REPORT OF THE
DEPARTMENT OF MEDICAL ASSISTANCE SERVICES

A REPORT ON THE METHODS FOR AND FEASIBILITY OF DEVELOPING A WAIVER FOR CHILDREN WITH PHYSICAL DISABILITIES THAT IS SEPARATE FROM CURRENT DEPARTMENT OF MEDICAL ASSISTANCE SERVICES WAIVERS

TO THE GOVERNOR AND
THE GENERAL ASSEMBLY OF VIRGINIA

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Department of Medical Assistance Services

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TO: Honorable James S. Gilmore, III

and

The General Assembly of Virginia

This report contained herein is pursuant to House Joint Resolution 182, passed by the 1998 General Assembly.

This report constitutes the response of the Department of Medical Assistance Services to this resolution and evaluates the methods for the feasibility of developing a waiver for children with physical disabilities that is separate from current department of Medical Assistance Services waivers.

Respectfully submitted,

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Enclosure

PREFACE

The 1998 General Assembly passed House Joint Resolution (HJR) 182 which requests the Department of Medical Assistance Services to study the methods for and feasibility of developing a waiver for children with physical disabilities that is separate from current Department of Medical Assistance Services waivers. For purposes of this study, this will be referred to as a study of *children's waiver* services. Under HJR 182 it was anticipated that DMAS would develop a waiver that would provide services to children with physical disabilities and provide parents with as much control as possible in the care of their children. Incorporating a self-directed model of service into a program designed to meet the needs of a population that requires an institutional level of service necessitates careful consideration.

The Department of Medical Assistance Services convened a Workgroup for the purpose of evaluating the impact on consumers, provider and other agencies in the community of offering a waiver for children. The members of the Workgroup were:

Virginia Association for Home Care	Ms. Kelly Carter
Consumer Representative/Centers for Independent Living	Ms. Maureen Hollowell
Department of Social Services	Mr. Vincent Jordan
Department of Rehabilitative Services	Ms. Martha Adams
Department of Education	Ms. Barbara Klear
	Mr. John Mitchell
Department of Health	Ms. Joy Price
Department of Mental Health/Mental Retardation & Substance Abuse Services	Ms. Shirley Ricks
Department of Medical Assistance Services	Ms. Michelle Baker
	Ms. Anita Cordill
	Ms. Karen Lawson

We wish to extend our appreciation of the time and efforts the members of the HJR 182 Workgroup expended in their review and input to this report. We would also like to acknowledge the contributions of Dr. Barbara Ettner of the Virginia Board for People with Disabilities and Ms. Cathy Maybe.

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EXECUTIVE SUMMARY

House Joint Resolution 182 (Appendix I) directed the Department of Medical Assistance Services ("DMAS") to "study the methods for and feasibility of developing a waiver for children with physical disabilities that is separate from current Department of Medical Assistance Services waivers." For purposes of this study, this will be referred to as a study of *children's waiver* services. Under HJR 182 it was anticipated that DMAS would develop a waiver that would provide services to children with physical disabilities and provide parents with as much control as possible in the care of their children.

DMAS convened a workgroup for the purpose of evaluating the feasibility of developing a waiver for children with physical disabilities that is separate from current DMAS waivers. The members of the workgroup included: representatives from the Virginia Association for Home Care, Department of Health, Department of Education, Department of Mental Health, Mental Retardation, and Substance Abuse Services, Department of Rehabilitative Services, Consumer Representatives for Children with Physical Disabilities, Centers for Independent Living, Department of Social Services, and DMAS .

There is consensus among the Workgroup and DMAS that Virginia could develop a new home and community-based waiver to offer children with physical disabilities services that would help keep them in their homes and communities. The following recommendations address the feasibility and advisability of offering a home and community-based care waiver for physically disabled children and are in no way intended to fully outline all the details which must be addressed in developing and implementing a waiver for physically disabled children.

Recommendations:

- DMAS could develop a new home and community-based care waiver could serve children with severe physical disabilities under 18 years of age and who meet functional and eligibility requirements. Functional requirements include those children who have related conditions as specified in 42 CFR § 435.1009. These requirements would be in accordance with the population HJR 182 seeks to maintain in the community, thus avoiding institutionalization.

- There is a possibility that offering a new Medicaid home and community-based care waiver for children with developmental disabilities would encourage entry into the waiver of a population that previously did not participate in a waiver, even though they may have met programmatic and financial eligibility criteria. This also might include some children with related conditions who are on the waiting list to receive services in the Mental Retardation Waiver. To provide DMAS with a better understanding regarding the number of children who may access services under a new waiver, DMAS could develop a model 1915(c) home and community-based care waiver with an initial enrollment limit of 200 children per year during the first three years of operation. After DMAS obtains a better understanding of

the number of children who would be eligible for services, the limit could be removed and costs could be adjusted to account for all children who need the service, although this would not be required.

- Services that could be provided in a home and community-based care waiver include personal care, respite care, assistive technology, home modifications and case management.

- The waiver could contain a consumer-directed model of service for parents of children enrolled in the waiver who are under 18 years of age. Under this model, parents could have the ability to hire, train, supervise and fire the personal attendants who provide care. DMAS would need to identify what guidelines would be used to determine if a parent is incapable of independently managing the child's personal attendant. In addition, parents who are interested in being the employer in the CD-PAS Program could receive consumer training that will assure that the parents understand how to manage the child's service.

    * If this model is chosen, DMAS could mandate additional requirements for personal attendants in the consumer-directed model of service. For example, personal attendants would be screened through the DSS Child Protective Services Registry in addition to completing a criminal history record check with the State Police.

- A new Medicaid home and community-based care waiver that serves 200 disabled children who meet ICF/MR level of care criteria would demonstrate a cost savings to the Commonwealth of $6,536,000 per year to provide services in the home or community versus the ICF/MR institutional setting. The total projected costs for a new waiver to serve approximately 200 physically disabled children per fiscal year would be $6,535,800. Of this amount, approximately $4,403,592 in additional Medicaid funding would be needed to implement the waiver. DMAS would also require additional funding of $99,200 to pay for Medicaid Management Information System development and implementation and staffing to provide waiver oversight.

- The new Medicaid Management Information System (MMIS) system is projected to begin operation in sometime beginning in the year 2001. Since the new system will not be ready for implementation under after January 1, 2001, the existing MMIS system will need to be prepared for Year 2000 Compliance. Preparing the existing MMIS system for Year 2000 Compliance or implementation of the new MMIS system will be given priority over other projects. Therefore, the most realistic proposal to develop and implement a new home and community-based waiver would be January 2001.

INTRODUCTION

The Department of Medical Assistance Services currently offers four home and community-based care waiver to children in need of long-term care services. The waivers provide services as an alternative to institutionalization and help to keep children at home with their families and in their communities. Current Medicaid waivers that provide services to children include the Elderly and Disabled Waiver, the Mental Retardation Waiver, the AIDS Waiver, and the Technology Assisted Waiver. As of May 1998, 465 children were receiving long-term care services through the home and community-based care waivers.

Although the waiver services provided are effective in keeping children in the community, there are limitations with the waivers that can preclude some children from receiving services and providing parents with as much control as they would wish over the provision of services to their children. Limitations include: diagnosis specific criteria for admission to certain waivers; services provided in waivers that were not developed with the consideration of the needs of children; an assessment process that does not take childhood development into consideration when assessing functional limitations; and restriction from a waiver that allows for consumer-directed personal attendant services because beneficiaries have to be 18 years of age and older.

Virginia's Medicaid program does not have a home and community-based care waiver that is specifically designed to serve physically disabled children with long-term care needs. Rather, children receive services in home and community-based care waivers that are designed for all ages, such as the Elderly and Disabled and Mental Retardation Waivers. Concerned citizens and families would like to see DMAS develop a waiver for children at risk of institutional care that would specifically provide services to children with physical disabilities and provide parents with as much control as possible in the care of their children. Services could include personal care, respite care, home modifications, assistive technology and specialized day care services that would meet the needs of the children and families alike.

