DECISION BRIEF FOR:
The Honorable James S. Gilmore, III
Governor

SUBJECT: EMERGENCY REGULATION for Individual and Family Developmental Disabilities Waiver Services

ACTION NEEDED
BY ----JUNE 29
RETURN TO DMAS

SUMMARY

1. REQUEST: The Governor is hereby requested to approve this agency's adoption of the emergency regulation entitled Individual and Family Developmental Disabilities Waiver Services, permitting the implementation of another service delivery method as an option to long-term care community-based services, effective July 1, 2000.

2. RECOMMENDATION: Recommend approval of the Department's request to take an emergency adoption action regarding Individual and Family Developmental Disabilities Waiver Services. The Department intends to initiate the public notice and comment requirements contained in the Code of Virginia §9-6.14:7.1.

____
Dennis G. Smith, Director Date

3. CONCURRENCES:

Secretary of Health and Human Resources:		Department of Planning and Budget:	
Concur	________	Concur	________
Concur w/Modifications	________	Concur w/Modifications	________
Disapprove	________	Disapprove	________

____
Claude A. Allen Date

____
Signature Date

____
Title

4. ACTION: Governor

Approve ________
Approve w/ Modifications ________
Deny ________

____
James S. Gilmore, III Date

5. FILED: Registrar of Regulations

Jane D. Chaffin Date

DISCUSSION

6. BACKGROUND: The regulations added by this action are the Individual and Family Developmental Disabilities Waiver Services (12 VAC 30-120-700 through 899).

The 1999 General Assembly, through Item 335.LL of the 1999 Appropriations Act, mandated that the Director of the Department of Medical Assistance Services (DMAS) develop a Medicaid-funded home and community-based care waiver for persons with developmental disabilities, including persons with autism. The "Individual and Family Developmental Disabilities Support (IFDDS) Waiver" must offer a full array of appropriate, flexible individual-and family-driven control of services to meet their individualized needs.

Federal provisions governing home and community based services (HCBS) waivers are found in § 1915 (c) of the *Social Security Act*. Under this authority, states can waive the federal requirements for statewide service coverage, comparability of services (rules that require states to provide services on an equal basis to all recipients who are eligible for services under the State Plan), community income and resource rules. This waiver capability affords states the flexibility to design waivers selecting the mix of services that best meet the needs of the targeted waiver populations. HCBS waivers are approved for an initial three-year period and federally renewed every five years. The Commonwealth of Virginia currently has five HCBS Waivers: AIDS; Elderly and Disabled; Consumer-Directed Personal Attendant Services (CD-PAS); Mental Retardation (MR); and Technology Assisted.

In order to develop a waiver to specifically serve persons with developmental disabilities who do not have a diagnosis of mental retardation, there must be an alternative institutional placement. 42 CFR § 435.1009 specifies that the alternative institutional placement for individuals with developmental disabilities must be an Intermediate Care Facility for the Mentally Retarded (ICF/MR). Although many individuals with developmental disabilities do not have mental retardation, many of the services offered in an ICF/MR are more appropriate for these individuals than standard services offered in nursing facilities. Currently, Virginia has very few institutional placements for individuals with developmental disabilities.

The 1999 Appropriations Act language directed DMAS to convene a workgroup composed of representatives from various state agencies, consumers, families, advocates, and public and private providers to assist with the development of the waiver proposal. The members of the workgroup represented the Brain Injury Association of Virginia; Centers for Independent Living; Consumer Representatives for Persons with Disabilities; Consumer Service Boards; the Department of Education; the Department of Medical Assistance Services; the Department of Mental Health/Mental Retardation, & Substance Abuse Services; the Department of Rehabilitative Services; the Department for the Rights of Virginians with Disabilities; the Department of Social Services; Disability Service Boards; the Epilepsy Association of Virginia; the Epilepsy Foundation of Virginia; family representatives for persons with disabilities; UCP of Washington & Northern Virginia; the Virginia Association for Home Care; the Autism Program of Virginia (TAP-VA); the

Virginia Board for People with Disabilities; and the Virginia Network of Private Providers. The work group's activities and recommendations are located in Appendix A.

