation because the condition results in impairment of general intellectual functioning or adaptive behavior")	Adult companion care Assistive technology Attendant care Crisis Stabilization Day support Environmental modifications Family and caregiver training In-home residential support Personal care services Personal emergency respons systems Respite care Skilled nursing services Supported employment Therapeutic consultation
Mental Retardation 5,056 recipients	"Individuals with mental retardation or children under the age of 6 at developmental risk who have been determined to require the level of care provided in an Intermediate Care Facility for the Mentally Retarded."	Assistive technology Companion services Day support/Environmental modifications/Personal assistance services Prevocational Services Residential support/Respite care/Skilled nursing services Supported employment Therapeutic consultation
Technology Assisted 280 recipients	"Individuals who need both a medical device to compensate for the loss of a vital body function and substantial and ongoing skilled nursing care."	Durable medical equipment Environmental modification Personal care/Private duty nursing/Respite care

Source: DMAS' Long-Term Care and Waiver Program descriptions.

maintenance allowance was reduced to only \$545. However, his basic expenses for mortgage payments and utilities alone are \$748 per month.

Keith, a 51-year old quadriplegic lives in Dale City. His rent and utilities exceed \$1000 per month. He also has expenses for uncovered medical needs and maintenance on his special equipped ramp van. "It doesn't make sense for the AIDS Waiver to allow people to keep up to 300% SSI. It discriminates one type of disability against another and forces those to live in an institution who could otherwise live at home at a lesser cost to the state. ... I have no spouse or living rich parents to help subsidize my living expenses so I'm forced to seek HUD vouchers, food stamps and fuel subsidies... I've turned down offers to work, because there is no incentive to work in the E&D waiver. Every penny I earn would have to be paid as my co-pay. Many disabled people have unnecessarily ended up in nursing homes because they couldn't find housing they could afford with only \$545 per month. They become so frustrated that they just give up and exist a ho hum life when they still have so much more that they could contribute to society if they were only allowed the opportunity to do so."

Scarlett, an elderly woman in Norfolk needed an extended period of personal care services following surgery. She was happy to return home, rather than enter a nursing home. She was shocked to learn that she could only keep \$545 of her monthly Social Security check if she went home. Her rent is higher than that amount! She was humiliated to ask her children to help pay her utility and food bills.

Marie was an 80 -year old widow in Suffolk. She received about \$1200 in monthly Social Security. Because of a variety of medical problems including severe dementia, she required daily care and could not be left alone. While an adult daughter was available on evenings and weekends, she needed E&D waiver services during the day. Her home mortgage, taxes and insurance cost \$739 per month; her utilities exceed \$100 per month. While she received a small

amount of food stamps, she could not pay her basic shelter expenses with only \$545.

According to an Independent Living counselor in Winchester, apartments in that area cost at least \$350 to \$400 per month. Even agency-operated housing for people with serious disabilities charges \$295/month for one room and shared bath, cooking and common room facilities. Subsidized housing, such as Section 8, is nonexistent. The counselor knows about several people who were unable to accept community based care because of the low maintenance allowance. One gentleman applying for services told her, "I couldn't afford the waiver and still eat."

A waiver participant in Rockbridge tries to manage on \$545 per month. She needs to pay for several medical services which are not provided by her personal care aide, such as evening care. It's difficult to get DSS to properly adjust her patient pay when she has out of pocket expenses. A disabled advocate in Northern Virginia agrees that "most of the people that I deal with haven't a clue that these out of pocket expenses can help offset their co-pay and allow them to keep more money than the \$545 per month."

The aforementioned examples are anecdotal cases of individuals who were unable to support themselves on the personal maintenance allowance. There is no comprehensive data available to determine the extent to which the personal maintenance allowance is a problem or what the resulting consequences are. JCHC staff will be working with the League of Social Services Executives in the next few months in an attempt to collect this type of data in a systematic manner from local social services agencies. In addition, information will be collected regarding whether these individuals entered long-term care facilities and if so, at what cost to the Commonwealth.

Advocates Indicate that the Personal Maintenance Allowance for One Individual Is Particularly Inadequate. As noted previously, federal regulation requires maintenance allowances to be "based on a reasonable assessment of need." Some advocates question whether 100 percent of SSI (\$545) is a reasonable assessment of need particularly for an individual who lives alone. Advocates cite examples of individuals who have had to enter a nursing facility because they were unable to afford to continue to live in the community. A case worker in a Northern Virginia social

services agency noted that she has a client in her 90s who lives alone and requires personal assistance in order to remain in her home. The client cannot benefit from the Medicaid E&D waiver because her monthly rent for a small apartment is \$900 despite the fact that she receives a housing grant. Her client is receiving three hours of personal assistance a day on the basis of needing adult protective services. This is a temporary solution however, and there may be no option other than a nursing facility that this client will be able to afford. The case worker indicated that this is a problem she deals with often in Northern Virginia because of the high cost of rent in that area.

Cost Estimates Provided by Three Centers for Independent Living Indicate Average Living Costs that Exceed \$545 Per Month. Three Centers for Independent Living located in Norton, Norfolk, and Arlington provided estimates of the cost of living for one disabled person in their local area (Figure 4). Centers for Independent Living are non-profit organizations which provide services which support the self-sufficiency of disabled Virginians. There are 16 Centers for Independent Living in Virginia.

Figure 4
Estimates of Monthly Cost of Living Expenses for A Disabled Individual

Expense Category	Far Southwest	<u>Norfolk</u>	<u>Arlington</u>
Rent	\$379	\$552	\$964*
Food	\$150	\$200	\$300
Transportation	\$300	\$200	\$200
Clothing	\$ 50	\$ 50	\$ 50
Personal Care Items	\$ 15	\$ 15	\$ 75
Telephone	\$ 50	\$ 50	\$ 50
Disability Items	\$ 50	\$ 50	\$ 75
Furniture	\$ 30	\$ 30	\$ 50
Emergency Fund	\$ 65	\$ 35	\$ 50
Miscellaneous	<u>\$ 65</u>	<u>\$ 65</u>	<u>\$100</u>
TOTAL	\$1,154	\$1,247	\$1,914

^{*}Note: The HUD fair market rent is \$964 including utilities but the average monthly rent for an accessible apartment is reported to be \$1,200.

Source: Centers for Independent Living located in Norton, Norfolk, and Arlington.

As shown in Figure 4, the cost of living for both rural and urban areas of Virginia is estimated to be more than two to three times the \$545 per month personal maintenance allowance with the estimates of \$1,154 in far southwest Virginia to \$1,914 in Northern Virginia. The Director of Advocacy and Services of the Center for Independent Living in Norfolk wrote regarding the estimate she submitted: "Actual cost of living will vary depending on the significance of the disability and the number of people living in the household. The estimate provided is for a single individual living alone. Specialized equipment, dietary issues and the need for maintenance assistance in the home are examples of items that would add to the cost of living but not included in the estimate."