One aspect parents would especially like to see in a home and community-based care waiver includes the parents' ability to have more consumer direction regarding their child's care, specifically for personal care. In a consumer-directed model of service, the parent (as the employer) would be responsible for hiring, training, supervising, and firing the personal care aides that provide services to their children. This option, to the knowledge of DMAS, is not currently being offered under any other Medicaid-funded home and community-based care waivers in the nation. Although the concept of allowing parents control over their child's personal care needs through a Medicaid-funded consumer-directed model is relatively new, consumer-directed personal attendant services is not a new type of service to the Commonwealth. Consumer-directed services provided through the Department of Rehabilitative Services' Personal Assistance Services Program and the DMAS Consumer-Directed Personal Attendant Services (CD-PAS) Waiver have been successfully implemented.

MEDICAID-FUNDED LONG-TERM CARE SERVICES FOR CHILDREN

The Department of Medical Assistance Services (DMAS) offers a variety of home and community-based long-term care services to children and their families in Virginia.

Home and Community-Based Care Waivers

Medicaid home and community-based care (HCBC) waivers, established in 1981, afford States the flexibility to develop and implement creative alternatives to placing Medicaid-eligible individuals in medical facilities such as nursing homes. The HCBC waiver program recognizes that many individuals at imminent risk of being placed in an institutional setting can be cared for in their homes and communities, preserving their independence and ties to family and friends at a cost no higher than that of institutional care.

Under section §1915(c) of the Social Security Act (the Act), States may request waivers of certain Federal Requirements which impede the development of Medicaid-financed community-based treatment alternatives. The requirements that may be waived are in section 1902 of the Act and deal with statewideness, comparability of services, community income and resource rules, and rules that require States to provide services to all persons in the State who are eligible on an equal basis. States have the flexibility to design each waiver program and select the mix of waiver services that best meets the needs of the population they wish to serve.

To receive approval to implement HCBS waiver programs, State Medicaid agencies must assure the Health Care Financing Administration (HCFA) that the cost of providing home and community-based services will not exceed the cost of care for the identical population served in an institutional setting. The Medicaid agency must also document that there are safeguards in place to protect the health and welfare of beneficiaries. A full description of the waivers (and the services currently offered in each) can be found in Appendix II.

Although DMAS currently offers services to children in four home and community-based care waivers, there are limitations that can preclude some children from receiving services and providing parents with as much control as they would wish over the provision of services to their children. In the Technology Assisted, Mental Retardation, and AIDS Waivers, the eligibility criteria is diagnosis or condition specific, thereby limiting waiver access to special populations. One waiver, the Mental Retardation Waiver, has a waiting list of over 5,000 individuals and primarily serves individuals with mental retardation. In addition, although the Elderly and Disabled Waiver provides personal and respite care services to children, it is geared toward the needs of the elderly and older disabled individuals and does not necessarily meet the needs of younger children and their families. For example, adult day health care services offered under the Elderly and Disabled Waiver is not a service that could provide day care services for children with special health care needs. The personal care

program is also an agency-directed model of care that does not provide parents with much control over the persons who provide services to their children.

Other States' Experiences with Providing Long-Term Care Services for Children

Virginia is similar to other states in that the Commonwealth does not have a home and community-based waiver that provides long-term care services exclusively to children. Rather, children are eligible for services under various waivers that were not specifically developed for children or their families, such as the Elderly and Disabled Waiver.

In preparation for this study, DMAS researched how other states currently provide long-term care services specifically to children with developmental disabilities. DMAS contacted states that were identified by the American Public Welfare Association (APWA) as providing Medicaid-funded home and community-based care waivers specifically developed for children only and inquired about the funding mechanism used and services offered. Long-term care waivered services provided by states include environmental modifications, assistive technology, private duty nursing, respite care, case management, transportation, personal care, etc. Some states, such as Colorado, Georgia, Michigan, and Texas offer waivered services to children with developmental disabilities. Some states have waivers with an enrollment cap that limits the number of children that can be served at any given time on the waivers. Long-term care services vary from state to state as well as the number of children that are being served. On average, the per capita rate for states providing services to children with developmental disabilities is $29,548.

One state, Colorado, offers a 1915(c) model home and community-based waiver for physically disabled children and children with developmental disabilities from birth to 17 years of age. The waiver has a cap of 200 children and a waiting list of 300 children for each level of care. One level of care provides private duty nursing for children who are technologically dependent and would require hospital care without the provision of the waivered services. The other level of care provides personal care and case management services to children who would be at risk of entering a nursing facility without the provision of these services. This state is currently considering lifting the cap for services if its General Assembly provides the additional state funding to provide services to children on the waiting list. Colorado does have an Elderly and Disabled Waiver that is similar to the Virginia Elderly and Disabled Waiver but it does not serve children under this waiver. Instead, children must meet qualifications for services offered under the children's waivers. Children must also have a caregiver that provides a set amount of care to the child, as the waiver does not provide 24-hour care.

ISSUES TO BE CONSIDERED WHEN DEVELOPING A MEDICAID WAIVER FOR CHILDREN WITH PHYSICAL DISABILITIES

Type of Waiver

Some Workgroup members suggested DMAS develop a "family friendly" home and community-based care waiver which offered families "one stop shopping", or an array of services for all children requiring long-term care services. Children who may require long-term care services include children with mental retardation, physical and sensory disabilities, those with a diagnosis of HIV/AIDs, and those who are technologically dependent or require skilled nursing care.

When considering offering a comprehensive array of long-term care services for all children under one waiver, it must be noted that the administration of a waiver to provide long-term care services to children would be cumbersome and difficult. This is because children with varying disabilities and illnesses qualify for differing types of services under different funding streams. For instance, individuals who qualify for specialized services that are similarly provided in the Mental Retardation Waiver must meet intermediate care facilities for the mentally retarded (ICF/MR) criteria, whereas individuals who qualify for services similarly provided under the Elderly and Disabled Waiver must meet nursing facility level of care criteria. Children who require long-term care services are currently placed in waivers that are geared to provide services that meet their needs in accordance with specified levels of care.

It can be argued that some children "fall between the cracks" of existing waivers because they cannot access some waivers that are restricted to them (i.e., the Consumer-Directed Personal Attendant Services Waiver), or services provided in existing waivers do not meet the needs of children and their families. Examples of children that cannot access existing waivers include children with autism and some forms of cerebral palsy.

A new home and community-based care waiver could assist with providing services to physically disabled children who are being inappropriately served in existing waivers or who cannot access existing waivers due to eligibility requirements. The type of waiver that DMAS could seek is the 1915(c) Model Home and Community-Based Care Waiver. This waiver is similar to the other home and community-based care waivers that DMAS uses to offer existing long-term care services to Medicaid beneficiaries, only the waiver would have an initial enrollment cap of 200 individuals during its first three years of operation. Since the legislation requested the feasibility of offering services under a waiver separate from existing waivers, this format could be the best method to accomplish this. Services offered under the waiver could be in lieu of what is currently offered under existing waivers and could offer more consumer choice and control to parents than what is offered under the existing waivers. This type of waiver could also provide beneficiaries with freedom of choice of service providers.

Eligibility Criteria

The Workgroup assisted DMAS with identifying minimum eligibility criteria for services under a new 1915(c) home and community-based care waiver. If a new waiver was developed, the criteria outlined below identify what a child would have to meet in order to receive services under a new waiver. The child would have to:

- Be under 18 years of age;
- Be determined to be at imminent risk of institutional (ICF/MR) placement; and
- Have a primary caregiver that will accept responsibility for the child's care and be available to provide the child's care for a specified period of time per day.

In addition, DMAS would require the child to meet the definition of a person with related conditions, as specified in Title 42, Code of Federal Regulations § 435.1009. The definition of a person with related conditions is an individual who has a severe, chronic disability that meets all of the following conditions:

(A) It is attributable to -
  (1) Cerebral palsy or epilepsy; or
  (2) Any other condition, other than mental illness, found to be closely related to mental retardation because this condition results in impairment of general intellectual functioning or adaptive behavior similar to that of mentally retarded persons, and requires treatment or services similar to those required for these persons.
(B) It is manifested before the person reaches age 22.
(C) It is likely to continue indefinitely.
(D) It results in substantial functional limitations in three or more of the following areas of major life activity:
  (1) Self-care.
  (2) Understanding and use of language.
  (3) Learning.
  (4) Mobility.
  (5) Self-direction.
  (6) Capacity for independent living.