WAIVER ELIGIBILITY

"Developmentally disabled" is a term used to refer to individuals who have mental retardation, as well as a "related condition" to mental retardation. However, states distinguish between individuals with mental retardation and individuals with related conditions when developing waivers such as this one.

Since individuals up to age 6 with developmental disabilities and individuals with mental retardation are already being served through the Home and Community Based Services waiver (Mental Retardation), the IFDDS waiver will be available only to individuals age 6 and older who meet the "related conditions" requirements as defined in 42 CFR § 435.1009: "Persons with related conditions means individuals who have 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 *[such as autism]*, 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."

Action by the 1999 General Assembly specifically added the diagnosis of autism which is to be covered by this new waiver service.

In addition to the above requirements, the individual cannot have, for purposes of this new waiver service, a diagnosis of mental retardation as defined by the American Association on Mental Retardation (AAMR) (refer to Appendix B). An individual must meet all of the following criteria:

1. The individual must meet the ICF/MR level of care, as established at 42 CFR § 435.1009. This will be determined through a screening process conducted by qualified individuals under contract with DMAS;
2. The individual's monthly income must not exceed 300% of the SSI income level. Currently this amount is $1,536 and increases in January of each year;
3. The income of parents would not be deemed to a child; and
4. No individual can be enrolled in more than one waiver at a time.

Appendix C contains two case studies of individuals who will benefit from this new waiver service.

WAIVER SERVICES

All individuals determined eligible for the IFDDS waiver will have a case manager/support coordinator. Individuals will select a support coordinator who will assist them and their families with accessing needed medical, psychiatric, social, educational, vocational, and other services essential to meeting the individuals' needs. Support coordinator services will include: assessment and planning (including referrals) services; linking the individuals to services and supports specified in the Individualized Service Plan (ISP); assisting the individuals (or family) directly to develop or obtain needed resources, including crisis assistance supports; coordinating services and treatment planning with other agencies and providers; enhancing community integration; monitoring service delivery (including assessment and reassessment of program participant level of care, oversight of the cost-effectiveness of services, review of plans of care at designated intervals); and benefits counseling. Support coordination providers will not be permitted to be service delivery providers.

The medical care services that will be offered under the IFDDS waiver include adult companion care, assistive technology, personal emergency response systems, crisis intervention/stabilization, environmental modifications, in-home residential supports, skilled nursing services, supported employment, therapeutic consultation, family and caregiver training, day support, personal care, respite care, and consumer-directed personal services (attendant and consumer-directed respite care). These services are defined and discussed in the attached Appendix D.

DMAS asked the workgroup to provide projections of the potential number of individuals who could be eligible for the IFDDS waiver. Because Virginia does not allow individuals with developmental disabilities without a diagnosis of mental retardation to be admitted to state funded ICF/MRs, there was no institutional population from which to determine potential numbers of eligible individuals. The projections contained in Appendix E were provided by the workgroup and DMAS

In addition, many states have a waiting list for services for individuals with developmental disabilities. DMAS anticipates that there will be a demand for services that will exceed available funding within the first year of waiver operation and, therefore, has incorporated the use of a waiting list into its program design. Any time there are more qualifying individuals than there is funding for their needed services, these individuals will be maintained on the waiting list until additional waiver funding should be come available. Individuals will be served from the waiting list on a first-come, first-served basis.

Because this waiver itself and the design of the service system are new, DMAS also believes that the mechanics of the program should be well established before expansion is sought. The long-term interests of the recipients of these services will be best served by a well-designed and functioning system. The health care system holds numerous examples of how poor planning or coordination can frustrate the intended beneficiaries and undermine confidence in the program. DMAS will work with consumers and providers to firmly establish this waiver program while maintaining cost effectiveness.