The Creating and Implementing Responsiveness in Community Living to Endependence or CIRCLE Report States that Virginia's Personal Maintenance Allowance Is Often Inadequate for Individuals with Disabilities. The Virginia Statewide Independent Living Council in conjunction with the Virginia Department of Rehabilitative Services contracted with the Endependence Center of Northern Virginia to complete the CIRCLE report which was submitted in September 2001. The stated purpose of the report "was to conduct a review of current laws, regulations, and policies pertaining to Virginia's Medicaid and Medicaid Home and Community-Based Services (HCBS) Waiver program and to make recommendations...for potential systems change activities to address the lack of community support services needed to prevent the unnecessary institutionalization of individuals who have significant disabilities." In reviewing the adequacy of the personal maintenance allowance, the report states:

Federal regulations and the State Medicaid Manual...[indicate] that the state should use a "reasonable amount that reflects the needs of an individual residing in the community." Oftentimes in Virginia, 100% of SSI is not a sufficient amount for the maintenance needs deduction for individuals with disabilities, for many of the same reasons that it is proven to be insufficient for persons with AIDS.

As noted previously, the personal maintenance allowance for the AIDS waiver is 300 percent of SSI. The CIRCLE report recommended, "DMAS should establish and use a consistent and reasonable amount for consideration of the maintenance needs deduction....The amount should reasonably reflect the needs of an individual residing in the community,

and the level established should not be less than the level of true costs for rent, food & clothing in any region."

The Extent to Which Individuals Enter Nursing Facilities Because They Are Unable to Financially Remain in the Community Represents a Cost to Medicaid

Figure 5 contains the figures provided by DMAS as the average perperson and total program costs to Medicaid for individuals receiving services through the E&D waiver or by being in a nursing facility. These figures indicate that the average Medicaid cost in FY 2001 for an individual on the E&D waiver (\$14,856) was 65 percent of the average Medicaid cost for the nursing facility reimbursement (\$22,749) for an individual. (Note that these figures do not represent the cost of an individual being on the waiver or in a nursing facility for an entire year but instead represent the average cost of providing waiver and nursing facility services on a perperson basis in FY 2001.) These are the figures that were reported by DMAS to CMS to demonstrate the cost-effectiveness the E&D waiver when compared to nursing facility care. Thus on a per-person basis, the average

Figure 5
Comparison of E&D Waiver and Nursing Facility
Costs on a Per-Person and Program Basis
FY 2001

Average Per Person Cost

<u>Program Type</u>	Direct Costs	Other Costs	Total Costs				
E&D Waiver	\$ 9,198	\$ 5,658	\$14,856				
Nursing Facility Care	\$18,936	5 \$ 3,813 \$22,7°					
Program Cost							
Program Type	Direct Costs	Other Costs	Total Costs				
E&D Waiver	\$ 87,997,814	\$ 52,683,300	\$140,681,114				
Nursing Facility Care	\$496,814,283	\$ 98,825,497	\$595,639,780				

Note: The figures include federal and state Medicaid funding. The federal share for FY 2001 was

51.81 percent.

Source: Department of Medical Assistance Services.

nursing facility cost to Medicaid was \$7,893 higher than the average perperson cost to for the E&D waiver. In FY 2001, DMAS reports that 9,567 individuals received services through the E&D waiver and 27,240 individuals lived in a nursing facility.

DMAS Provided Estimates of the Cost to Medicaid of Increasing the Personal Maintenance Allowance for Four HCBS Waivers

Although Item 11 of the Appropriations Act addresses only Virginia's E&D Medicaid waiver, an argument can be made for establishing the personal maintenance allowance at 300 percent of SSI for each of Virginia's HCBS waivers. (As noted previously, the AIDS waiver's personal maintenance allowance is already set at 300 percent of SSI.)

Figure 6 includes the DMAS estimates for increasing the personal maintenance allowances for four HCBS waivers to 150 percent, 200 percent, 250 percent, and 300 percent of SSI. Estimates were not provided for the DD waiver because of delays in getting this relatively new waiver program operating.

Figure 6

DMAS Estimate of Annual Cost to Increase
Personal Maintenance Allowance to Higher Percentages of SSI

Waiver and Number of	Recipients COST TO INCREASE ALLOW with				ANCE TO:	
Recipients	Patient Pay	150% SSI	<u>200% SSI</u>	<u>250% SSI</u>	300% SSI	
CD-PAS 151 recipients	17 (11%)	\$11,929	\$13,540	\$13,540	\$13,540	
E&D 9,567 recipients	1,791 (19%)	\$2,059,427	\$2,849,389	\$3,050,760	\$3,252,131	
MR 5,056 recipients	791 (16%)	\$1,007,383	\$1,502,252	\$1,660,767	\$1,819,282	
Technology 280 recipients	6 (2%)	\$8,607	\$13,940	\$16,430	\$18,919	
TOTAL	2,605 (17%)	\$3,087,347	\$4,379,121	\$4,741,497	\$5,103,872	

Note: The figures include federal and state Medicaid funding. The participation rate for FY 2003 will be 50.53 percent federal and 49.47 percent state funding.

Source: Department of Medical Assistance Services.

As noted previously, individuals who have income that is at or near 100 percent of SSI or have high "allowable" expenses do not have a patient pay share. Figure 6 indicates that the percentage of waiver recipients who have a patient pay share ranges from two percent in the technology assisted waiver to 19 percent in the E&D waiver. Thus, the largest number of waiver recipients who would benefit from a change in the personal maintenance allowance is in the E&D waiver (1,791 individuals). Only six waiver recipients in the technology assisted waiver have a patient pay share because most of the recipients are children and only the children's income, not the income of the parents is counted in determining the patient pay share.

IV. Policy Options

The following Policy Options are offered for consideration by the Joint Commission on Health Care. They do not represent the entire range of actions that the Joint Commission may wish to recommend with regard to the personal maintenance allowances provided within Virginia's Medicaid Home and Community-Based Waivers.

Option I:

Take no action.

Option II:

Introduce a budget amendment (language and funding) directing the Department of Medical Assistance Services to increase the personal maintenance allowance for the Elderly and Disabled waiver to one of the following levels:

- A. 150 percent of Supplemental Security Income at an estimated GF cost of \$1,018,800;
- B. 200 percent of Supplemental Security Income at an estimated GF cost of \$1,409,600;
- C. 250 percent of Supplemental Security Income at an estimated GF cost of \$1,509,220; or
- D. 300 percent of Supplemental Security Income at an estimated GF cost of \$1,608,830.