Once a child in the new waiver turns 18 years of age, he or she would have the opportunity to access other Medicaid-funded home and community-based services, such as those provided under the Elderly and Disabled Waiver or the CD-PAS Waiver.

Initial Assessment of Needs and Service Planning Process

If a new waiver is developed, the child's status as an individual in need of waivered services could be determined by the Nursing Home Preadmission Screening (NHPAS) team. DMAS currently contracts with 249 NHPAS teams, which are responsible for performing Nursing Home Preadmission Screening for nursing home or community-based care

placements, and they provide a comprehensive identification of the functional, medical, and psychosocial status of the beneficiary as well as an assessment of their physical environment and support system. For children who live in the community, the NHPAS team is comprised of a nurse and physician from a local department of health and a social worker from a local department of social services. For children who are hospitalized in acute care facilities, the NHPAS team is a social worker and/or a registered nurse and a physician. If a new waiver is developed, the NHPAS teams would receive training from DMAS regarding the content of the new waiver and eligibility criteria.

The current preadmission screening assessment process uses a comprehensive assessment instrument, the Uniform Assessment Instrument (UAI), and the established Medicaid criteria for waiver services to assist the NHPAS team to objectively assess the child's strengths and needs. The NHPAS team uses the assessment process to determine whether the child meets nursing home level of care criteria and, if so, helps the parent to determine what would be the most appropriate placement for the child. Placement options could include various home and community-based care services.

Cost

The costs of care for any individual in a home and community-based care waiver must not exceed what it would cost to care for the child in an institutional setting. This is required of all Medicaid home and community-based care waivers by HCFA. DMAS could use the yearly average cost of ICF/MR institutional care for comparison when setting a cost limit for services under the new home and community-based care waiver. The costs for waiver services in addition to other Medicaid services the beneficiary receives, such as drugs, acute care hospital stays, and physician services are also factored into formulating the cost limit. Caregivers and case managers would be able to customize a care plan within the cost limit for children that would be a cost-effective alternative to ICF/MR institutional care.

Administrative Responsibility for the Waiver

DMAS is the single state agency responsible for determining client eligibility for Medical Assistance under Title XIX of the Social Security Act (42 CFR § 431.10). As such, DMAS would assume all administrative responsibilities for providing services to children with physical disabilities under the home and community-based care waiver. This would include ensuring that all requirements of the waiver are met, including performing quality assurance and utilization review, and ensuring payment to service providers.

POTENTIAL SERVICES FOR CHILDREN UNDER THE NEW MEDICAID WAIVER

Selection of Services Available

The following describes services suggested by the Workgroup and DMAS that could be included in a waiver that could provide services to children with physical disabilities:

Case Management

This service would assist the parent with gaining access to needed waiver and other State plan services, as well as needed medical, social, educational, and other services that would help meet the needs of the child and family. This would be a mandatory service in the waiver, and it would be provided by Medicaid approved providers of case management services. The current monthly cost for case management services under the Mental Retardation Waiver is $175.40 per month, or $2,108 per year. The costs for case management services under a new waiver would be similar.

If a new home and community-based care waiver for children is developed, each eligible child would be able to receive a variety of services under the waiver. The parent would be able to work with the case manager to "choose" which services would best meet the child's needs, which would not exceed the individual cost limit for services under the new home and community-based care waiver. The parent would additionally be able to develop a plan of care with a case manager, which would identify the child's needs and specify the amount of services to be provided. The parent's ability to select services and individualize their child's care plan will provide the caregiver with more choice and autonomy, and control over the types of services the child receives.

Assistive Technology

The child would have an annual limit of $5,000 for special medical equipment and supplies that would enable the child to be more independent in the home or community. This is a limit that has already been established in the Mental Retardation waiver. An example of assistive technology includes TDD for the hearing impaired. Payment of assistive technology items will be restricted to items that are not currently available under the State Durable Medical Equipment state plan benefit. A case manager would need to determine what is medically necessary for children who need assistive technology.

Home Modifications

The child would have an annual limit of $5,000 on renovations. This is a limit that has already been established in the Mental Retardation waiver. The purchase of home modifications that would assist in changing the child's physical surroundings in order to

maintain that child's health. Examples of home modifications include building wheelchair ramps, widening doorways, installing grab bars in the bathtub, etc. Case managers would need to determine what would be medically necessary for children who need home modifications.

Personal Care

Personal care services are long-term maintenance or support services necessary to enable the individual to remain at or return home rather than enter a nursing care facility. Personal Care services include assistance with personal hygiene, nutritional support, and the environmental maintenance necessary for beneficiaries to remain in their homes. Medicaid cannot pay for personal care services if there is no medical care component to it and it will not be used for "baby-sitting" purposes. If a new home and community-based care waiver for children were developed, this service would be the same as is currently offered in the Elderly and Disabled Waiver. This service is currently referred to as an agency-directed model of care.

Under the Elderly and Disabled Waiver, personal care agencies are licensed or certified under a state or federal entity before they are enrolled by DMAS as a provider of services. Registered nurses with Virginia licensure are hired to provide supervision of the personal care attendant and oversee the consumer's needs and fulfillment of the criteria for the waiver. The registered nurse makes supervisory visits as often as needed (at least every 30 days) to ensure both quality and appropriateness of services. The plan of care is developed by a nurse supervisor and submitted to DMAS for approval; reevaluations are conducted every six months. The ratio of registered nurses to attendant staff is one full-time RN to forty personal care attendants or one full time RN to thirty-five consumers.

Persons who are personal care attendants under the waiver must: 1) be registered as a Certified Nurse Aide; or 2) graduate from an approved education curriculum such as Nursing Assistant, Geriatric Assistant, or Home Health Aide; or 3) receive pre-approved DMAS curriculum training from the provider agency. Other requirements include documentation of a positive work history, a copy of the attendant's certification, and at least two reference checks. Personal care attendants may not be a member of the consumer's family or have legal guardianship of the consumer.

Under a new waiver, personal care agencies would give parents as much control and choice as possible regarding the development of the child's plan of care and the provision of personal care services rendered to the child.

Respite Care

Respite care is a service that is specifically designed to provide caregivers with temporary relief of caregiving responsibilities of an individual who is incapacitated or dependent due to frailty or physical disability. Respite Care Services includes assistance with personal hygiene, nutritional support and environmental maintenance authorized as either

episodic, temporary relief or as a routine periodic relief of the caregiver. Medicaid cannot pay for respite care services if there is no medical care component to it and it will not be used for "baby-sitting" purposes.

In addition, DMAS could offer facility-based respite care through the waiver. Members of the Workgroup stressed to DMAS that if facility-based respite care is offered, that children be also offered residential models of respite-based care. DMAS would further define what would constitute a residential model of care. Examples of residential models could include subacute facilities, such as ICFs/MR, that would provide temporary care to children in an environment that would provide for their custodial needs and also keep them active with age appropriate activities.

"Savings Account"

The family may elect not to spend the entire allotment for services in the year, but may choose to place them in a "savings account" that would be used toward future services. For example, if a piece of assistive technology would cost more than $5,000, the family may choose to "save" the money until the following year to enable them to purchase a more expensive piece of technology. Or, the family may anticipate needing more personal care in one year due to expected surgery and could "save" some of the funds to be used the following year.

CONSUMER-DIRECTED APPROACH TO PERSONAL CARE SERVICES

A consumer-directed model of service is based on the principle that individuals should have the primary responsibility for making decisions regarding the assistance they receive. This maximizes the independence and autonomy of persons who need functional assistance from others. Under the consumer-directed model the consumer recruits, hires, trains, manages and directs his or her own provider of services, known as a personal attendant. The consumer is directly responsible for: 1) Determining what activities the attendant performs on a daily basis; 2) Negotiating what times the attendant arrives and departs; 3) Having a back-up plan in place for those times when the attendant cannot provide the needed service; 4) Generating any paperwork necessary to assure accountability of public funds; and 5) Notifying appropriate persons when needs change. The personal attendant is accountable to the consumer rather than to a supervisor of a provider agency, and follows the consumer's directions as to how to meet his or her needs. Persons that receive consumer-directed services also report greater flexibility on the part of the person providing service to work early mornings or late nights and weekend hours than is experienced by consumers receiving an agency-directed model of care.