A method for initial acceptance into the waiver will include an initial application period of sixty days, beginning July 1, 2000, and ending August 31, 2000. This application period will be followed by an assessment of all applications based on established criteria. Applicants will be placed on the IFDDS waiver in accordance with available funding.

7. FAMILY IMPACT: This regulatory action will not have any negative affects on the institution of the family or family stability. It will not increase or decrease disposable family income or erode the marital commitment. It will not discourage economic self-sufficiency, self-pride, nor the assumption of family responsibilities. The IFDDS Waiver will offer families the choice of keeping their loved ones home and in the community rather than living in an institutional setting. The IFDDS Waiver will also offer supportive services to families and caregivers, such as family and caregiver training, companion care, and respite care in an effort to ease their care giving burdens and prevent or delay institutional placement of loved ones.

8. AUTHORITY TO ACT: The Code of Virginia (1950) as amended, §32.1-325, grants to the Board of Medical Assistance Services (BMAS) the authority to administer and amend the Plan for Medical Assistance. The Code of Virginia (1950) as amended, §32.1-324, grants to the Director of the Department of Medical Assistance Services (DMAS) the authority to administer and amend the Plan for Medical Assistance in lieu of Board action pursuant to the Board's requirements. The Code also provides, in the Administrative Process Act (APA) §9-6.14:4.1(C)(5), for an agency's adoption of emergency regulations subject to the Governor's prior approval.

Subsequent to the emergency adoption action and filing with the Registrar of Regulations, this agency intends to initiate the public notice and comment process contained in Article 2 of the APA. Therefore, approval to file the required Notice of Intended Regulatory Action is also necessary and hereby being requested by this action.

Without an emergency regulation, these regulations cannot become effective until the publication and concurrent comment and review period requirements of the APA's Article 2 are met.

Therefore, an emergency regulation is needed to meet the July 1, 2000, effective date established by the General Assembly.

9. NEED FOR EMERGENCY ACTION: The Code §9-6.14:4.1(C)(5) provides for regulations which an agency finds are necessitated by an emergency situation. To enable the Director, in lieu of the Board of Medical Assistance Services, to comply with the 1999 General Assembly through Item 335.LL of the 1999 Appropriations Act, he must develop a Medicaid-funded home and community-based care waiver for persons with developmental disabilities, including persons with autism. This issue qualifies as an emergency regulation as provided for in § 9-6.14:4.1(C)(5)(ii) of the *Code*, because Item 319(U) of the 2000 Appropriation Act requires this regulation to be effective within 280 days from the enactment of the law. As such, this regulation may be adopted without public comment with the prior approval of the Governor.

   Although the emergency regulation process does not have a specified formal period of public comment, DMAS demonstrates its ongoing efforts to confer with all parties interested in this issue by its extensive collaboration with the identified work group (Attachment A). Since this emergency regulation will be effective for no more than 12 months and the Director wishes to continue regulating the subject entities, the Department is initiating the Administrative Process Act Article 2 procedures.

10. FISCAL/BUDGETARY IMPACT: The Medicaid-funded IFDDS program will be offered under a *Social Security Act* § 1915(c) home and community-based-care waiver which must be a cost-effective alternative to institutionalization. Including medical funding and administrative costs, the waiver is projected to cost $8 million ($3.8 million GF) in FY 2001 and $11 million ($5.3 million GF) in FY 2002. The Governor and General Assembly approved these amounts in the 2000 Appropriation Act. The appropriations for the waiver are sufficient to fund at least 300 positions in the waiver.