Option III:

Introduce a budget amendment (language and funding) directing the Department of Medical Assistance Services to increase the personal maintenance allowance for the Medicaid HCBS waivers for the elderly and disabled, consumer-directed personal attendant services, mental retardation, and technology assistance to one of the following levels:

- A. 150 percent of Supplemental Security Income at an estimated GF cost of \$1,527,311;
- B. 200 percent of Supplemental Security Income at an estimated GF cost of \$2,166,351;

- C. 250 percent of Supplemental Security Income at an estimated GF cost of \$2,345,619; or
- D. 300 percent of Supplemental Security Income at an estimated GF cost of \$2,524,885.

Appendix A:

Item 11 of the 2002-2004 Appropriations Act

Item 11 of the 2002-2004 Appropriations Act

The Joint Commission on Health Care, with the cooperation of the Department of Medical Assistance Services, shall evaluate the personal maintenance allowance of the Medicaid Elderly and Disabled Waiver Program. Such evaluation shall consider the adequacy of such allowance, the effect of the allowance on the selection or continuation of community-based services as compared to institutional services, whether individuals unnecessarily receive institutional care because of the allowance, whether adjustments in the allowance are warranted, and the estimated costs of any changes.

Appendix B:

Summary of Public Comments



JOINT COMMISSION ON HEALTH CARE

SUMMARY OF PUBLIC COMMENTS: Personal Maintenance Allowance of the Medicaid E&D Waiver

Organizations/Individuals Submitting Comments

Forty-four persons/organizations submitted comments in response to the evaluation of the personal maintenance allowance of the Medicaid E&D waiver:

- AARP
- Ann Alexander
- The Arc of Northern Virginia
- The Arc of Virginia
- Arlington Commission on Aging
- Arlington County Department of Human Services
- Betty Hunter Bazemore
- LaKeisha Branch
- Central Virginia Community Services
- Evelyn Colonna
- Tiffany and Margaret Cortapasso
- Richard Cowan
- Crossroads Community Services Board
- Developmental Services
- Disabled Action Committee
- ElderAlliance
- Endependence Center, Incorporated
- Endependence Center of Northern Virginia, Incorporated
- Fairfax County Department of Family Services
- Friendship Industries, Incorporated
- Charity Gray
- Bill Hammond
- Health Systems Agency of Northern Virginia
- Deanne Jansohn
- Doris P. Johnson
- Mariam G. Kurtyka

- Grover Long
- Joan Manley
- Mount Rogers Community Mental Health and Mental Retardation Services Board
- Northern Virginia Aging Network
- Planning District 1 Community Services Board
- Bonita Reid
- David J. Rissmeyer
- Mary Jane Sidoti
- Stonewall Jackson Hospital Home Health
- Marjorie M. Streicher
- Jennifer Thornburg
- 12th Planning District Advocacy Project
- Valley Associates for Independent Living, Incorporated
- Virginia Department of Medical Assistance Services
- Virginia Poverty Law Center
- Lisbet Ward
- Waynesboro Disability Services Board
- Lynn Weiss

Policy Options Included in the Issue Brief Evaluating the Personal Maintenance Allowance of the Medicaid E&D Waiver

Option I: Take no action.

Option II:

Introduce a budget amendment (language and funding) directing the Department of Medical Assistance Services to increase the personal maintenance allowance for the Elderly and Disabled waiver to one of the following levels:

- E. 150 percent of Supplemental Security Income at an estimated GF cost of \$1,018,800;
- F. 200 percent of Supplemental Security Income at an estimated GF cost of \$1,409,600;
- G. 250 percent of Supplemental Security Income at an estimated GF cost of \$1,509,220; or
- H. 300 percent of Supplemental Security Income at an estimated GF cost of \$1,608,830.

Option III:

Introduce a budget amendment (language and funding) directing the Department of Medical Assistance Services to increase the personal maintenance allowance for the Medicaid HCBS waivers for the elderly and disabled, consumer-directed personal attendant services, mental retardation, and technology assistance to one of the following levels:

- E. 150 percent of Supplemental Security Income at an estimated GF cost of \$1,527,311;
- F. 200 percent of Supplemental Security Income at an estimated GF cost of \$2,166,351;
- G. 250 percent of Supplemental Security Income at an estimated GF cost of \$2,345,619; or
- H. 300 percent of Supplemental Security Income at an estimated GF cost of \$2,524,885.

Overall Summary of Comments

Forty commenters supported Option III to increase the personal maintenance allowance for the Medicaid Home and Community-Based Services Waivers. Twenty-five of these individuals and organizations specifically supported Option III D which would increase the personal maintenance allowance to 300 percent of the Supplemental Security Income (SSI) benefit level. (The other 14 commenters did not specify the level they supported for increasing the allowance.) A number of the 37 commenters specifically supported including the Individual and Family Developmental Disabilities Support (DD) Waiver in any increasing of the personal maintenance allowance.

Two commenters (Arlington County Department of Human Services and Betty Bazemore) supported Option II to increase the personal maintenance allowance for the Elderly and Disabled waiver. The ENDependence Center of Northern Virginia, while supporting Option III D asked that if Option II is supported by the Joint Commission, that consideration be given to increasing the personal maintenance allowance for the CD-PAS waiver also.

George Barker of the Health Systems Agency of Northern Virginia did not indicate support of any of the proposed options but noted that some Virginians are unable to "find housing and meet other expenses with the amount that they are allowed to keep under [a] Waiver program." Mr. Barker was concerned that the study's cost estimates did not show offsetting savings

that would result from individuals remaining in the community and using Medicaid waiver services rather than going into a nursing facility.

Patrick W. Finnerty commenting on behalf of the Department of Medical Assistance Services (DMAS) did not indicate support for any of the proposed Options. Mr. Finnerty stated that DMAS has several work groups which are reviewing services provided to individuals with disabilities through the Medicaid program. Mr. Finnerty would therefore like to "provide input on these options at a later date once we have had the chance to conduct a thorough evaluation of the impact of the suggested changes on the clients and the program."

Summary of Individual Comments

AARP

William L. Lukhard, Advocacy Consultant for Virginia commented in support of Option III D. Mr. Lukhard stated: "Increasing the PMA for elderly and disabled Medicaid Waiver beneficiaries would eliminate the funding bias towards nursing home care. If the PMA is not increased, the only option for hundreds of beneficiaries who could otherwise be safely and cost-effectively served at home and in their communities would be a nursing home. Therefore, AARP supports increasing the personal maintenance allowance to 300% of S.S.I. for all elderly and disabled Medicaid Waiver beneficiaries. This would enable more persons to access care options to enable them to remain in their homes or communities as they age. AARP believes that the personal maintenance allowance should be at the same percentage level for all Medicaid Waiver programs. Though AARP recognizes the funding situation facing the Commonwealth, we believe that raising the personal maintenance allowance in Medicaid Waiver programs in the right thing to do for some of the Commonwealth's most vulnerable population. The projected cost savings as an alternative to nursing facility care would more than offset the relatively small cost of increasing the personal maintenance allowance."