HJR 182 requested DMAS to study offering parents of children receiving services in the waiver more consumer direction regarding their child's care. In this model of service, the parent (as the employer) would be responsible for hiring, training, supervising, and firing the personal care aides that provide services to their children. This option, to the knowledge of DMAS, is not currently being offered under any other Medicaid-funded home and community-based care waivers in the nation. Although consumer-directed personal attendant services is not a new type of service to the Commonwealth, the concept of allowing parents control over their child's personal care needs through a consumer-directed model is relatively new. This section addresses the consumer-directed model and brings attention to issues that will need to be explored before this service, if approved, becomes effective in a new children's home and community-based care waiver.

Other State Medicaid Agencies' Experience with Consumer-Directed Services for Families

DMAS reviewed other states that provide waivered services to children and could not find other states that currently provide Medicaid-funded personal attendant waiver services to parents of children with physical disabilities. The consumer-directed personal care programs are instead geared toward individuals 18 years of age and older.

DMAS did find the exception with one state, Alaska, which has been operating a 1915(c) waiver since 1994 and offers a consumer-oriented model of respite care services for parents of developmentally disabled children receiving waiver services. Alaska's program uses a voucher system for respite care. Due to the remoteness of most Alaskan communities, the labor pool is restricted to individuals in the immediate area. Furthermore, provider agencies are concentrated in larger towns and cities, thus making it difficult or impossible to deliver respite services in traditional manners. Therefore, Alaska offers respite care under a voucher

system as an option in the waiver. Voucher services empower families by giving them direct control over how and when the services are provided and will enable closer scrutiny of the quality of those services. Voucher respite care may be provided only if approved in the beneficiary's plan of care.

The family selects and trains an individual to render respite services. The family signs a letter of agreement with the provider agency acknowledging responsibility for compliance with waiver caregiver qualifications and IRS rules. The provider agency issues coupons to the family based on the number of hours of service at the rate approved in the plan of care. The coupon includes a line for the family's signature stating that the renderer meets qualifications defined in the waiver. When the service is rendered, the family notifies the provider that the service was rendered satisfactorily. The coupon is submitted to the provider agency for payment of services rendered.

Although the Alaska's voucher program is not necessarily a example that Virginia would choose to model and implement, it does demonstrate that a consumer-directed model of care for parents of children can be successful. This program has served over 300 families and is strongly supported in the Alaskan community.

Current State Approaches to Providing Consumer-Directed Services

Consumer-Directed Personal Attendant Services Waiver

The DMAS Consumer-Directed Personal Attendant Services (CD-PAS) Home and Community-Based Care Waiver became effective on July 1, 1997, as a result of advocates' efforts to expand the provision of consumer-directed personal attendant services to Medicaid beneficiaries. The CD-PAS Waiver has served approximately 28 individuals since February 1998.

Personal attendant services under the CD-PAS Waiver are long-term maintenance or support services which are necessary to enable elderly or disabled individuals over the age of 18 to remain at or return to their home rather than enter a nursing facility or hospital for a specified condition. Services include assistance with activities of daily living (ADLs), such as feeding, tolieting, dressing, and ambulation. Supportive services include assistance with instrumental activities of daily living (IADLs), such as grocery shopping and house cleaning.

Consumers who express interest in the CD-PAS Program must be elderly or, if disabled, at least 18 years of age and are capable of managing their own affairs (have no cognitive impairments). Consumers must meet additional functional and eligibility requirements for the program, which include meeting the nursing facility level of care criteria and being at imminent risk of nursing facility placement if not for the provision of the service.

If found eligible for this service, individuals have the primary responsibility for making decisions regarding the types of assistance they receive. Under the CD-PAS Waiver, beneficiaries can hire, train, supervise, and fire their own personal attendants. The beneficiary

of these services is in charge of recruiting their own personal attendants and finding alternates for emergency, back-up care. The personal attendants who provide the care are paid $8.25 an hour in the Northern Virginia area and $6.00 an hour for all other areas of the State.

After demonstrating their ability to manage and supervise their own attendants, individuals choose a service coordination provider that will provide supportive services to the beneficiary. Some supportive services the service coordinator provides to the beneficiary include training individuals about their rights and responsibilities as employer in the CD-PAS Waiver, developing and periodically monitoring the beneficiary's plan of care, and submitting criminal history record checks (on the personal attendant) on the beneficiary's behalf. Another supportive service available to the beneficiary is the fiscal agent. The fiscal agent is a state agency, DRS, that has contracted with DMAS to handle payroll and employment tax issues on the beneficiary's behalf. The fiscal agent processes the personal attendant's timesheets and pays the personal attendants on the beneficiary's behalf and handles employment tax issues as required by the Internal Revenue Service (IRS) for the beneficiary.

Department of Rehabilitative Services' Personal Assistance Services Program

The Personal Assistance Services (PAS) Program began as a pilot project under the Department of Rehabilitative Services (DRS) in September 1990 and became a statewide state-funded consumer-directed personal assistance program. Federal vocational funds are also used to provide personal assistance to individuals participating in educational and job training programs. Personal assistance services provided to individuals in the DRS PAS Program are similar to those provided in the CD-PAS Waiver.

Consumers who express interest in the PAS Program must be able to demonstrate they are capable of managing their own care needs, directing others in providing their care, managing their own affairs and have no cognitive disability that impairs their ability to direct their assistants. Services include, but are not limited to, personal care needs, homemaking needs, shopping or transportation. In this program, the consumer is responsible for hiring, training, and supervising his own attendant. Although there is no age limit for beneficiaries, the average age is 42 years of age.

Unlike a Medicaid waiver program, consumers do not have to be at imminent risk of nursing home placement although approximately 45% of the beneficiaries have met the nursing home admission criteria at some point. There is a waiting list to receive services, although high priority is given those in nursing homes who could return to the community with adequate help, as well as those at risk of entering a nursing home. The personal attendants who provide the care are paid at rate of $8.25 an hour for the Northern Virginia area and $6.00 an hour for all other parts of the State.

The DRS PAS Program has served approximately 60-70 children over the age of 10 and their families since 1990. If children are enrolled, the parent is in charge of hiring, training, supervising, and firing the personal assistant. Enrollment is also contingent upon the

premise that when the child is enough that he or she will successfully manage his or her own care.

PROPOSED CONSUMER-DIRECTED SERVICES UNDER THE CHILDREN'S WAIVER

Consumer Choice and Informing the Consumers of Rights, Risks & Responsibilities

One critical component of HJR 182 is the request to make the services in the new children's waiver as consumer-oriented as possible for the parent caring for the child. DMAS and members of the Workgroup recognized there has been an interest in offering personal care services in a consumer-directed model of care, wherein the parent is the person who selects, hires, trains, supervises, and fires the personal attendant that provides services to the child. This service is currently offered to adults over 18 years of age who are capable of managing their own attendants but is not available to parents of children with disabilities.

If a consumer-directed model of personal attendant services were to be offered to parents of children who received services under the new waiver, DMAS and the Workgroup recommend the use of the existing model of service in the CD-PAS Waiver. Appendix III provides a more detailed description of the Medicaid CD-PAS program. The consumer-directed model of service in the new children's waiver could allow a parent to be the employer and recruit, hire, train, supervise, and fire the personal attendants.

A description of how the consumer-directed model of service would apply to parents and their children and issues that would need to be addressed if parents are to serve as the employer for the child's care is presented below:

Provision of Personal (Care) Attendant Services

A consumer-directed model of personal attendant services would be available to families who are seeking an alternative to the agency-directed model personal care services. The definition of personal attendant services would remain the same as is currently defined in the CD-PAS waiver. Services include assistance with activities of daily living (ADLs), such as feeding, tolieting, dressing, and ambulation. Supportive services include assistance with instrumental activities of daily living (IADLs), such as grocery shopping and house cleaning.

Quality of Service Issues

Assessment Cognitive Abilities and Authorization of Child (and Parent) for CD-PAS Services

The current preadmission screening assessment process will also be used when determining if a child and the parent qualify for the CD-PAS program. The preadmission screening process will use the UAI and the established criteria for waiver services to provide a

comprehensive assessment of the functional, medical, psychosocial status of the child as well as an assessment of child's physical environment and support systems.

