

# Proposed Regulation Agency Background Document

Agency Name:	Dept. of Medical Assistance Services 12 VAC 30
VAC Chapter Number:	Chapter 120
Regulation Title:	Individual and Family Developmental Disability Support Waiver
Action Title:	DD Waiver
Date:	11/22/2000; NEED ACTION BY DEC. 15, 2000 (ER lapsing)

This information is required pursuant to the Administrative Process Act (§ 9-6.14:9.1 *et seq.* of the *Code of Virginia*), Executive Order Twenty-Five (98), Executive Order Fifty-Eight (99), and the *Virginia Register Form, Style and Procedure Manual*. Please refer to these sources for more information and other materials required to be submitted in the regulatory review package.

### Summary

Please provide a brief summary of the proposed new regulation, proposed amendments to an existing regulation, or the regulation proposed to be repealed. There is no need to state each provision or amendment or restate the purpose and intent of the regulation; instead give a summary of the regulatory action and alert the reader to all substantive matters or changes. If applicable, generally describe the existing regulation.

This proposed regulation establishes the program and provider requirements, service limitations and coverages, and recipient eligibility standards for the new DMAS program entitled Individual and Family Developmental Disability Support Waiver.

## Basis

Please identify the state and/or federal source of legal authority to promulgate the regulation. The discussion of this statutory authority should: 1) describe its scope and the extent to which it is mandatory or discretionary; and 2) include a brief statement relating the content of the statutory authority to the specific regulation. In addition, where applicable, please describe the extent to which proposed changes exceed federal minimum requirements. Full citations of legal authority and, if available, web site addresses for locating the text of the cited authority must be provided. Please state that the Office of the Attorney General has certified that the agency has the statutory authority to promulgate the proposed regulation and that it comports with applicable state and/or federal law.

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) §§9-6.14:7.1 and 9-6.14:9.1, for this agency's promulgation of proposed regulations subject to the Governor's review.

Subsequent to an emergency adoption action, the agency is initiating the public notice and comment process as contained in Article 2 of the APA. The emergency regulation became effective on July 1, 2000. The Code, at §9-6.14:4.1(C) requires the agency to file the Notice of Intended Regulatory Action within 60 days of the effective date of the emergency regulation if it intends to promulgate a permanent replacement regulation. The Notice of Intended Regulatory Action for this regulation was filed with the Virginia Register on July 21, 2000.

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, and 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.

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 states that the institutional placement for individuals with related conditions is an institution for the mentally retarded or persons with related conditions. In Virginia, this institution is called 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.

#### Purpose

Please provide a statement explaining the need for the new or amended regulation. This statement must include the rationale or justification of the proposed regulatory action and detail the specific reasons it is essential to protect the health, safety or welfare of citizens. A statement of a general nature is not acceptable, particular rationales must be explicitly discussed. Please include a discussion of the goals of the proposal and the problems the proposal is intended to solve.

The purpose of this action is to promulgate permanent regulations for the Individual and Families Developmental Disability Support Services (DD) Waiver. These regulations will help improve the health and welfare of families with children and adults who are affected by developmental disabilities. These regulations will provide community support services to enable these children and adults to live successfully in their homes and communities.

#### Substance

Please identify and explain the new substantive provisions, the substantive changes to existing sections, or both where appropriate. Please note that a more detailed discussion is required under the statement providing detail of the regulatory action's changes.

The sections of the State Plan affected by this action are Case Management Services for Individuals with Developmental Disabilities (12 VAC 30-50-490) and Methods and Standards for Establishing Payment Rates-Other Types of Care: Fee-for-Service Case Management (12 VAC 30-80-110). The regulations affected by this action are Individual and Families Developmental Disability Support Waiver (12 VAC 30-120-700 through 120-800).

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 new Medicaid-funded home and community-based care waiver for persons with developmental disabilities, including persons with autism, to offer a full array of appropriate, flexible individual- and family-driven control of services to meet individuals' needs. The 2000 Appropriations Act specifically required that persons with autism be included in this waiver proposal to the federal government.

In order to comply with this mandate, DMAS convened 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 are 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; 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

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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 Mental Retardation Home and Community Based Services waiver, the DD 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, 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."

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 § § 435.217 and 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. The income of parents would not be deemed to a child, and; 3. 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 to receive services in the DD waiver will have a case manager (support coordinator). Only individuals who are also receiving other DD waiver services will receive Medicaid-funded DD support coordination. No individuals will receive only IFDDS support coordination without other waiver services as well.

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 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 serve individuals with developmental disabilities without diagnoses of mental retardation in 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. 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.

These regulations are essential to the health and welfare of developmentally disabled citizens. Prior to the onset of this waiver service, these affected individuals were either situated in their homes with little to no ability to function or institutionalized in other states far from their

families and support systems. 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. DMAS will work with consumers and providers to firmly establish this waiver program while maintaining cost effectiveness.