Ann Alexander

Ann Alexander of Virginia Beach commented in support of Option III. Ms. Alexander stated: "Due to my circumstances it is a hardship to pay my nursing assistant a co-pay each month. I am disabled and on oxygen 24/7. Besides my rent, utilities, prescriptions and other medical necessities this additional expense is almost impossible for me to pay since I am on a small monthly fixed income....I urge you to reform the present system and pass

Option 3 as I am sure there are other elderly people in Virginia who are having a hard time getting nursing assistance with the present plan."

The Arc of Northern Virginia

Jeannie Cummins, Director of Advocacy and Programs commented in support of Option III D. Ms. Cummins indicated:

The Arc of Northern Virginia has advocated on behalf of several individuals who receive Medicaid Mental Retardation Waiver services, and who, because they have resources in excess of 100% of the maximum SSI payment, are required to contribute a co-payment for their waiver services....These individuals generally have rigid personal budgets, and experience great difficulty paying their bills on time and in full from month to month.

Many residential providers are not receiving full co-payments from these individuals every month because they simply do not have the money. These residential providers often do not collect the co-pays they are owed from months at a time because they understand their residents are in difficult financial straits. However, the loss of revenue is becoming a hardship for the providers. The Arc fears that we will soon see a day when residential providers are forced to discharge individuals who cannot afford their co-payments, because the providers must be able to collect enough revenue to sustain their programs and avoid putting other program participants at risk.

Likewise, one vocational provider has told us there are several consumers in their program who may be at risk of losing their vocational services because they cannot pay their co-payments. Again, these individuals will be in double jeopardy: they will lose their vocational support services *and* their jobs, since the agency that gives them services is also their employer.

By raising the PMA to 300% of the maximum SSI payment, we can eliminate burdensome paperwork, the loss of revenue to providers, the destabilization of residential and vocational programs, and the risk that individuals will lose the very community services the Medicaid Waivers are supposed to provide, thereby rendering them jobless and homeless.

The Arc of Virginia

Lisa L. Ownby, President and Teja S. Stokes, Executive Director, commented in support of Option III D. Ms. Ownby and Ms. Stokes noted the following reasons for supporting the increasing the PMA for all Medicaid waiver programs:

- 1. For individuals at risk of institutionalization, the current PMA of \$545 is inadequate to support themselves in the community.
- 2. Because the current PMA of \$545 is inadequate to support people in the community, some individuals end up in nursing homes costing Virginia more money.
- 3. Increasing the PMA to 300% of SSI promotes simplicity in the program because it would eliminate the need for frequent adjustments to the PMA and all related paperwork.
- 4. Increasing the PMA to 300% of SSI in <u>all</u> Medicaid Waivers promotes uniformity between various community-based programs, as currently there are varying rules for the different waivers.
- 5. Increasing the PMA to 300% of SSI ends the current discrimination against non-married persons.
- 6. Increasing the PMA to 300% of SSI is consistent with the requirements of the Americans with Disabilities Act and the Olmstead decision to enable people with disabilities to be served in the 'most integrated setting' and to enable people to use their own income to support themselves in the community.

Arlington Commission on Aging

Helen C. McMahon, Chair, commented in support of Option III D. Ms. McMahon stated: "We have heard over and over from staff in the Arlington Department of Human Services Aging and Disability Services Division that Arlington residents are unable to use the Medicaid waiver for personal care or adult day care because they would not have enough funds remaining to pay for basic needs such as meals, rent, transportation for non-Medicaid funded medical services. The Elderly and Disabled Waiver program is an important strategy in enabling older persons and persons with disabilities to remain in the community and avoid the need to build additional nursing homes. However, the current personal maintenance allowance of 100% of the SSI benefit level (\$591 per month) frequently thwarts the intent of the program, particularly in Northern Virginia, where the cost of living is higher. It is always difficult for us in Northern Virginia to use Medicaid effectively when Medicaid rates have fallen further behind the cost of living."

Arlington County Department of Human Services

Joe Schwartz, Eligibility Supervisor, Bureau of Assistance Programs commented in support of Option II. Mr. Schwartz indicated: "I supervise the Long-Term Care Medicaid unit in Arlington County. We often see instances

where individuals are unable to afford housing in Arlington while receiving Waivered services. Apartments in Arlington are typically between \$800 and \$1,200 per month. It is not possible to remain in such an apartment on \$545 per month. The result is that persons who might otherwise reside in the community, are forced to go into a nursing facility. The Medicaid Elderly/Disabled Waiver is a wonderful concept that allows persons to live where they are most comfortable as they struggle with aging and ill health. Your committee can make this idea a reality by voting for a higher PMA."

Betty Hunter Bazemore

Betty Hunter Bazemore of Spotsylvania commented in support of Option II. Ms. Bazemore indicated: "As a Social Worker in a local department of Social Services, part of my job is to assist clients in making health care decisions. While Personal Care Services is a more cost effective service than nursing home placement, it causes families to question their ability to manage once the personal maintenance allowance is assessed....For many individuals living in their own home, the PMA of \$546 leaves them with such a limited amount of income that it is difficult to cover expenses such as rent and utilities, as well as buying food. These individuals, once comfortable in their own homes, become indigent....In many cases where CBC [community-based care] is needed the client finds himself/herself forced to choose between the best of two evils; the financial struggle of living with less income, but with the benefit of adequate care and medication coverage or the financial struggle of paying one's own medical costs and living without adequate care. Neither choice is good."

LaKeisha Branch

LaKeisha Branch of Virginia Beach commented in support of Option III with the addition of the DD waiver. Ms. Branch stated that as a personal care attendant "I see first hand that 545.00 is not enough money to live on a month."

Central Virginia Community Services

Michael Doherty, Residential Manager, commented in support of Option III. Mr. Doherty indicated: "I would like to that this opportunity to support the urgent need for an increase in the 'Personal Maintenance Allowance.' This money would greatly assist these individuals in maintaining proper dental care and paying for medical expenses not covered by insurance. Although these are more obvious needs, the not so obvious is the cost of creating and maintaining normal social interactions. These interactions lead to greater involvement in the

community and a greater range of supports for the individual. Please take these issues into consideration and the important impact they have on individual lives."