The current assessment tool (DMAS-95 Addendum) for determining an individual's ability to independently manage personal attendants would need to be revised if parents are allowed to consumer-directed their child's personal care. This is because the parent will be in control of the personal attendant, not the child (who is the beneficiary.) DMAS will need to identify what guidelines will be used to determine if a parent is incapable of independently managing their child's personal attendant. DMAS could also use the DMAS-95 Addendum as a resource when developing a tool to assess a parent's ability to manage the personal attendant.

The assessment tool would ensure, at a minimum, the parent exhibits the following knowledge, skills and abilities:

- The ability to understand the DMAS consumer-directed program requirements, including the risks, responsibilities, and their child's rights;
- The ability to perform personal attendant management skills, including the skills necessary to recruit, interview, hire, train and supervise the personal attendants;
- A willingness to take consumer management training;
- The ability and willingness to report changes in their child's physical health, other services rendered, household composition, which may affect the delivery of CD-PAS; and
- The ability to maintain the necessary documentation required to pay the personal attendant.

Supportive Services

Service Coordination Providers

One of the supportive services available under the consumer-directed model of care includes service coordination services. Services provided by the service coordinator include the comprehensive visit, consumer training, management training, routine onsite visits, reassessment onsite visits, conducting criminal history record checks, and maintaining a personal attendant registry. A more detailed description of the provision of these services can be found in Appendix IV.

Fiscal Agent

Another supportive service includes the use of a fiscal agent. A fiscal agent is an agency or organization that is contracted by DMAS and handles employment, payroll and tax responsibilities on behalf of the recipient who is receiving consumer-directed personal attendant services. The fiscal agent, currently the Department of Rehabilitative Services, processes the personal attendant timesheets, reimburses the personal attendant on behalf of the recipient, and handles any payroll issues for the recipient.

These supportive services would continue to be available to parents and their children who choose the consumer-directed personal attendant service in the children's waiver.

Service Standards

Service standards for providers could continue to remain the same in the consumer-directed model of service for families and their children who choose the CD-PAS component of service. Additional service standards for providers could be added, as appropriate. A more detailed outline of service standards for the CD-PAS program can be found in Appendix IV.

Training for Families

An integral component of a consumer-directed services is the ready availability of consumer training in how to self manage personal attendant services (including how to recruit, hire, train, supervise, fire personal attendants, and manage the paperwork). Consumer training is mandated in the CD-PAS Program and would also apply to families who would wish to utilize the consumer-directed model of service.

Standards for Attendants

The family member would have the same ability to hire their child's personal attendant and manage and supervise the attendant's performance. The parent would have to be mentally alert and be in complete control of his or her child's care. Therefore, the personal attendant should be able to provide, at the parent's discretion, any authorized services in the child's plan of care. The personal care attendant qualifications will be the same as the existing CD-PAS Program, with the addition of another qualification italicized below:

- Be 18 years of age or older;
- Have the required skills to perform personal care services as specified in the child's plan of care;
- Possess basic math, reading and writing skills;
- Possess a valid Social Security number;
- Be willing to submit to a criminal history record check. The personal attendant will not be compensated for services provided to the beneficiary if the records check verifies the personal attendant has been convicted of crimes described in 12 VAC 30-90-180;
- Be willing to attend training at the parent's request;
- Understand and agree to comply with DMAS program requirements;
- Be willing to register in a Personal Attendant Registry, which will be maintained by the provider agency chosen by the parent; and
- *Be willing to submit to a Child Protective Services Registry check.*

Personal care attendants could not be a member of the child's family. Family would be defined as a parent or stepparent, spouse, children or stepchildren, siblings or stepsiblings,

grandparents or stepgrandparents, and grandchildren or stepgrandchildren. In addition,. anyone who had legal guardianship or was a representative payee for the child would also prohibited from being a personal attendant under this program.

Service Coordinator

The service coordinator requirements would remain the same for the consumer-directed model of service provided in the children's waiver.

IMPACT ON VIRGINIA'S LONG-TERM CARE SYSTEM

Offering a new home and community-based care waiver for children with physical disabilities as an additional option would have an impact on the long-term care system. The impact is estimated to affect the provider community, consumers and their families, other state agencies, and the Medicaid budget.

The Provider Community

It is anticipated that the expansion of home and community-based care waivered services will benefit the provider community. Existing providers, such as service coordinators, would also be able to expand their services to children and their families. In addition, DMAS could issue a Request For Proposals (RFP) to contract with a company to exclusively provide case management services in the new waiver. This RFP would have a positive impact in the business community.

One disadvantage to the home health or personal care industry would be the loss of revenue from the children whose parents elect to switch from agency-directed to consumer-directed personal care services. The loss, however, would be minimal as there would only be a small percentage of parents who would opt this form of control. The agencies could also choose to offer both models of personal care and enroll as service coordination providers, which are the providers that are reimbursed for service oversight in the consumer-directed model of service.

Consumers

Advantages to the public include the availability of new home and community-based care service alternatives to institutionalization that offer more choice and control to eligible children and their families. For example, the consumer-directed personal care model could provide parents with additional control by giving them the choice to have more self direction over their child's personal care attendants.

Potential disadvantages to the public include the risk of fraud and abuse of Medicaid beneficiaries in the consumer-directed model of personal attendant care services. However, DMAS has safeguards in place to minimize this risk. Safeguards include criminal record checks on personal attendants, consumer training regarding how to self manage personal attendants, service coordinators who develop and periodically monitor the plan of care, and the fiscal agent, who handles tax and employment liability issues on behalf of the consumer.

State Agencies

The provision of a Medicaid-funded home and community based care waiver for children and their families could lessen the number of children who are currently being served or are on waiting lists in other state-funded programs, such as the DRS PAS Program. The

cost of services would go from all state dollars to a state and federal match of approximately 51 percent, which would be a cost-savings to the Commonwealth.

The Medicaid Budget

Projected Enrollment and Costs

There is a possibility that offering a new home and community-based care waiver for children with developmental disabilities would encourage entry into the waiver of a population that previously did not participate in a waiver, even though they may have met programmatic and financial eligibility criteria. This also might include some children with related conditions who are on the waiting list to receive services in the Mental Retardation Waiver. To provide DMAS with a better understanding regarding the number of individuals who may access services under a new waiver, DMAS proposes developing a model 1915(c) home and community-based care waiver with an initial enrollment limit of 200 individuals during the first three years of operation. After DMAS obtains a better understanding of the number of individuals who would be eligible for services, the limit could be removed and costs could be adjusted to account for all individuals who need the service, although this would not be required.

When estimating the costs for a new children's waiver, DMAS projects the children currently being served in the Elderly and Disabled Waiver will be "switched" over to the new waiver. It is estimated that 104 children currently being served in the Elderly and Disabled Waiver could access services under a new children's waiver. In Fiscal Year 1998, the average total cost for children in the Elderly and Disabled waiver was $20,502, compared to the average total cost of $12,105 for all individuals being served in the Elderly and Disabled waiver. The average 1998 annual cost per child was $7,947 for personal and respite care, $7,339 for practitioner services, $1,694 for pharmacy services, and $3523 for inpatient hospital services. A child who received services in the Elderly and Disabled waiver was eligible for an average of 83 months, or almost 7 years, on the waiver. The shortest eligibility period was 9 months, compared to the longest eligibility period of 184 months, or 15 years. Although the average annual cost for providing services to children under the waiver is higher than the average annual cost for the entire waiver population, the cost is still considered to be cost effective because it is less than the average annual cost for nursing facility care. Reasons for higher costs of service include an increase in the utilization of physical therapy/occupational therapy services by children and low utilization of services by some individuals in the waiver that drive the overall average costs for all waiver recipients down.

For the purposes of a new children's waiver, the average cost of ICF/MR institutional care would be considered when determining the annual costs of care. In Fiscal Year 1997, the average annual cost for ICF/MR institutional care was $65,359. To help maintain costs, a percentage of the average annual cost of ICF/MR institutional care could be set as a limit, or "cap", for expenditures of home and community-based care services in the waiver. The waiver could stipulate that care provided to individuals in a new home and community-based care waiver would not exceed that percentage limit. Services provided under the waiver would

be capped at 50% of the ICF/MR institutional care costs, which would be $32,679 per child. This would demonstrate a cost savings to the Commonwealth of $32,680 per child to provide services in the home and community versus the ICF/MR institutional setting. By providing long-term care services to approximately 200 children under a waiver in lieu of ICF/MR institutional care, the Commonwealth would save $6,536,000 per year.