    FEDERAL COST EFFECTIVENESS STANDARD

    In order for HCFA to approve a HCBS waiver, it must be cost effective. A waiver can be cost-effective in the aggregate or can be individually cost-effective. Aggregate cost-effectiveness means that the average cost to Medicaid of individuals on the waiver cannot exceed the average cost to Medicaid of individuals in the alternative institutional placement. Individual cost-effectiveness means that an individual's expected waiver costs cannot exceed those of an individual's institutional expected cost. Regardless of the method the state chooses to determine cost effectiveness, aggregate costs are reported to HCFA.

    There are arguments for adopting either method of determining cost effectiveness. The work group felt very strongly that aggregate cost effectiveness should be used. However, without some cost controls built into the IFDDS Waiver, all funds could be used by a small number of high cost individuals, leaving families who need some or moderate supports without services. This could thus increase the likelihood that these lower-cost family placements will fail and will increase the need for out-of-home (institutional) placements.

States are beginning to use other options in lieu of the "all or nothing" approach that has been the norm. The DMAS has secured HCFA approval of an approach geared to controlling costs while providing as much consumer choice as possible. DMAS believes that most individuals, given an array of services, will choose those that best meet their needs and are the most cost effective. The services chosen would have to be necessary to avoid institutionalization and the Consumer Service Plan (care plan) would need to be developed subject to approval by DMAS.

In order to assure cost effectiveness of this Waiver, funds would be allocated between two “budget” levels to assure that, on the average, DMAS does not exceed cost effectiveness. For this waiver, DMAS will establish a threshold for waiver costs for recipients in “Level One” at approximately $25,000. Recipients whose care plans exceed $25,000 per year will be funded in “Level Two”. There would not be a budget threshold for “Level Two”.

DMAS, upon the workgroup’s recommendation, has targeted 55 percent of waiver funds to level one and targeted 40 percent of waiver funds to level two. The remaining 5 percent of funds would be allocated for emergencies. While the primary purpose of this bi-level cost allocation is to assure that the waiver remains cost effective, with good support coordination and stewardship of funds, it may be possible to serve more than the projected number of individuals. If individuals who cost up to or more than the actual institutional cost are covered, the potential number of waiver recipients served would decrease. The unknown factors are the cost of non-waiver Medicaid covered services and the actual cost of recipients who would be eligible for services.

In compliance with HCFA requirements, the budget level chosen would fully fund the recipient’s plan of care after taking into account other community and family resources. Since family dynamics change frequently, sometimes rapidly, some funds will be set aside for emergency situations. These funds would be distributed according to emergency criteria that have been developed in conjunction with workgroup and are located at 12 VAC 30-120-850.

There are no localities that are uniquely affected by these regulations as they apply statewide.

11. RECOMMENDATION: Recommend approval of this request to adopt this emergency regulation to become effective July 1, 2000. From its effective date, these regulations are to remain in force for one full year or until superseded by final regulations, promulgated through the APA. Without an effective emergency regulation, the Department would lack the authority to implement the Medicaid-funded Individual and Family Developmental Disabilities Support Waiver on July 1, 2000, as mandated by the General Assembly.

12. APPROVAL SOUGHT FOR 12 VAC 30-120-700 through 899.

Approval of the Governor is sought for an emergency modification of the Medicaid State Plan in accordance with the Code of Virginia § 9-6.14:4.1(C)(5) to adopt the following regulation:

IFDDA Waiver Work Group

The work group met five times from May 10 through September 15, 1999. The goals that the group wanted to accomplish were to:

- develop a waiver for individuals with developmental disabilities as an option to institutionalization;
- have a consumer directed approach whenever possible;
- de-institutionalize individuals who could benefit from services in the waiver;
- provide services in the workplace as well as other places;
- develop individually tailored services;
- offer family and caregiver training;
- work in close coordination with schools and other training areas;
- maximize other financial resources;
- minimize duplication of services; and
- in order to receive approval from the Health Care Financing Administration (HCFA) for a waiver, the DMAS added the goal that the services must be cost effective and necessary to prevent institutionalization.