Evelyn Colonna

Evelyn Colonna of Chesapeake commented in support of Option III. Ms. Colonna stated: "My mother receives services from the consumer directed personal assistance waiver. She is required to pay \$112.00 in a co-payment every month in order to receive these services. This comes out of a very small social security monthly check of \$647.00. That is a huge part of her monthly income. After her co-pay, she is left with a mere \$545.00 per month to pay all of her other expenses including food, medication, utilities, clothing, personal hygiene supplies, etc. She would be able to afford much needed necessities for the minimum quality of life, if she did not have to pay the co-pay, which is currently beyond her means. She must have the personal assistance, so in order to remain in the community, she goes without. She loves her home and wants to stay as active as she can. She does not want to move to a nursing home. Please support option III with the addition of the DD Waiver. Getting rid of the co-pay requirement will make a tremendous difference in so many people's lives, including my mother."

Tiffany and Margaret Cortapasso

Tiffany and Margaret Cortapasso commented in support of Option III. Ms. Margaret Cortapasso indicated that she was writing on behalf of Tiffany who receives DD waiver services. Tiffany "receives services at home and pays a copay of \$254.68 a month. Since Tiffany is an 18 year old with limited financial resources, this letter is a request that she be converted to option 3 so her co-pay can be waived. Regardless of the outcome of this request, Tiffany would like to say that she appreciates all of the services that the DD Waiver has thus far afforded her. The program has greatly enhanced her quality of life."

Richard Cowan

Richard Cowan commented in support of Option III. Mr. Cowan stated: "If it wasn't for my son and daughter-in-law, I would be placed in a nursing home facility like I have been before. By the way, that particular nursing home was closed by the state of Virginia due to incompetence. When I came out of that nursing home, it cost Medicare approximately \$400,000 to repair two badly infected bed sores due to their negligence. Also, I would have enough money to

have my own van to go to & from the doctor's office visits which cost Medicare & Medicaid \$127 each trip. I visit at least one doctor a week due to my current condition."

Crossroads Community Services Board

F. Will Rogers commented on behalf of the Crossroads CSB "and the mental health/mental retardation/substance abuse consumers, their families and the communities of Planning District 14" in support of Option III D. Mr. Rogers included two examples of individuals who have given up needed services because of the current personal maintenance allowance level. The following is one of those examples:

Kathy (not her real name), one of our long term Mental Retardation Waiver consumers, recently had to terminate the Day Support services she had been receiving for the past eight years. She began to receive \$610 in Social Security benefits and \$595 in pension benefits per month upon her father's death. Based on this monthly income of \$1205, Social Services determined that after keeping the standard \$545 per month for expenses, she had to be charged \$660 per month to attend her day support services. Kathy lives at home with her aging mother, who received a kidney transplant almost a year ago. The mother herself receives minimal financial support for her own disability, which is due to her medical condition and physical limitations. As a result of these, the mother is also unable to hold a job....When faced with paying \$660 per month or keeping Kathy out of day support, they decided Kathy would remain at home, just to survive financially. Case management continues, so we are able to witness the destructive results of this forced choice. Kathy misses her day support activities, opportunities for community integration, and socialization with friends at the program. Kathy has regressed in her self-care skills without the reinforcement of daily habilitation services. The mother is not able to provide the training or even to carry out dependent care due to her physical limitations. Both are miserable and stressed to their limits. This situation exacerbates the mother's physical deterioration and has made Kathy anxious and depressed. If the PMA was increased as proposed, both need not make this choice and Kathy could return to day support and receive badly needed services and care.

Developmental Services

Wendy Miller, Case Management Services Coordinator, commented in support of Option III D. Ms. Miller included three examples of individuals who were eligible for the Mental Retardation waiver but were unable to accept the waiver services because they could not afford the co-payments. Ms. Miller stated: "An adjustment to the PMA would enable disabled individuals to use

their own income to support themselves in the community. This would be both a reasonable and cost effective way to maintain individuals in their own community and prevent further institutionalization."

Disabled Action Committee

Keith Kessler commented in support of Option III D. Mr. Kessler indicated:

Although the cost of raising the PMA to higher levels up to 300% of SSI for all of the waivers is estimated to cost a total of \$5.1 million which about ½ would be state funds, the long term and short term savings would be immediate and cost effective throughout many state agencies. This would in effect nullify any direct costs to the state....

By raising the PMA to 300% of SSI this will PROMOTE SIMPLICITY in the entire program. Currently, providers of care must bill their patients for the required co-payment....[T]he process for getting this done is very cumbersome and time-consuming for both DSS, the provider and the consumer.

Proof of bills, paperwork, and notices are required EACH time there is a non-covered medical expense! By raising the PMA, you eliminate the need fro frequent adjustments to the PMA and all the related paperwork – the consumer can simply keep up to \$1635 of his own income and use that income to cover all living expenses, including out of pocket medical costs....

Again, raising the PMA to 300% of SSI IN ALL THE WAIVERS PROMOTES UNIFORMITY between the various community based programs. Currently, there is a confusing array of different rules for different waivers....All the people in these waivers are trying to remain in the community – they should be treated similarly....

This would also end the current discrimination against non-married persons and against discriminating one disability against another. Currently when a Waiver participant is married, the spouse is allowed A MINIMUM of \$1493 per month (effective 7/02) to meet her expenses. This amount can go as high as \$1940 if there are high shelter costs. Added to the Waiver participant's \$545 PMA, this married couple can keep almost \$2500 per month to meet their monthly expenses (and MORE if there are dependent children). There is no justification for the huge disparity in treatment between single and married waiver participants. While economies of scale actually favor the married couple, in our current system the single person is somehow expected to survive on a small fraction of the amount allowed couples.

Finally, by raising the PMA to 300% of SSI is consistent with the requirements of the Americans with Disabilities Act and the Olmstead decision.... An adjustment to the PMA to enable disabled people to use their own income to support themselves in the community is a reasonable way to achieve both cost-effectiveness and the goals of the ADA.

ElderAlliance

John Taylor, VP, commented in support of Option III D. Mr. Taylor stated: "As an advocate for elderly independence and better quality of life, this option allows Virginia to meet its obligations in a manner better suited for many elderly and disabled than institutionalization. First of all, since nursing home beds in Virginia have not increased to keep pace with the very rapid growth of Virginia's fragile elderly, home-based options must be supported. Secondly, it appears to be a more cost-effective option that institutionalization. Finally it appears such a program would allow Virginia to demonstrate compliance with the Olmstead ruling."

