



State of West Virginia  
DEPARTMENT OF HEALTH AND HUMAN RESOURCES  
Office of Inspector General  
Board of Review  
P.O. Box 2590  
Fairmont, WV 26555-2590

Joe Manchin III  
Governor

Martha Yeager Walker  
Secretary

March 24, 2009

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Dear -----:

Attached is a copy of the findings of fact and conclusions of law on your hearing held January 29, 2009. Your hearing request was based on the Department of Health and Human Resources' proposal to terminate your benefits and services through the MR/DD Waiver Program.

In arriving at a decision, the State Hearing Officer is governed by the Public Welfare Laws of West Virginia and the rules and regulations established by the Department of Health and Human Resources. These same laws and regulations are used in all cases to assure that all persons are treated alike.

Eligibility for the MR/DD Home and Community-Based Waiver Program is based on current policy and regulations. Policy states that in order to be eligible for the Title XIX MR/DD Home & Community-Based Waiver Program, an individual must have a diagnosis of mental retardation and/or a related condition. The condition must be severe and chronic with concurrent substantial deficits that require the level of care and services provided in an Intermediate Care Facility for individuals with Mental Retardation and /or related conditions (ICF/MR Facility). (West Virginia Medicaid Regulations, Chapter 513 – Covered Services, Limitations, And Exclusions, For MR/DD Waiver Services, effective 11/1/07).

Information submitted at your hearing fails to demonstrate that you continue to meet the criteria necessary to establish medical eligibility for participation in the MR/DD Waiver Program.

It is the decision of the State Hearing Officer to **uphold** the Department's proposal to terminate your benefits and services through the Medicaid, Title XIX, MR/DD Waiver Program.

Sincerely,

Thomas E. Arnett  
State Hearing Officer  
Member, State Board of Review

Pc: Chairman, Board of Review  
Mary McQuain, Esq., AG's Office  
[REDACTED] Esq., WV Advocates

**WEST VIRGINIA DEPARTMENT OF HEALTH & HUMAN RESOURCES  
BOARD OF REVIEW**

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**Claimant,**

vs.

**Action Number: 07-BOR-698**

**West Virginia Department of  
Health and Human Resources,**

**Respondent.**

**DECISION OF THE STATE HEARING OFFICER**

**I. INTRODUCTION**

This is a report of the State Hearing Officer resulting from a fair hearing concluded on March 24, 2009 for ----- . This hearing was held in accordance with the provisions found in the Common Chapters Manual, Chapter 700 of the West Virginia Department of Health and Human Resources. This fair hearing was originally scheduled to convene on March 23, 2007, May 17, 2007, September 12, 2007, November 29, 2007, January 7, 2008, June 16, 2008, and November 29, 2008 but was convened on January 21, 2009 on a timely appeal filed January 25, 2007.

All continuances were agreed upon by both parties.

**II. PROGRAM PURPOSE:**

The program entitled MR/DD Home and Community-Based Waiver is set up cooperatively between the Federal and State Government and administered by the West Virginia Department of Health and Human Resources.

The *Medicaid Home and Community-Based MR/DD Waiver* (authorized under Title XIX, Section 1915(c) of the Social Security Act) provides an alternative to services available in Intermediate Care Facilities for individuals with Mental Retardation or related conditions (ICF/MR). The primary purpose of an ICF/MR facility is to provide health and rehabilitative services. An ICF/MR facility provides services to persons who are in need of and who are receiving active treatment.

West Virginia's MR/DD Waiver Program provides for individuals who require an ICF/MR level of

care, and who are otherwise eligible for participation in the program, to receive certain services in a home and/or community-based setting for the purpose of attaining independence, personal growth, and community inclusion.