During this period of time, the work group and DMAS discussed issues pertaining to waiver eligibility and access, consumer choice, the populations to be served, service coordination and service availability. The DMAS compiled this information and prepared a report which proposed the development of a new Medicaid waiver to serve individuals with developmental disabilities, beginning July 1, 2000. The report, entitled the "Individual and Family Developmental Disabilities Support Waiver Study", was submitted to the General Assembly in November 1999. The report can be found online at http://www.cns.state.va.us/dmas/Studies_and_Reports/Studies_TOC.htm .

The work group continues to meet on a regular basis with DMAS to assist DMAS with implementation issues affecting the waiver.

AAMR Definition of Mental Retardation

The AAMR defines mental retardation as being substantially limited in present functioning as characterized by significantly subaverage intellectual functioning, existing concurrently with related limitations in two or more of the following applicable adaptive skill areas: communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure, and work. Mental retardation manifests itself before age 18.

A diagnosis of mental retardation is made if the person's intellectual functioning level is approximately 70-75 or below, as diagnosed by a licensed clinical professional; and there are related limitations in two or more applicable adaptive skill areas; and the age of onset is 18 or below; and the person meets existing criteria for placement in an ICF/MR. If a valid IQ score is not possible, significantly subaverage intellectual capabilities means a level of performance that is less than that observed in the vast majority of persons of comparable background. In order to be valid, the assessment of the intellectual performance must be free of errors caused by motor, sensory, emotional, language.

Case Studies for the IFDDS Waiver

1. “Ryan” is a 22 year old young man whose mother is recently and unexpectedly deceased. He is living with his older brother, Drew, age 25 who is a recent college graduate. Drew has just begun a career in journalism, working as a reporter for a city newspaper. “Ryan” and Drew’s mother had been a single parent for many years; the boys were ages four and nine when their parents divorced. “Ryan” is also a recent graduate from high school. He was enrolled in the public school system and receiving special education services beginning at age four. Several months before he entered school, “Ryan’s” mother began to suspect her son had autism. “Ryan’s” education began both in and out of school. “Ryan” learned to read and write using a keyboard rather than paper and pencil. By high school, “Ryan” had become proficient at caring for, and using, a Canon communicator as his primary means of self-expression throughout his environment. This piece of assistive technology was provided as part of his educational program. When “Ryan” was 15 years old, his family and high school began to formally plan for transition into the community as an individual, away from school. However, there were no services that would support “Ryan” in his transition from school to community. “Ryan’s” brother Drew is left as both Ryan’s family and caregiver. It is apparent that “Ryan” cannot live on his own, as there are safety issues, self-reliance and daily living concerns, and the need for ongoing support to establish and maintain himself in a work setting.

2. “Colin” was born on November 26, 1984. He was a normally developing baby up to the age of 15 months when he went into a coma and suffered anoxia. He was rushed to the hospital on March 3, 1986. It was initially called a near-SIDS (Sudden Infant Death Syndrome) with no known reason for the coma. Two years later it was learned that he had an underlying metabolic condition called MCAD (Medium-Chain Acyl Co-A Dehydrogenase Deficiency). “Colin” could not use any part of his body, nor could he talk. At that point, if the family could have gotten some respite it would have helped a great deal. There was none available. His father and mother co-parented him over the next eight years. At that point his father moved out of the house and his mother continued to provide his care. “Colin's” mother applied for the Medicaid Elderly and Disabled Waiver and “Colin” was able to receive personal care. This, however, did not work well for “Colin”. The home health agencies were unable to serve “Colin” for various reasons: because he was a child, because “Colin” did not live on a bus route, because he needed a split shift, and because there were not enough hours to make it worthwhile for the personal care agency. “Colin” is not able to use his body functionally and, in fact has to try to control movement that is constantly produced in the form of spasticity. “Colin” is highly intelligent and flourishes academically. He attends a regular school and sits alongside his peers in the classroom He maintains honor role grades and has many friends. “Colin” is now receiving state-funded Personal Assistance Services under the Department of Rehabilitative Services program. Attendant care is a proposed service under the IFDDS Waiver. “Colin’s” best hope for completing his academic goals, which includes a college degree, is assistive technology, which is a proposed service under the IFDDS Waiver.