#### **I**ssues

Please provide a statement identifying the issues associated with the proposed regulatory action. The term "issues" means: 1) the primary advantages and disadvantages to the public, such as individual private citizens or businesses, of implementing the new or amended provisions; 2) the primary advantages and disadvantages to the agency or the Commonwealth; and 3) other pertinent matters of interest to the regulated community, government officials, and the public. If there are no disadvantages to the public or the Commonwealth, please include a sentence to that effect.

The primary advantage for the Commonwealth's citizens will be that developmentally disabled individuals will be able to live as independently as possible in their communities. It will allow some of these individuals to live on their own and enable others to remain with their families. To the extent of their abilities, they will be able to function in their communities, attending school and obtaining employment. The only disadvantage of this waiver is the limited funding which is expected to be exceeded by the demand for these services. Therefore, the agency projects no other negative issues involved in implementing this proposed change.

## Fiscal Impact

Please identify the anticipated fiscal impacts and at a minimum include: (a) the projected cost to the state to implement and enforce the proposed regulation, including (i) fund source / fund detail, (ii) budget activity with a cross-reference to program and subprogram, and (iii) a delineation of one-time versus ongoing expenditures; (b) the projected cost of the regulation on localities; (c) a description of the individuals, businesses or other entities that are likely to be affected by the regulation; (d) the agency's best estimate of the number of such entities that will be affected; and e) the projected cost of the regulation for affected individuals, businesses, or other entities.

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 254 individuals in FY 2001 and 323 individuals in FY 2002 positions in the waiver.

Reimbursement for case management services will be handled through the agency's existing fee-for-service methodology as reflected in 12 VAC 30-80-110.

# 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, and 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". Regardless of the budget level an individual comes under, coverage of all individuals under this waiver program will be limited to available funding.

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 nonwaiver Medicaid covered services and the actual cost of recipients who would be eligible for services.

Since family dynamics change, 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 the 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.

The following provider groups are expected to experience an expansion in their patient loads in providing these new waiver services: home health agencies, personal care agencies, and respite/attendant care providers. These providers who are already enrolled with Medicaid providing services to other individuals are being automatically enrolled to provide DD waiver services. Some provider groups (family caregiver training, companion care, Personal Emergency Response Systems) will have new opportunities to expand their patient populations to those served by Medicaid.

Funding Source/Cost to Localities/Affected Entities: The Department of Medical Assistance Services is established under Title 32.1, Chapter 10, of the Code of Virginia and receives federal financial participation pursuant to Title XIX of the Social Security Act (42 U.S.C. §§ 1396 through 1396v). The Virginia Medicaid Program is funded with both federal and state funds. The current federal funding participation (FFP) for medical assistance expenditures is 51.85%, which became effective on October 1, 2000.

# **Detail of Changes**

Please detail any changes, other than strictly editorial changes, that are being proposed. Please detail new substantive provisions, all substantive changes to existing sections, or both where appropriate. This statement should provide a section-by-section description - or cross-walk - of changes implemented by the proposed regulatory action. Where applicable, include citations to the specific sections of an existing regulation being amended and explain the consequences of the proposed changes.

This entire regulation is new and varies substantially from the current emergency regulations.

# **Alternatives**

Please describe the specific alternatives to the proposal considered and the rationale used by the agency to select the least burdensome or intrusive alternative that meets the essential purpose of the action.

Alternatives to this proposal were evaluated with the technical advisory committee that DMAS convened to design this new waiver program.

# Public Comment

Please summarize all public comment received during the NOIRA comment period and provide the agency response.

No comments were received during the NOIRA comment period.

# **Clarity of the Regulation**

Please provide a statement indicating that the agency, through examination of the regulation and relevant public comments, has determined that the regulation is clearly written and easily understandable by the individuals and entities affected.

DMAS has examined these regulations and, in so far as is possible, has ensured that they are clearly written and easily understandable by the individuals and entities affected.

**Periodic Review** 

Please supply a schedule setting forth when the agency will initiate a review and re-evaluation to determine if the regulation should be continued, amended, or terminated. The specific and measurable regulatory goals should be outlined with this schedule. The review shall take place no later than three years after the proposed regulation is expected to be effective.

Due to the periodic federal review process (every three years) attendant with the waiver approval, DMAS will be evaluating this program for its effectiveness and service coverage.

## Family Impact Statement

Please provide an analysis of the proposed regulatory action that assesses the potential impact on the institution of the family and family stability including the extent to which the regulatory action will: 1) strengthen or erode the authority and rights of parents in the education, nurturing, and supervision of their children; 2) encourage or discourage economic self-sufficiency, self-pride, and the assumption of responsibility for oneself, one's spouse, and one's children and/or elderly parents; 3) strengthen or erode the marital commitment; and 4) increase or decrease disposable family income.

This regulatory action will not have any negative effects 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, or the assumption of family responsibilities. The IFDDS Waiver will offer families the choice of keeping their loved ones at home and in the community rather than 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 their loved ones.