### **III. PARTICIPANTS**

-----, Esq., WV Advocates, Counsel for the Claimant

██████████ Service Coordinator, REM

██████████ Therapeutic Consultant

-----, Claimant's mother (Participated telephonically)

Mary McQuain, Esq., AG's Office, BMS, Counsel for the Department (Participated telephonically)

Steve Brady, Program Coordinator, MR/DD Waiver, BMS (Participated telephonically)

Richard L. Workman, Psychologist Consultant, BMS (Participated telephonically)

Presiding at the hearing was Thomas E. Arnett, State Hearing Officer and a member of the State Board of Review.

### **IV. QUESTION(S) TO BE DECIDED**

The question to be decided is whether the Department was correct in its proposal to terminate the Claimant's benefits and services through the MR/DD Waiver Program.

### **V. APPLICABLE POLICY**

West Virginia Medicaid Regulations, Chapter 513, Covered Services, Limitations, and Exclusions, For MR/DD Waiver Services.

Code of Federal Regulations - §§42 CFR 435.1010, 42 CFR 483.440 & 42 CFR 440.150

### **VI. LISTING OF DOCUMENTARY EVIDENCE ADMITTED**

#### **Department's Exhibits:**

D -1 West Virginia Medicaid Regulations, Chapter 513 – Covered Services, Limitations, And Exclusions, For MR/DD Waiver Services, effective 11/1/07

D-2 DD 2-A-ICF/MR Level of Care Evaluation dated 12/12/06

D-3 Annual Psychological Evaluation dated 9/26/06; Modified 12/13/06

D-4 Notice of Denial dated 1/11/07

D-5 ABS-S:2 scores "recalculated" by ██████████ PhD – dated 1/26/07

- D-6 Individualized Education Program (IEP) dated 10/3/06
- D-7 Correspondence from [REDACTED] CPNP (Neuro-Oncology Nurse Practitioner), Children's Hospital of [REDACTED] – dated 2/7/07
- D-8 Psychological Evaluation – dated 3/13/07
- D-9 WVEIS Information Sheet & Individualized Education Program (IEP) – dated 10/2/07
- D-10 Psychological Evaluation – dated 4/10/08
- D-11 DD 2-A-ICF/MR Level of Care Evaluation – dated 4/2/08
- D-12 Notice of Denial /Termination – dated 6/3/08
- D-13 Notice of Denial /Termination – dated 8/29/08
- D-14 National Institute of Neurological Disorders and Stroke, NINDS Neurofibromatosis Information page–  
<http://www.ninds.nih.gov/disorders/neurofibromatosis/neurofibromatosis.htm> - dated 9/5/07
- D-15 Normative Procedures - Examiners Manual, AAMR Adaptive Behavior Scale School, Second Addition (ABS-S:2)

**VII. FINDINGS OF FACT:**

- 1) There are three (3) different notification letters stemming from the Claimant's attempt at recertification for participation in the MR/DD Waiver Program. The notices all resulted in a proposed termination of benefits based on failure to meet medical eligibility criteria and state, in pertinent part:

Exhibit D-4, Notice of Denial dated 1/11/07 – “Documentation submitted for re-certification review does not support the presence of mental retardation or a related condition. The ABS:S2 results are derived from an inappropriate norms group. Please resubmit using non-mr norms. Please submit -----’s current IEP and any current psycho-metric assessments conducted by the school system which may support the presence of an eligible diagnosis with concurrent substantial deficits in three or more of the six major life areas. Also please provide documentation which would support neurofibromatosis as a “related condition; within 30 days.”

Exhibit D-12, Notice of Denial / Termination dated 6/3/08 – “Additional documentation is requested. Please submit the most current psycho-educational assessments conducted by the school system and -----’s current IEP.”

Exhibit D-13, Notice of Denial /Termination dated 8/29/08 – “Documentation does not support the presence of mental retardation or a related condition.” This notice goes on to say - “Documentation submitted does not support the presence of substantial adaptive deficits in three or more of the six major life areas identified for Waiver eligibility. Specifically, the documentation failed to demonstrate substantial limitations in the following major life areas: Learning, Self-Direction, Receptive or Expressive Language, Mobility and Capacity for

Independent Living.” It should be noted that Self-Care is identified as substantially deficient.