SERVICES TO BE COVERED UNDER THE IFDDS WAIVER

Adult Companion Care. This waiver service will provide non-medical care, supervision and socialization to a functionally impaired adult. Companions may assist or supervise the individual with tasks such as meal preparation, laundry and shopping, but do not perform these activities as discrete services. The provision of companion services would not entail hands-on nursing care. Providers may also perform light housekeeping tasks which are incidental to the care and supervision of the recipient. The service will be provided in accordance with a therapeutic goal in the plan of care. This service is not currently offered in the Medicaid program and will be considered a new waiver service.

Assistive Technology. Assistive technology consists of specialized medical equipment and supplies including those devices, controls, or appliances, specified in the plan of care but not available under the State Plan for Medical Assistance, which enable recipients to increase their abilities to perform activities of daily living, or to perceive, control, or communicate with the environment in which they live or which are necessary to the proper functioning of such items.

Personal Emergency Response Systems (PERS). PERS is a service designed to electronically monitor recipient safety and provide access to emergency crisis intervention for medical or environmental emergencies through the provision of communication systems. PERS can be authorized when no one else is in the home that is competent to call for help in an emergency.

Crisis Intervention/Stabilization. This service will consist of immediate health care, available 24 hours a day, seven days per week, to provide assistance to recipients experiencing acute mental health dysfunction requiring immediate clinical attention. Objectives of the service include preventing exacerbation of the condition; preventing injury to the recipient or others; and providing treatment in the context of the least restrictive setting. Crisis intervention services include assessing the crisis situation; providing short-term counseling to stabilize the recipient and/or family unit; providing access to further immediate assessment and follow-up; and linking the recipient and family with on-going care to prevent future crises.

Environmental Modifications. Modifications would be provided as needed only for situations of direct medical or remedial benefit to the recipient. These would be provided in a recipient’s home. Modifications may not be used to bring a substandard dwelling up to minimum habitation standards. Activities include:

In-Home Residential Supports. In-home residential support services means support provided in the developmentally disabled recipient's home which includes training, assistance, and supervision in enabling the recipient to maintain or improve his health, assistance in performing recipient care tasks, training in activities of daily living, training and use of community resources, providing life skills training, cognitive rehabilitation, and adapting behavior to community and home-like environments. Services will typically focus on the development and implementation of compensatory strategies that would allow an individual to function as independently as possible in home, work and community settings of choice.

Skilled Nursing. This service will be for recipients with serious medical conditions and complex health care needs which require skilled nursing services ordered by a physician and which are not available under the Virginia State Plan for Medical Assistance. This service will be necessary to enable a recipient to live in a non-institutional setting in the community and cannot be provided by non-nursing personnel. It will be provided in a consumer's home and/or other community setting on a regularly scheduled or intermittent need basis. Activities include monitoring of the recipient's medical status, administering medications and/or other medical treatment, and provide caregiver training related to providing necessary medical care to the recipient.

Supported Employment. Supported employment services are those services needed by individuals for whom competitive employment at or above the minimum wage is unlikely, and who, because of their disabilities, need intensive ongoing support, including but not limited to personal care, supervision, training, and ongoing supports to perform in a work setting. Supported employment will be conducted in a variety of settings, particularly work sites in which persons without disabilities are employed. Supported employment services will include activities needed to sustain paid work by waiver clients, including supervision and training. Supported employment services provided through the DD waiver will not be provided if they are services provided by the Department of Rehabilitative Services, under IDEA, or if they are an employer's responsibility under the Americans with Disabilities Act, or Section 504 of the Rehabilitation Act.