With an enrollment limit of 200 children into the waiver its first three years of service, the average cost of care for children under the waiver is estimated to be $6,535,800. The amount takes into account a projected assumed utilization rate of services in the waiver. To help control service utilization in the waiver, DMAS-approved case managers would have the ability to authorize up to $20,000 worth of waiver services per child, per year. Any additional costs beyond this amount would have to be pre-authorized by DMAS. Since it is projected 104 of the children currently being served in the Elderly and Disabled Waiver could "switch" to the new home and community-based care waiver, their existing Medicaid waiver costs of $2,132,208 would reduce the amount of additional Medicaid funding needed to $4,403,592.

System Development and Implementation

The costs of Medicaid Management Information System (MMIS) program development and implementation will need to be considered when estimating a budgetary impact for this waiver. It is estimated that the cost for developing and implementing MMIS system changes for a new home and community-based care waiver service and service population could cost up to $50,000. This estimation was derived from the costs of implementing changes in the existing MMIS system for the most recent home and community based waiver, Consumer-Directed Personal Attendant Services. The costs for developing and implementing changes to either system may cost more depending on the staff available to work on the project.

The new MMIS system is projected to begin operation in sometime beginning in the year 2001. Since the new system will not be ready for implementation under after January 1, 2001, the existing MMIS system will need to be prepared for Year 2000 Compliance. Preparing the existing MMIS system for Year 2000 Compliance or implementation of the new MMIS system will be given priority over other projects. Therefore, the most realistic proposal to have a new home and community-based waiver developed and implemented would be January 2001.

Agency Monitoring and Review

Since DMAS is the single agency responsible for determining client eligibility for Medical Assistance under Title XIX of the Social Security Act, it would be responsible for all administrative responsibilities of a new home and community-based care waiver. This includes ensuring that all requirements of the waiver are met, including performing quality assurance and utilization control procedures, and for ensuring proper payment to providers. DMAS would need to hire a full-time employee to meet the requirements and ensure compliance with program standards for providers and recipients. The cost for a Utilization Review Analyst, Sr., at a grade 11 would be $49,200.

CONCLUSION AND RECOMMENDATIONS

The report presents the options identified by the HJR 182 Workgroup and the Department of Medical Assistance Services (DMAS) in relation to the advisability of offering a home and community-based care waiver for children with physical disabilities. The options outlined in this report are in no way intended to fully outline all the details which must be addressed in the implementation of home and community-based care waivered services for children with physical disabilities.

There is consensus that DMAS could develop a new home and community-based care waiver with a consumer directed component for personal care that would offer a variety of long-term care services to children with physical disabilities. The waiver could serve children under 18 years of who meet functional and eligibility requirements. The following recommendations address the feasibility and advisability of offering a home and community-based care waiver for physically disabled children and are in no way intended to fully outline all the details which must be addressed in developing and implementing a waiver for physically disabled children.

Recommendations:

- DMAS could develop a new home and community-based care waiver could serve children with severe physical disabilities under 18 years of age and who meet functional and eligibility requirements. Functional requirements include those children who have related conditions as specified in 42 CFR § 435.1009. These requirements would be in accordance with the population HJR 182 seeks to maintain in the community, thus avoiding institutionalization.

- There is a possibility that offering a new home and community-based care waiver for children with developmental disabilities would encourage entry into the waiver of a population th

- The waiver could contain a consumer-directed model of service for parents of children enrolled in the waiver who are under 18 years of age. Under this model, parents could have the ability to hire, train, supervise and fire the personal attendants who provide care. DMAS would need to identify what guidelines would be used to determine if a parent is incapable of independently managing the child's personal attendant. In addition, parents who are interested in being the employer in the CD-PAS Program could receive consumer training that will assure that the parents understand how to manage the child's service.

    * If this model is chosen, DMAS could mandate additional requirements for personal attendants in the consumer-directed model of service. For example, personal attendants would be screened through the DSS Child Protective Services Registry check in addition to completing a criminal history record check with the State Police.

- A new Medicaid home and community-based care waiver that serves 200 disabled children who meet ICF/MR level of care criteria would demonstrate a cost savings to the Commonwealth of $6,536,000 per year to provide services in the home or community versus the ICF/MR institutional setting. The total projected costs for a new waiver to serve approximately 200 physically disabled children per fiscal year would be $6,535,800. Of this amount, approximately $4,403,592 in additional Medicaid funding would be needed to implement the waiver. DMAS would also require additional funding of $99,200 to pay for Medicaid Management Information System development and implementation and staffing to provide waiver oversight.

- The new Medicaid Management Information System (MMIS) system is projected to begin operation in sometime beginning in the year 2001. Since the new system will not be ready for implementation under after January 1, 2001, the existing MMIS system will need to be prepared for Year 2000 Compliance. Preparing the existing MMIS system for Year 2000 Compliance or implementation of the new MMIS system will be given priority over other projects. Therefore, the most realistic proposal to develop and implement a new home and community-based waiver would be January 2001.

APPENDIX I

HOUSE JOINT RESOLUTION 182

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HOUSE JOINT RESOLUTION NO. 182

Requesting the Department of Medical Assistance Services to study the methods for and feasibility of developing a waiver for children with physical disabilities that is separate from current Department of Medical Assistance Services waivers.

Agreed to by the House of Delegates, February 17, 1998
Agreed to by the Senate, March 10, 1998

WHEREAS, the severe disability of a child presents financial, emotional, and social pressures on parents as they seek to provide needed care and defray medical expenses; and
WHEREAS, it is in the best interest of the Commonwealth and its residents to encourage family stability and to avoid institutionalization of disabled children; and
WHEREAS, such institutionalization deprives the child of parental care and attention; now, therefore, be it
RESOLVED by the House of Delegates, the Senate concurring, That the Department of Medical Assistance Services be requested to study the methods for and feasibility of developing a waiver for children with physical disabilities that is separate from current Department of Medical Assistance Services waivers. The Department shall also examine methods for allowing parents as much control as possible in the care of their children.
All agencies of the Commonwealth shall provide assistance to the Department for this study, upon request.
The Department of Medical Assistance Services shall complete its work in time to submit its findings and recommendations to the Governor and the 1999 Session of the General Assembly as provided in the procedures of the Division of Legislative Automated Systems for the processing of legislative documents.

APPENDIX II

MEDICAID-FUNDED LONG-TERM CARE SERVICES FOR CHILDREN

MEDICAID-FUNDED LONG-TERM CARE SERVICES FOR CHILDREN

Elderly and Disabled Waiver Services

The Elderly and Disabled Waiver became effective in 1982 as a home and community-based care waiver. Three alternative service programs are provided under this waiver to elderly and disabled individuals, including children, who are eligible for institutional (nursing facility) placement under the Medicaid Program. Currently, there are 104 children under the age of 18 being served in this waiver. The following services are provided under the waiver:

- **Personal care**: Reimbursement for services of Personal Care Aides who assist with the beneficiary's activities of daily living such as bathing, dressing, transferring, ambulation and meal preparation. Exclusions include transportation and skilled services.

- **Adult day health care**: Reimbursement for services offered to beneficiaries in a congregate daytime setting where a group of professionals and aides provide personal care, socialization, nursing, rehabilitation and transportation services.

- **Respite care**: Reimbursement for aides or LPN's who perform personal care type activities. This service differs from personal care in that the focus is on the need of the regular caregiver for a break rather than the need of a beneficiary for continuous care. Services are limited to 30 days or 720 hours per 12 month period.

To receive any of these services, beneficiaries must meet the waiver's target population which includes those individuals who (1) meet the nursing facility level of care criteria (i.e. are functionally dependent and require medical and nursing supervision of care), and (2) are determined to be at imminent risk of nursing facility placement and for whom community-based care services under the waiver are the critical services that enable the individual to remain at home rather than being placed in a nursing facility. Community-based care services under the waiver cannot be offered to individuals unless it can reasonably be expected that the individual would, without these services, enter a nursing facility. Provision of this waiver service must be determined by a Preadmission Screening Team or a DMAS utilization review team to be a medically appropriate cost-effective alternative to institutionalized care. Individuals may not receive any other home and community-based care waiver while receiving services under this waiver.