- 2) The Department contends that evidence fails to demonstrate the Claimant presents an eligible diagnosis of Mental Retardation (MR), and that her present diagnosis of Neurofibromatosis does not qualify as a related condition. The Department further contends that even if the Claimant’s diagnosis of Neurofibromatosis was assumed to be a related condition, the Claimant is not demonstrating substantial adaptive deficits in three (3) of the six (6) major life areas, and therefore, does not qualify for the level of care provided in an Intermediate Care Facility for individuals with Mental Retardation (ICF/MR level of care).
- 3) As a matter of record, both parties agreed that the Claimant does not present a diagnosis of Mental Retardation; that she is demonstrating a substantial adaptive deficit in Self-Care; and that Non-MR Norms is the appropriate “norms” group when assessing adaptive deficits with the ABS-S:2 (Adaptive Behavior Scale Score, Second Edition) evaluation tool.
- 4) The Claimant contends, however, that Neurofibromatosis is a related condition and in addition to Self-Care, the Claimant is demonstrating substantial adaptive deficits in her Capacity for Independent Living and Self-Direction.
- 5) The Department’s psychologist consultant purported that documentation fails to demonstrate a diagnosis of MR or confirm that Neurofibromatosis is a related condition (Any 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 services similar to those required for persons with mental retardation). The Department’s psychologist indicated that his research resulted in the discovery that only 5 to 10% of individuals with Neurofibromatosis are diagnosed with MR. Because there is a low incidence of MR associated with Neurofibromatosis, and there was no information submitted to the contrary, he was unable to determine Neurofibromatosis is a related condition.

The Department’s psychologist further indicated that while the Claimant is demonstrating a substantial adaptive deficit in Self-Care, there is no evidence to support the finding of a substantial adaptive deficit in any of the five (5) remaining major life areas – Learning, Mobility, Language, Capacity for Independent Living and Self-Direction.

The Department’s psychologist asserts that the most recent ABS-S:2 scores submitted appear to be from a psychological evaluation completed on 12/13/06. While Exhibit D-5 clearly indicates that the ABS scores are recalculated to Non-MR Norms from the 12/13/06 evaluation, the same ABS Raw Scores can be found in Exhibit D-10 (although scored inappropriately with MR Norms). The Department’s psychologist testified that ABS scoring must be done annually, and therefore, the outdated ABS scores cannot be relied upon for a

clinical evaluation of current substantial adaptive deficits. More specifically, he stated it appears as though the evaluation is comparing the ABS results of a 9-year-old with an 11-year-old norms group. He further stated that even if these scores were current, they demonstrate a substantial adaptive deficit in Independent Functioning (Self-Care) only as an eligible score for Non-MR Norms is less than one percentile (or a Standard Score of 2 or less).

Exhibit-9, IEP dated 10/2/07, indicates on page 2 that the Claimant is in 5<sup>th</sup> Grade and is in the Learning Disability Program. The Department's psychologist indicated that individuals who participate in the Learning Disability Program are not demonstrating severe cognitive deficits and the Claimant is in Special Education only 18% of the day in public school (See Exhibit D-9, page 14 of 15).

- 6) The only evidence submitted to provide a medical explanation of Neurofibromatosis is the NINDS (National Institute of Neurological Disorders and Stroke) Neurofibromatosis Information Page (Exhibit D-14). While there are two types of Neurofibromatosis, NF1 and NF2, the prognosis states – “In most cases, symptoms of NF1 are mild, and patients live normal and productive lives. In some cases, however, NF1 can be severely debilitating. In some cases of NF2, the damage to nearby vital structures, such as other cranial nerves and the brainstem, can be life-threatening.”

This document fails to note any correlation between Neurofibromatosis and mental retardation or that Neurofibromatosis results in impairment of general intellectual functioning or adaptive behavior similar to that of mentally retarded persons.