Therapeutic Consultation. Therapeutic consultation consists of consultation and technical assistance provided by members of psychology, behavioral analysis, speech therapy, occupational therapy or physical therapy professionals to assist the recipient, parent/family members, and services providers in implementing an plan of care. Therapeutic consultation services would be provided, based upon the plan of care, for those recipients who, in addition to their developmental disability, have secondary disabilities which restrict their ability to function in the community. This service will need to be clinically necessary to enable the utilization of waiver services.

Family and Caregiver Training. This service provides identified training and education related to disabilities, community integration, family dynamics, stress management, behavior interventions and mental health to a parent, other family members or primary caregiver. For purposes of this service, "family" is defined as the persons who live with or provide care to a recipient served on the waiver, and may include a parent, spouse, children, relatives, a legal guardian, foster family, or in-laws. “Family” does not include individuals who are employed to care for the recipient. All family training must be included in the recipient’s written plan of care.

Respite Care. Respite care are services given to individuals who are unable to care for themselves and/or who need supervision in their place of residence and while in the community. They are provided on a short-term basis because of the absence or need for relief of those persons normally providing the care. The individual, along with the parent or legal guardian, will make an informed choice about the provider and level of this service, with options, information and related assistance (meeting potential providers, etc.) provided to them by the support coordinator.

Day Support. Day support services will include training in intellectual, sensory, motor, and affective social development including awareness skills, sensory stimulation, use of appropriate behaviors and social skills, learning and problem solving, communication and self care, physical development, transportation to and from training sites, services and support activities, and prevocational services aimed at preparing a recipient for paid or unpaid employment.

Personal Care Services. Personal care services are long-term maintenance or support services necessary to enable the recipient to remain at or return home rather than enter an ICF/MR. Personal care services include assistance with personal hygiene, nutritional support, and the environmental maintenance necessary for recipients to remain in their homes and in the community.

Consumer Directed Services: Attendant and Consumer-Directed Respite Care. The IFDDS Waiver will also include consumer direction for personal (attendant) and respite care services. This would mean that the recipient (or, if the recipient is under 18, the recipient's parent or legal guardian) would be responsible for hiring, training, supervising, and, if necessary, firing the personal attendants that provide services.

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.

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 recipient recruits, hires, trains, manages and directs his or her own provider of services, known as a personal attendant. The personal attendant is accountable to the recipient or the recipient's parent or legal guardian rather than to a supervisor of a provider agency, and follows the recipient or the recipient's parent or legal guardian's directions as to how to meet his or her needs.

The DMAS already has a model for consumer directed services for adults and this model would be adopted for this waiver. Although consumer-directed care 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.

An additional component to attendant care will be work-related personal attendant services (PAS). This service will extend the ability of the personal attendant to provide assistance in the workplace. Some services might include filing, retrieving work materials that are out of reach or providing travel assistance for an employee with a mobility impairment; helping employee with a cognitive disability with planning or decision making; reading handwritten mail to an employee with a visual impairment; or ensuring that a sign language interpreter is present during staff meetings to accommodate an employee with a hearing impairment. This service will only be available to individuals who also require PAS services to meet their ADLs. Workplace supports through the IFDDS Waiver will not be provided if they are services provided by the Department of Rehabilitative Services, under IDEA, if they are an employer's responsibility under the Americans with Disabilities Act, or Section 504 of the Rehabilitation Act.