Personal care agencies are licensed or certified under a state or federal entity before they are enrolled by DMAS as a provider of services. Registered nurses who are licensed to practice in Virginia are hired to provide supervision of the personal care attendant and oversee the consumer's needs and fulfillment of the criteria for the waiver. The registered nurse makes supervisory visits as often as needed (at least every 30 days) to ensure both quality and appropriateness of services. The plan of care is developed by a nurse supervisor and submitted

to DMAS for approval; reevaluations are conducted every six months. The ratio of registered nurses to attendant staff is one full-time RN to forty personal care attendants or one full time RN to thirty-five consumers.

Persons who are personal care attendants under the waiver must: 1) be registered as a Certified Nurse Aide; or 2) graduate from an approved education curriculum such as Nursing Assistant, Geriatric Assistant, or Home Health Aide; or 3) receive pre-approved DMAS curriculum training from the provider agency. Other requirements include documentation of a positive work history, a copy of the attendant's certification, and at least two reference checks. Personal care attendants may not be a member of the consumer's family, or have legal guardianship of the consumer.

Personal care agencies are also responsible for billing DMAS for services rendered by the personal care attendant. DMAS is billed on a calendar-month basis according to the number of hours approved in the plan of care and the number of hours actually delivered according to the attendant log sheets, which are signed and dated by the attendant and the beneficiary or family member. The rate of pay for the provider agency is $11.50 an hour for Northern Virginia, and $9.50 an hour for the rest of the state.

AIDS Waiver Services

Four alternative service programs are provided under this waiver to individuals with AIDS, or who are HIV+ and symptomatic, who are at risk of institutionalization. To receive such services, an individual must be at risk of hospital or nursing home care and the provision of home and community-based care must be determined by a PAS team or a DMAS Utilization Review team to be a medically appropriate, cost-effective alternative to institutional care. Individuals may not receive services under any other home and community-based waiver while receiving services under this waiver. However, they may receive services solely or in combination under any of the service programs included in the AIDS waiver. As of May 1998, 25 children currently being served on the waiver. Services provided under the waiver include:

- **Private Duty Nursing**: Reimbursement for care provided by a registered nurse or a licensed practical nurse. The amount is limited only by medical necessity and cost effectiveness.

- **Personal Care:** Reimbursement for services of Personal Care Aides who assist with the beneficiary's activities of daily living such as bathing, dressing, transferring, ambulation and meal preparation. Transportation except when the Personal Aide is essential for the safe transport of the beneficiary and skilled services requiring professional skill or invasive therapies are excluded.

- **Respite Care:** Reimbursement for care provided by either an RN, LPN, or Aides as respite for regular caregivers for up to 30 days or 720 hours per 12 month period.

- **Case Management**: Reimbursement for monitoring, reevaluation, revisions to the plan or care and integration of services provided by case managers for approved AIDS waiver beneficiaries. A maximum 10 hours of case management services may be billed per month per beneficiary.

Personal care services, like other services offered, became effective in January 1991. Under the AIDS Waiver, reimbursement is made for services of personal care attendants who assist with the beneficiary's activities of daily living. Skilled services requiring professional skill or invasive therapies are considered an excluded service.

Like the Elderly and Disabled Waiver, individuals who may qualify for personal care services are assessed with a comprehensive assessment by a Pre-Admission Screening Team or a DMAS Utilization Review Team. Personal care agencies are also contracted to supervise personal care attendants and the care received by the consumer. Provider agencies also bill on a monthly schedule based on the number of hours of care provided by the attendant. The hourly reimbursement rate differs; Northern Virginia agencies are reimbursed $12.50 an hour, and the rest of the state is reimbursed $10.80 an hour.

Providers of respite care services are the same as personal care providers, only with a different reimbursement rate according to the beneficiary's level of need. The hourly rate of pay for a certified nurse's aide is the same as personal care, but a pier diem rate is $110.00 a day for Northern Virginia and $90.00 a day for the rest of the State. For Licensed Practice Nurses (LPNs), the hourly rate of pay is $26.00 for Northern Virginia and $21.45 for the rest of the State. Per diem rates for LPNs include $140.00 per day for Northern Virginia and $120.00 per day for the rest of the State.

Mental Retardation Waiver Services

The Mental Retardation Waiver Program is targeted to provide home and community-based services to individuals with mental retardation or related conditions and children under the age of six years at developmental risk who have been determined to require the level of care provided in an ICF/MR. All clients receiving waiver services must meet the program and financial Medical eligibility criteria and be Medicaid-eligible in a medical institution. The resource and income rules are applied to waiver eligible individuals as if the individual were residing in a medical institution. The income limit used for this waiver is 300% of the current SSI payment standard for one person. Medically needy individuals are not eligible for this waiver. As of May 1998, approximately 282 children diagnosed with mental retardation were being served in this waiver.

Services provided under this waiver include residential support, personal care services, habilitation, respite care, private duty nursing, environmental modification, assistive technology, supported employment, day health and rehabilitation services, and therapeutic

consultation. All individuals receiving Mental Retardation Waiver services must also receive case management services.

The individuals' need for services provided under this waiver is determined by the Community Mental Health Services Board (CSB) or the Department of Rehabilitative Services (DRS) case manager after completion of a comprehensive assessment. All recommendations are submitted to the Department of Mental Health, Mental Retardation and Substance Abuse Services or DMAS staff for final authorization.

Community Service Boards or private agencies not affiliated with Community Services Boards often contract as provider agencies. The provider agencies perform fiscal and service provision functions under the contract. In terms of fiscal reimbursement, DMAS contracts with each provider to bill DMAS monthly for services rendered. For example, the personal care reimbursement for Northern Virginia is $11.50 an hour, with the rest of the state receiving $9.50 an hour; case management reimbursement averages $175.40 per month.

Technology Assisted Waiver Services

This 1915(b) home and community-based (model) waiver became available in 1988. The provision of in-home care as an alternative to institutional care for individuals who are dependent upon technological support and require substantial, ongoing nursing care. If the individual is under age 21 it must be determined that the individual would otherwise require hospitalization. If over age 21, the individual must be eligible for a specialized nursing facility bed or other comparable institutional setting at least 90 days prior to the admission to the waiver. To receive waiver services, the provision of home and community-based care must be pre-authorized by DMAS. Individuals may not receive services under any other home and community based waiver while receiving services under this waiver. As of May 1998, 117 children were being served in the waiver. Services provided under the waiver include:

- **Private Duty Nursing:** Reimbursement for care provided by a Registered Nursing or a Licensed Practical Nurse for up to 24 hours/day the first month of service and up to 16 hours/day thereafter. The amount of private duty nursing is limited only by medical necessity and cost effectiveness.

- **Respite Care:** Reimbursement for care provided by a Registered Nurse or a Licensed Practical Nurse as respite for up to 15 days or 360 hours per 12 month period.

- **Personal Care:** Reimbursement for a Personal Care Aide or Respiratory Therapist to provide non-skilled services such as bathing, dressing, transferring, ambulation and meal preparation.

Health Care Coordination: This function is provided by an employee of DMAS. Visits are made to the private duty nursing provider on an as-needed bases to review adherence to standards and policies. The coordinator monitors care rendered to waiver beneficiaries through frequent communication with provider, family and other interested parties and review

of required monthly documentation submitted by the nursing provider.

APPENDIX III

MEDICAID-FUNDED CONSUMER-DIRECTED PERSONAL ATTENDANT SERVICES

MEDICAID-FUNDED CONSUMER-DIRECTED PERSONAL ATTENDANT SERVICES SERVICE DESCRIPTION

Personal attendant services are long-term maintenance or support services which are necessary to enable elderly or disabled individuals over the age of 18 to remain at or return to their home rather than enter a nursing facility or hospital for a specified condition. Services include assistance with activities of daily living (ADLs), such as feeding, tolieting, dressing, and ambulation. Supportive services include assistance with instrumental activities of daily living (IADLs), such as grocery shopping and house cleaning.