- 7) The two major life areas contested by the Claimant are Self-Direction and Capacity for Independent Living. As noted previously, the ABS:S-2 scores found in Exhibit D-10 did not use the appropriate norms group and it is unclear if the results from Exhibit D-10 are current (given the fact that the Raw Scores are identical to those found in the “recalculated” ABS:S-2 identified as Exhibit D-5), and there is no mention in Exhibit D-10 that a new ABS:S-2 assessment was completed.

The ABS-S:2 results in Self-Direction, Non-MR Norms found in Exhibit D-5, indicate that while the Claimant is ranked in the 1<sup>st</sup> percentile, her Standard Score is 3 (A Standard Score of 2 or less indicates eligibility - less than 1 percentile). Narrative information found in Exhibit D-8 and Exhibit D-10 indicates that the Claimant likes going to school and she likes other children. She loves her cat and she likes other age appropriate activities, such as dolls and coloring. It is noted under the Behavioral History Section in both evaluations (D-8 & D-10) that the Claimant complains that she is treated unfairly, that she exhibits attention-seeking behavior and needs frequent reassurance. Exhibit D-9 notes under the Educational Specialist Report (Testing Observations) that the Claimant is extremely cooperative and anxious to know results of her performance. An individual who demonstrates the ability to

manipulate their environment, expresses known likes and dislikes, as well as interest in testing results, is clearly demonstrating developed Self-Direction skills. Based on the evidence, the Claimant is not demonstrating a substantial adaptive deficit in Self-Direction.

Although multiple safety issues were noted in testimony presented at the hearing, a finding specific to the Claimant's Capacity for Independent Living is moot without a favorable finding in Self-Direction.

- 8) West Virginia Medicaid Regulations, Chapter 513, – Covered Services, Limitations, And Exclusions, For MR/DD Waiver Services, effective 11/1/07, includes the following pertinent medical eligibility criteria:

**Medical Eligibility Criteria**

The MR/DD State Waiver Office determines the medical eligibility for an applicant in the MR/DD Waiver Program. In order to be eligible to receive MR/DD Waiver Program Services, an applicant must meet the following medical eligibility criteria:

- Have a diagnosis of mental retardation and/or a related condition,
- Require the level of care and services provided in an ICF/MR (Intermediate Care Facility for the Mentally Retarded) as evidenced by required evaluations and corroborated by narrative descriptions of functioning and reported history. An ICF/MR provides services in an institutional setting for persons with mental retardation or related condition. An ICF/MR facility provides monitoring, supervision, training, and supports.

MR/DD State Waiver Office determines the level of care (medical eligibility) based on the Annual Medical Evaluation (DD-2A), the Psychological Evaluation (DD-3) and verification if not indicated in the DD-2A and DD-3, that documents that the mental retardation and/or related conditions with associated concurrent adaptive deficits were manifested prior to the age of 22, and are likely to continue indefinitely. Other documents, if applicable and available, that can be utilized include the Social History, IEP for school age children, Birth to Three assessments, and other related assessments.

The evaluations must demonstrate that an applicant has a diagnosis of mental retardation and/or a related developmental condition, which constitutes a severe and chronic disability. For this program individuals must meet the diagnostic criteria for medical eligibility not only by the relevant test scores, but also the narrative descriptions contained in the documentation. To be eligible, the

member:

- Must have a diagnosis of mental retardation, with concurrent substantial deficits (substantial limitations associated with the presence of mental retardation), and/or

- Must have a related developmental condition which constitutes a severe and chronic disability with concurrent substantial deficits.

Examples of related conditions which may, if severe and chronic in nature, make an individual eligible for the MR/DD Waiver Program include but are not limited to, the following:

- Any 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 services similar to those required for persons with mental retardation.

- Autism

- Traumatic brain injury

- Cerebral Palsy

- Spina Bifida

- Tuberous Sclerosis

Additionally, the member who has a diagnosis of mental retardation and/or related conditions and associated concurrent adaptive deficits must have the following:

- Manifested prior to the age of 22, and

- Likely to continue indefinitely.