Endependence Center, Incorporated (ECI)

Maureen Hollowell, Director of Advocacy and Services, commented in support of Option III D with the addition of the DD waiver. Ms. Hollowell stated: "ECI strongly supports the use of Medicaid Waivers to help people with physical and cognitive disabilities live rewarding lives within their own communities and outside of institutions. At this time, however, many Waiver recipients are required to pay huge co-pays for their support services. These copayments reduce their income to less than \$545.00 per month, an amount that must cover rent, food, utilities, transportation, personal care items and unexpected needs. Many people tetter between community placement and an institutional setting, with every expense increasing their changes of losing their autonomy and their freedom. The Joint Commission on Health Care now has the opportunity to improve the quality of life of its citizens using Waiver services, by increasing the Personal Maintenance Allowance for unearned income to 300% of Supplemental Security benefits. Option III with the addition of the DD Waiver would eliminate co-payments for persons who live far below the poverty level and use Waiver services. This additional income each recipient would retain could be used to pay for basic life and health sustaining necessities; necessities that are now considered luxuries in the monthly struggle between community life and life with dignity."

ENDependence Center of Northern Virginia, Incorporated

Michael J. Cooper, Executive Director and Doris M. Ray, Advocacy and Outreach Coordinator, commented in support of Option III D in stating:

Too frequently individuals with significant disabilities who live on fixed incomes from Social Security Disability Insurance (SSDI) are simply unable to afford the co-payment [required by the Medicaid waiver]. The cost of living (rent, food, clothing, and assistive technology and other costs related to living with a disability) are simply too high, leaving the individual insufficient funds for the co-payment. Thus citizens with disabilities and seniors are faced with the agonizing decision of paying for needed services, such as personal assistance, in order to continue to live in their own homes amidst their family and friends, or be forced into a nursing home or other institution.

Some choose to go without food or other necessities so they can stay in the community. Many individuals are unable to make this choice and are unnecessarily institutionalized. This tears families apart and is a waste of human resources, especially when it means that a youth or young adult of working age is needlessly warehoused in an institution whereas if they were in the community they might have the chance to get training, go to work and become taxpaying, contributing members of society....

Such unnecessary institutionalization is diametrically opposed to the statutory intent of Congress in establishing the Section 1915(c) Home and Community Based Services (HCBS) Waiver Program. Congress also recognized that institutionalization is more costly in terms of public expenditures than are home and community-based services....

Mr. Cooper and Ms. Ray asked that if Option II (which would limit increasing the PMA to recipients of the E&D waiver) is selected, that consideration be given to increasing the PMA for the CD-PAS waiver also. This would benefit the approximately 200 CD-PAS waiver recipients who "would be in the E&D Waiver except that they chose to exercise the option of directing and supervising their own personal care."

Fairfax County Department of Family Services

Elizabeth Shirley, Program Manager of Adult and Aging Services, commented in support of Option III D. Ms. Shirley noted that the Fairfax County Long Term Care Task Force has developed four themes for its strategic planning, one of which is "Promoting Independent, Supportive Living....The task force recognized that persons who are elderly and persons with disabilities express an overwhelming desire to remain in the community rather than go to an

institution. Many in this group are at risk of institutionalization, and yet cannot choose Medicaid waiver services because the personal maintenance allowance is not adequate to support basic needs. Some individuals end up choosing nursing facility care because they cannot afford to stay in the community....federal regulation requires that maintenance allowances be 'based on a reasonable assessment of need.' The current regulation does not provide that level of support. Maximizing continued independence by enabling individuals to be in the community with supports available in response to their needs should be the goal."

Friendship Industries, Incorporated

George Homan, Vice President for Operations and Judy Thompson, Rehabilitative Services Counselor commented in support of Option III D with the inclusion of the DD waiver. Mr. Homan stated: "Many individuals desire to remain in their home environment. They wish to experience the least restrictive environment and to live independently for as long as they possibly can. The Medicaid E & D Waiver has potential to make this goal a reality. The cost of remaining in ones community is less than a nursing home facility. The current stumbling block to individuals with disabilities accessing Medicaid Waivers is the hardship that co-pays present to many individuals. As noted in the report, 31 states (in 1998) allowed higher personal maintenance allowances within their Medicaid elderly waivers than Virginia. The Federal government sets the limit for personal maintenance allowance at 300% of SSI. States have substantial latitude in setting the amount of the PMA for living expenses."

Charity Gray

Charity Gray commented in support of Option III. Ms. Gray indicated that she is 26 years old and receives SSI and Medicaid waiver services. Ms. Gray states: "It is impossible to live on 545.00 a month. We are talking poverty levels of existing, should one be punished for their limitations or inability to work? No! As you can tell I am greatly in favor of Option 3. I do not like to see people on a fixed income forced to settle for intolerable conditions or be forced to be where they can afford. Realistically just to live in an apartment can run anywhere from six hundred to eight hundred."

Bill Hammond

Bill Hammond commented in support of Option III D. Mr. Hammond noted: "I urge the JCHC to support and adopt Option III D of the report,

introduce a budget amendment (language and funding) directing the Department of Medical Assistance Services to increase the PMA for the Medicaid HCBS waivers for the E&D, CDPAS, MR, DD, and Tech waiver to 300% of Supplemental Security Income....We urge the inclusion of the DD waiver in Option III D of the report."

Health Systems Agency of Northern Virginia

George Barker, Associate Director, commented without indicating support of any of the proposed Options. Mr. Barker stated:

It is important that those who do not need nursing home care be able to avail themselves of alternative care, particularly if that alternative care in the community is less expensive. Most Virginia nursing homes provide good care, but Virginians should not have to go permanently to nursing homes if they could do well in the community at a reasonable cost.

Although the development of community alternatives has helped to decrease agespecific use rates, we are aware that there still are Medicaid patients who go to nursing homes not because it is the best or least expensive place for them but because the alternatives that they need are not available. These people generally fall into one or two categories.

Some need assisted living or adult care residence services but either cannot find such care under the very low auxiliary grant payment level or are in that "inbetween" group with too much income to qualify for the auxiliary grant program but not enough to afford the charges at local assisted living facilities.

Others need Personal Maintenance Assistance but cannot find housing and meet other expenses with the amount that they are allowed to keep under that Waiver program. Many of these are single individuals, for whom the housing cost issue is predominant.

As a result of those situations, we still have Medicaid nursing home patients who do not need to be in a nursing home and for whom Medicaid is paying more than the cost of caring for the person in the community or an assisted living facility. We believe that it is not wise public policy for the state to pay more to provide the individual the wrong level of care.

We question one aspect of the report that was presented to you in May. The report shows estimates of the increased Medicaid expenditures for people in the Personal Maintenance Allowance program if the waiver allowance were increased. What it does not show is the offsetting savings that would result from others being able to use the Personal Maintenance Allowance program rather than

nursing home care if the waiver allowance were increased. It is essential that such a calculation be made so that you have full information on net costs or savings associated with increasing the waiver allowance.