Service Coordination Providers

One of the supportive services available under the consumer-directed model of care includes service coordination services. DMAS contracts with agencies and organizations to provide service coordination services to individuals in the waiver. Services provided by the service coordinator include:

- **The Comprehensive Visit.** The comprehensive onsite visit is performed during the first month of service. During the home visit, the service coordinator determines that personal attendant services can be offered as a safe and cost-effective alternative to nursing home care and sets number of hours per week that a beneficiary can receive personal attendant services. The service coordinator develops a plan of care with the beneficiary which highlights what services are needed and when they will be provided. The service coordinator also ensures that the beneficiary understands his rights, risks and responsibilities as employer in the CD-PAS Waiver.

- **Consumer Training**. Consumer training is performed upon entry into the program.

During the training, the service coordinator provides the beneficiary with the skills necessary to recruit, interview, hire, train and supervise a personal assistant, and help the beneficiary to understand the requirements and responsibilities of the CD-PAS program.

- **Management Training**. This training allows the service coordinator to provide additional assistance as need, up to 4 hours within any six-month period. This includes providing management training to the personal attendant and/or additional training to the beneficiary upon the request of the beneficiary. The degree of training varies according to the beneficiary's needs.

- **Routine Onsite Visits.** During the first two months following the comprehensive visit the service coordinator will visit the beneficiary to ensure the plan of care is being followed and that services provided are appropriate to the beneficiary's needs. After the beneficiary is established in the program, routine visits can be arranged by the service coordinator and beneficiary (depending on the beneficiary's needs) to occur once every month, every other month, or every three months. During the routine onsite visit, the service coordinator, monitors the plan of care, including the ability of the attendant to perform the tasks

outlined on the plan of care and personal attendant's timesheets. The service coordinator will work with the beneficiary and/or DMAS when the plan of care demonstrates that the number of approved hours, days or type of tasks needed change.

- **Reassessment Onsite Visit.** The visit will be performed once every six months to determine whether the beneficiary continues to meet nursing facility criteria, is at imminent risk of nursing facility placement, and continues to be eligible for consumer directed personal attendant services. The service coordinator will review the plan of care to determine if the approved hours are still appropriate and the established goals have been met, and update as needed.

- **Criminal History Record Check.** The service coordination provider submit criminal record check on the personal attendant on behalf of the beneficiary and report any findings to the beneficiary. Personal attendants who have committed felonies (or misdemeanors within five years) will not be reimbursed by DMAS for services performed.

- **Personal Attendant Registry**. In addition, service coordination providers are required to maintain a personal attendant registry as a supportive source for the beneficiary, who may use the registry to obtain the names of potential personal attendants. Registries contain the names of persons who have experience with providing personal care attendant services or who are interested in providing personal attendant services. DMAS does not require service coordination providers to verify a personal attendant's qualifications prior to enrolling in a registry, but service coordination providers may set their own standards regarding the qualifications needed for personal attendants to enroll in their registries.

Service Standards

In the consumer-directed model of service, the state establishes standards for the consumer, supportive service providers, and direct care staff. The standards set in the consumer-directed model are sufficient to assure the provision of needed services and ensure individual control.

Training for Recipients

An integral component of a consumer-directed services is the ready availability of consumer training in how to self manage personal attendant services (including how to recruit, hire, train, supervise, fire personal attendants, and manage the paperwork). Consumer training is mandated in the CD-PAS Program.

The service coordinator provides the recipient with consumer training within seven days of the completion of the comprehensive visit, or complete the consumer training the same day the comprehensive visit is performed. During the consumer training, the service coordination provider trains the recipient on the skills necessary to recruit, interview, hire, train and supervise a personal assistant, and help the beneficiary to understand the

requirements and responsibilities of the CD-PAS program. The beneficiary must successfully complete this training before he can begin recruiting, hiring, training, and supervising the personal attendant. The service coordinator must document that the training has been received prior to the recipient employing a personal care attendant.

Additional management training may be provided by the service coordinator upon the recipient's request. This may be additional management training for the recipient or special training for the personal care attendant at the request of the recipient. The recipient will be able to receive up to four hours of training within any six month period.

Standards for Attendants

Recipients must have the ability to hire their personal attendant and manage and supervise the attendant's performance. The recipient must be mentally alert and be in complete control of his or her care. Therefore, the personal attendant should be able to provide, at the parent's discretion, any authorized services in the recipient's plan of care. The personal care attendant qualifications are the described below. The personal care attendant must:

- Be 18 years of age or older;
- Have the required skills to perform personal care services as specified in the child's plan of care;
- Possess basic math, reading and writing skills;
- Possess a valid Social Security number;
- Be willing to submit to a criminal history record check. The personal attendant will not be compensated for services provided to the beneficiary if the records check verifies the personal attendant has been convicted of crimes described in 12 VAC 30-90-180;
- Be willing to attend training at the parent's request;
- Understand and agree to comply with DMAS program requirements; and
- Be willing to register in a Personal Attendant Registry, which will be maintained by the provider agency chosen by the parent.

Personal care attendants could not be a member of the recipient's family. Family would be defined as a parent or stepparent, spouse, children or stepchildren, siblings or stepsiblings, grandparents or stepgrandparents, and grandchildren or stepgrandchildren. In addition,. anyone who had legal guardianship, was a representative payee, or was committee for the recipient would also prohibited from being a personal attendant under this program.

Service Coordinator

In the current consumer-directed model of service, the service coordination agency must employ (or subcontract with) and directly supervise a service coordinator who will provide ongoing supervision of the beneficiary's plan of care. It is preferred the service coordinator possess a minimum of an undergraduate degree in a human services field or be a registered

nurse currently licensed to practice in the Commonwealth of Virginia. In addition, it is preferable that the service coordinator have tow years of satisfactory experience in the human services field working with persons with severe physical disabilities or the elderly. The service coordinator must possess a combination of work experience and relevant education which indicates possession of the required knowledge, skills, and abilities as outlined in regulations.

If the service coordinator employed by the provider is not a Registered Nurse, the provider must have registered nurse (RN) consulting services available, either by a staffing arrangement or through a contracted consulting arrangement. The RN consultant is available as needed to consult with beneficiaries and service coordinators on issues related to the health needs of the beneficiary.

Oversight

In the current consumer-directed model of service, DMAS conducts an annual quality assurance review in which DMAS staff review documentation maintained by the provider agency, interview agency staff and interview the consumer or other caregivers in the consumer's home to assess the quality of services provided. This quality assurance activity will also be conducted for parents who are allowed to direct their child's personal attendants. In addition, DMAS can periodically conduct consumer satisfaction surveys and utilize client level database information and claims information in conjunction with specific outcome measures to assess quality of care. For example, the recipient's use of other acute care services, incidence of hospitalizations, etc., can be determined and compared with other similar beneficiaries who receive both consumer-directed and agency-directed services. Through this type of oversight, DMAS can detect any unusual service utilization patterns which may indicate a problem with quality of care.

Utilization Review and Control

Federal regulations for home and community-based care waivers require that there be a formal process of periodic reevaluation of the beneficiary's strengths, needs and available support, authorization of any changes to the plan of service and professional staff available to respond to any medical problems or change in overall needs. These regulations require that the qualifications of person performing these functions for someone in waiver be similar to the qualifications of persons who perform the same functions for persons entering a nursing facility.

In order to meet this requirement, DMAS currently requires in the CD-PAS Waiver that the service coordination provider employ or contract with an individual to serve as the service coordinator that meets the knowledge, skills and abilities established by DMAS. The service coordinator is responsible for conducting initial comprehensive visits and developing the plan of care, conducting routine on-site visits every 30-90 days, conducting reassessments every six months, authorizing changes to the plan of care, conducting management training for the recipient, conducting criminal history record checks on the personal attendant on behalf of

the recipient, and providing supportive services as needed by the recipient. However, it is very important that recipients understand their responsibility to report to the service coordinator any changes in their condition and social supports as they occur.

Plans of care are reviewed by DMAS staff upon initial authorization of the service, as well as every six months, or whenever a plan of care is revised, which reflects a change to the maximum hours approved or to the approved level of care. The review of the plan of care includes a comparison with the beneficiary's level of functioning and with the social support available to the beneficiary from any other source.