- Must have the presence of a least three (3) substantial deficits out of five of the major life areas (term is defined in Title 42, Chapter IV, Part 435.1009 (now 435.1010) of the Code of Federal Regulations or CFR.

Refer to 503.1, Functionality section for a list of the major life areas.

### **Functionality**



- Substantially limited functioning in three (3) or more of the following major life areas; (“substantially limited” is defined on standardized measures of adaptive behavior scores as three (3) standard deviations below the mean or less than one (1) percentile when derived from non MR normative populations or in the average range or equal to or below the seventy fifth (75) percentile when derived from MR normative populations. The presence of substantial deficits must be supported not only by the relevant test scores, but also the narrative descriptions contained in the documentation submitted for review, i.e., psychological, the IEP, Occupational Therapy evaluation, etc.). Applicable categories regarding general functioning include:

- Self-care

- Receptive or expressive language (communication)

- Learning (functional academics)

- Mobility

- Self-direction

- Capacity for independent living (home living, social skills, employment, health and safety, community and leisure activities).

For applicable major life functioning areas, refer to Code of Federal Regulation (CFR): 42 CFR435.1009.

### **Active Treatment**

- Requires and would benefit from continuous active treatment.

Medical Eligibility Criteria: Level of Care

- To qualify for ICF/MR level of care, evaluations of the applicant must demonstrate:

- o A need for intensive instruction, services, assistance, and supervision in order to learn new skills, maintain current level of skills, and increase independence in activities of daily living,

- o A need for the same level of care and services that is provided in an ICF/MR institutional setting.

The applicant or legal representative will be informed of the right to choose

between ICF/MR services and home and community-based services under the MR/DD Waiver Program and informed of his/her right to a fair hearing at the time of application (Informed Consent, DD-7).

### **Conditions Ineligible**

- Substantial deficits associated with a diagnosis other than mental retardation or a related diagnosis do not meet eligibility criteria.

- Additionally, any individual needing only personal care services does not meet the eligibility criteria.

- Individuals diagnosed with mental illness whose evaluations submitted for medical eligibility determination indicate no previous history of co-occurring mental retardation or developmental disability prior to age 22. The member's clinical evaluators must provide clinical verification through the appropriate eligibility documentation that their mental illness is not the primary cause of the substantial deficits and the mental retardation or developmental disability occurred prior to the age of twenty-two (22).

### **VIII. CONCLUSIONS OF LAW:**

- 1) The regulations that govern the MR/DD Waiver Program require eligible individuals to have a diagnosis of Mental Retardation (and/or a related condition), which must be severe and chronic, in conjunction with substantial deficits in three (3) or more of the major life areas. "Substantially limited" is defined on standardized measures of adaptive behavior scores as three (3) standard deviations below the mean or less than one (1) percentile when derived from non-MR normative populations, or in the average range or equal to or below the seventy-fifth (75) percentile when derived from MR normative populations.
- 2) The evidence fails to demonstrate that there is any correlation between Neurofibromatosis and Mental Retardation or that Neurofibromatosis results in impairment of general intellectual functioning or adaptive behavior similar to that of mentally retarded persons. Therefore, the Department's assessment that the Claimant does not present a related condition is affirmed. Furthermore, the standardized measures of adaptive behavior scores, as well as the clinical and narrative documentation found in the evaluations, fail to confirm substantial adaptive deficits in three or more of the major life areas.
- 3) Based on the evidence presented at the hearing, the Department was correct in its determination that the Claimant fails to meet medical eligibility criterion required to

participate in the Medicaid MR/DD Waiver Program.

**IX. DECISION:**

It is the decision of the State Hearing Officer to **uphold** the Department's proposal to terminate the Claimant's benefits and services through the MR/DD Waiver Program.

**X. RIGHT OF APPEAL:**

See Attachment.

**XI. ATTACHMENTS:**

The Claimant's Recourse to Hearing Decision.

Form IG-BR-29.

**ENTERED this 24<sup>th</sup> Day of March, 2009**

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**Thomas E. Arnett  
State Hearing Officer**