The regional health planning agencies are in the process of doing the quadrennial survey of all nursing home patients in Virginia. We have the support of the Virginia Health Care Association and the Virginia Department of Health in this effort. We provided a presentation of the survey information to the Joint Commission following the 1998 survey. We would be happy to do the same again once we have completed the 2002 survey.

We also would be willing to work with your staff and State Agencies to gather the information to estimate the savings that would result from individuals being placed in the Personal Maintenance Allowance program rather than a nursing home if the waiver allowance were increased. Please let us know how we can assist you in this effort.

Deanne Jansohn

Deanne Jansohn of Virginia Beach commented in support of Option III D for all waivers. Ms. Jansohn indicated: "As a voter in Virginia Beach, I am for Option III, to raise the personal maintenance allowance (PMA) in all waivers to 300% of poverty so people can properly support themselves w/out resorting to going into nursing homes after saving and scrimping, only to give up as they cannot afford to live at home. I have seen, as a social worker for the elderly and disabled, many folks live in poverty and go w/out basic needs to try to remain in the community – 100% of SSI (\$545) is ridiculously low!!"

Doris P. Johnson

Doris P. Johnson commented in support of Option III. Ms. Johnson indicated that she receives CD-PAS waiver services and that she has a copayment of \$314 each month which she states is too much considering her basic living expenses. Ms. Johnson noted: "Since I have had the CDPAS program, my 5 year wound under my left thigh is completely cleared up/healed because I have increased hours of care. I cannot risk my health by going back to a hospital setting, especially after I got a broken leg on the medical transport van in October due to a worker's failure to strap me down. The first hospital and rehab, never removed my leg brace for 3 weeks, not to wash it or anything else. Their neglect caused me to go back in the hospital & rehab again, and get skin breakdown again! I would rather die than go back to an institution. Please support Option III!"

Mariam G. Kurtyka

Mariam G. Kurtyka commented in support of Option III D. Ms. Kurtyka indicated that the letter was "written on behalf of the Kurtyka family and my sister Mary Catherine Kurtyka, who has Downs Syndrome and receives funding assistance from the Medicaid Elderly and Disabled Waiver Program....The Kurtyka family is aware of the requirements of the Americans with Disabilities Act and the Olmstead decision when the US Supreme Court found that programs such as Medicaid are required to serve disabled persons in the 'most integrated setting' unless doing so would require fundamental alterations in the program. Therefore, raising the PMA to 300% of SSI would assist in meeting this requirement. In addition, it is our understanding that when a waiver participant is married, the spouse is allowed a substantially higher PMA requirement per month to cover shelter and living expenses. If individuals who are not married receive a lesser amount, then this is discrimination against the non-married person and also should be corrected."

Grover Long

Grover Long commented in support of Option III. Mr. Long stated that he is responsible for paying \$674.29 per month for his medical attendants' care which leaves him less than \$500.00 per month to live. Mr. Long noted: "I already have no social life and I find myself turning to credit cards to pay for some bare essentials such as food and clothing....I hope this situation can be resolved to make things better for everyone involved. Thank you in advance for your attention in this matter."

Joan Manley

Joan Manley commented in support of Option III D. Ms. Manley indicated that she is a spinal cord injured quadriplegic who receives personal care services through the E&D waiver. Ms. Manley pays for additional care to supplement the daytime care she receives through the waiver. Ms. Manley stated: "Because I have established a good relationship with the home health agency over the years, they have provided well trained and familiar aides that I can count on. Only with the confidence in their reliable care have I felt able to pursue employment. Knowing that my aide will be there every morning and will tend to my needs with skill and familiarity did I feel I could begin working. But my expenses and my very high co-payment for home health are making it difficult to make ends meet....I truly hope that I can continue with the Elderly &

Disabled Waiver, continue to work, and be able to pay my bills. I understand that presently there is discussion to increase the personal maintenance allowance for Medicaid waivers including the Elderly & Disabled Waiver to 300% of Supplemental Security Insurance. I urge the Joint Commission to make this adjustment so that people like myself can live as independently as possible in the least restrictive environment."

Mount Rogers Community Mental Health and Mental Retardation Services Board

E. W. Cline, Jr., Executive Director commented in support of Option III D. Mr. Cline stated: "The Joint Commission on Health Care received a report on May 30th revealing that individuals receiving personal maintenance allowances are unable to support themselves in the community. However, community based care is the most integrated setting for individuals at risk of institutionalization. An adjustment to the personal maintenance allowance to enable disabled people to use their own income to support themselves in the community is clearly the most cost effective way and is also in support of the Americans with Disabilities Act and the Olmstead decision."

Northern Virginia Aging Network (NVAN)

Erica F. Wood, Legislative Chair, commented in support of Option III D. Ms. Wood stated: "Every year a key thrust of the NVAN legislative platform is to help older Virginians remain in homes of their choice. Under a banner of "No Place Like Home," NVAN supports measures to allow older persons and persons with disabilities at risk of institutionalization to function independently, stay in the least restrictive setting and receive the home and community based services they need. The Elderly & Disabled Waiver program is an important strategy in achieving these aims. However, the current personal maintenance allowance of 100% of the SSI benefit level frequently thwarts the intent of the program, particularly in Northern Virginia, where the cost of living is higher. Older individuals who want to live in the community may be forced to enter a nursing home because the allowance will not support their rent and basic living expenses. Moreover, supporting a realistic level for the allowance under the Elderly and Disabled Waiver is more cost-effective for the Commonwealth than paying for nursing home care, as the study clearly demonstrates. While the primary interest of NVAN is in the Elderly & Disabled Waiver, individuals eligible for the other waivers have similar needs and also would benefit from an increase in the personal maintenance allowance."

Planning District 1 Community Services Board

Regina Lawson, Mental Retardation Director, commented in support of Option III D. Ms. Lawson stated: "Currently, the PMA rate of \$545 is totally inadequate for people to support themselves in the community, putting them at risk of institutionalization or nursing home placement unnecessarily. A consistent PMA across all waivers would also promote uniformity and consistency since the PMA for the waivers vary as well as special rules and deductions. Raising the PMA to 300% of SSI would also allow persons with disabilities to use their own income to support themselves in the community, which would promote compliance with the Olmstead Act which requires programs to serve disabled persons in the most integrated setting. We have many consumers who struggle on a daily basis due to their incomes. The co-pay amount that the current low PMA necessitates results in many consumers having to choose between paying monthly bills and receiving critical MR Waiver services, which is a decision no one should have to make."