POPULATION ESTIMATES

- The DMAS estimates that there are 250 individuals on the Elderly and Disabled Waiver who meet the criteria for the Developmentally Disabled Waiver.
- In its Three Year State Plan on Developmental Disabilities (1998-2000), the Virginia Board for People with Disabilities utilized the widely accepted estimated prevalence rate of 1.8% for developmental disability. Thus, the Board estimated that there were some 119,130 Virginians with developmental disabilities as of 1995. This figure includes individuals with developmental disabilities who have mental retardation.
- The Department of Education provided data to show that 149,321 children received Special Education Services in FY 1997.
- The Autism Program of Virginia (TAP-VA) submitted information that showed, in 1998, 8,562 individuals birth through 21 years had Autism and 36,391 had Autism Spectrum Disorder; 3,791 individuals 22 years and over had Autism and 16,112 had Autism Spectrum Disorder.
- The Virginia Brain Injury Central Registry submitted information showing that for Traumatic Brain Injury occurring prior to age 22, 16,431 individuals were injured who were admitted to the hospital and 37,505 individuals were injured who were not admitted to the hospital.
- The Spinal Cord Injury Registry shows that there are 901 individuals with spinal cord injuries that occurred before the age of 22.

Advocates and family members recommended that funding be requested for 3,000 individuals.

REASONS FOR DEMAND OUTSTRIPPING SUPPLY:

The National Association of State Directors of Developmental Disabilities Services, Inc. and Gary A. Smith published a report in 1999, entitled “Closing the Gap: Addressing the Needs of People with Developmental Disabilities Waiting for Supports”, which discussed these reasons. The reasons are as follows:

> Broadly speaking, the demand for such services can be expected to track the incidence and prevalence rates of mental retardation and other developmental disabilities. Incidence is the rate at which a condition is present at birth. Prevalence describes how many individuals in the general population have a particular condition. However, available evidence suggests that the demand for publicly funded developmentally disabilities services has been growing at a markedly faster rate than a "demand follows population" model would predict. Nationwide, during the 1990s, the increase in demand for residential services and supports was well above the underlying nationwide rate of growth in population .

The factors for this growth seem to be:

- Increased longevity. Increasing longevity of people with developmental disabilities means that more and more people are outliving their parents (Braddock, 1998). There is a large and growing number of individuals who live with and are supported by elderly parents. In Maryland, 39 percent of the parents of individuals on the state's waiting list had parents over the age of 60, with 24 percent were over the age of 70.

- The Baby Boomer Generation (and its Echoes). The average age of individuals who live with caregivers age 60 or more is 38.4 years (Fugiara, 1998). Most are Baby Boomers with developmental disabilities. Increasing longevity has led to the Baby Boomer population's bubble affecting the demand for public developmental disabilities services one generation ahead of when it will affect other public long-term care systems. This bubble may explain in significant part why demand is growing more rapidly than population overall.

- Redirected Demand. In 1997, Congress enacted federal policies aimed at reducing the number of individuals with developmental disabilities (and mental illnesses) who were inappropriately placed in nursing facilities. (OBRA, 1987). This change shrank one type of capacity and redirected demand toward developmental disability systems.

- Changes in Eligibility. Some states have widened their criteria which has led to an increase in demand for services and supports.

- Individuals and Family Expectations. There is anecdotal evidence that younger parents of individuals with developmental disabilities have higher expectations concerning the services and supports that should be provided to their sons and daughters with developmental disabilities than older parents. In part, these expectations stem from the experiences of these parents with special education, where their children had a clear and enforceable right to receive all necessary services under the provisions of the federal Individuals with Disabilities Education Act.

- The "Woodwork Effect." Sometimes it is speculated that offering a new service causes individuals and families to seek the services when they would not otherwise. When the only service offered was placement in a state institution, many families decided that "nothing was better than something." The advent of community services and supports has undoubtedly increased the interest of individuals and families in seeking services because such services are regarded as more in tune with their needs. However, because community supports have been available in many states for a long period of time, it is doubtful that this has caused the demand to increase at an especially rapid rate. In addition, their availability has played a major role in diverting demand from more costly institutional placements.

- Family/Caregiver Circumstances. About 40 percent of all individuals with developmental disabilities live in households headed by a single parent. Individuals with developmental disabilities are twice as likely to live in a single parent household than is true for the general population (Fugiara, 1998).