Bonita Reid

Bonita Reid commented in support of Option III. Ms. Reid indicated that she receives DD waiver services and has a co-payment of \$97 per month that could go toward her utility bills.

David J. Rissmeyer

David J. Rissmeyer, ACSW, CPRP of Mt. Sidney, commented in support of Option III D. Mr. Rissmeyer stated: "Many individuals desire to remain in their home environment. They wish to experience the least restrictive environment for as long as they possibly can. They desire independent living. The U.S. Census shows that individuals are living longer and our ageing population is growing. It remains cost effective for individuals with all disabilities to live independently in the community versus an institutional setting."

Mary Jane Sidoti

Mary Jane Sidoti commented in support of Option III. Ms. Sidoti stated: "I have \$564.00 to meet my essential needs like housing and food! If I could keep the co-pay funds, I would use those funds for other needed items! Items such as housing, food, transportation and other medical items! As you know, Social Security is a very small sum to live on! Consider how you would survive on such little income! My vote is for option 3!!!"

Stonewall Jackson Hospital Home Health

Patricia Cooper, RN, BSN, commented in support of Option III D. Ms. Cooper stated: "I am not a recipient of any of the Medicaid waivers, however as a healthcare provider and friend to several folks how are, I am concerned about their increasing struggle to be able to keep enough money to cover their expenses (which are not excessive) and to maintain the human dignity of maximum independence and self-control."

Marjorie M. Streicher

Marjorie M. Streicher of Norfolk commented in support of Option III. Ms. Streicher stated: "This letter is to seek your assistance and support for Option 3 with the addition of the DD Waiver....Thomas has had cerebral palsy since birth but with the help of many people, he has been able to live a near normal life wherein he is able to function with the help of his very capable aides. If he is required to pay a co-pay...that will seriously limit his ability to enjoy some of the activities he has become accustomed to such as seeing an occasional play or concert and may even limit the amount of funds necessary to furnish him with the kind of food he needs to stay healthy and/or the seasonal clothes which are also necessary."

12th Planning District Advocacy Project

Carolyn LaViscount, Community Action Specialist commented in support of Option III D. Ms. LaViscount stated: "The 12th Planning District Advocacy Project is a group made up of consumers and stakeholders in our area formed with the explicit purpose of advocating for community-based services for those with disabilities. We want Virginia's policies and procedures to provide an opportunity for those with disabilities to stay out of institutions and in their own homes. We consider the Medicaid Waivers to be an essential and cost-effective means for facilitation of community-based services. We strongly support a recommendation to the General Assembly that the Personal Needs Allowance for ALL waivers be increased to 300% of SSI (\$1635). All consumers with disabilities face significant expenses in attempting to live in the community and should not face a prohibitive co-payment or be required to forego services. Raising the Personal Needs Allowance for all waivers will also simplify the system and make it more equitable."

Valley Associates for Independent Living, Inc.

Gayl Brunk, Outreach Director, commented in support of Option III D. Ms. Brunk stated: "Many individuals desire to remain in their home environment. They wish to experience the least restrictive environment for as long as they possibly can. They desire independent living. The Medicaid E & D Waiver has potential to permit this and make this goal a reality. The cost of remaining in ones community is less than a nursing home facility. The current stumbling block to individuals with disabilities accessing Medicaid Waivers is the hardship that co-pays present to many individuals....Census shows that individuals are living longer and our aging population is growing. It remains cost effective for individuals with all disabilities to live independently in the community versus an institutional setting. The above change would also simplify the process and paperwork involved."

Virginia Department of Medical Assistance Services

Patrick W. Finnerty, Director, does not comment on any of the proposed Options but states:

The Commission report clearly identifies that there are concerns with the current Medicaid policy for the personal maintenance allowance in our waiver programs. Department staff are currently involved in several work groups, which include all the major stakeholders. These groups are reviewing this issue and several related issues as they relate to providing institutional, community-based, and supportive services to individuals with disabilities. These work groups include such topics as the Olmstead decision, Medicaid Buy-In, and Medicaid Community Based Care Waiver programs. Therefore we would like to have the opportunity to provide input on these options at a later date once we have had the chance to conduct a thorough evaluation of the impact of the suggested changes on the clients and the program.

Virginia Poverty Law Center

Jill A. Hanken, Staff Attorney, commented in support of Option III D. Ms. Hanken stated: "To be consistent with the basic income eligibility level for Medicaid covered nursing home care, the PMA should be raised to 300% of SSI... This does not mean that the state would provide this level of cash to waiver participants! Instead, people would simply be able to keep their own income – up to this level – to meet their living expenses in the community." Ms. Hanken continues by listing and explaining the following six reasons for supporting Option III D:

- 1. People should be able to use their own income (up to \$1635 per month) to meet their living expenses.
- 2. Virginia can save money by keeping people home longer.
- 3. Raising the PMA to 300% of SSI promotes simplicity.
- 4. Raising the PMA to 300% of SSI in all the Waivers promotes uniformity between the various community based services.
- 5. Raising the PMA to 300% of SSI ends the current discrimination against non-married persons.
- 6. Raising the PMA to 300% of SSI is consistent with the requirements of the Americans with Disabilities Act and the Olmstead decision.

Lisbet Ward

Lisbet Ward commented in support of Option III with the addition of the DD waiver. Ms. Ward stated that before she became employed, she received SSI due to her disability. Ms. Ward indicated further: "It is not easy. What corners do you cut? Food? Electricity? Clothes? Now I have a full time job and making ends meet is still not easy. I don't know how I did it on SSI. I have friends still on SSI and I observe daily the tough choices they must make. Please take away the co-pay restriction and allow people to live with dignity."

Waynesboro Disability Services Board

Charles F. Downs, Chair, commented in support of III D. Mr. Downs indicated: "At this week's Waynesboro Disability Services Board meeting, we had a guest talk about the proposals for the Medicaid Elderly and Disabled Waiver Program. After some discussion, there was consensus and a motion passed to support Option III D. As you may know, DSB's were established throughout the Commonwealth to seek out unmet needs for those with physical and sensory disabilities and to advocate on their behalf for services, needs and accommodations within the community. We believe the above proposed option offers the most likely incentive and opportunity for this population to live independently in the community versus an institutional setting."

Lynn Weiss

Lynn Weiss commented in support of Option III with the addition of the DD waiver. Ms. Weiss stated: "I would like to say that a person with disabilities

cannot live on \$565.00 a month. I support option 3 and would like to have the DD waiver added to it. I sometimes wonder how adults with disabilities survive without family, church and friends. There has to be a better way for services and to be independ[ent]."

JOINT COMMISSION ON HEALTH CARE

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