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SUBJECT Revised Definition of Developmentally Disabled Persons who Receive Services in Intermediate Care Facilities for the Mentally Retarded (ICFs/MR)

BY

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Acting Deputy Secretary for Mental Retardation

SCOPE

Administrators, State-Operated ICF/MR Programs
Administrators, Non-State Operated ICF/MR Programs
Regional MR Program Managers
County MH/MR Administrators

PURPOSE

To provide ICF/MR providers with the new definition of the term "persons with related conditions" as it may pertain to such persons' eligibility for services provided by those ICFs/MR.

BACKGROUND

The Health Care Financing Administration (and its predecessor agency, the Social and Rehabilitation Service) have, since 1974 when the original Federal ICF/MR regulations were issued, utilized the statutory term "persons with conditions related to mental retardation" to designate a developmentally disabled individual as defined in the Developmental Disabilities Services and Facilities Construction Act of 1970 (P.L. 91-517). However, Medicaid rules were recodified in 1978, and the words "as amended" were added following reference to the 1970 Act. This served to promote some advocates for the mentally ill to argue that the new functional definition of the term "developmental disability" as contained in the 1978 amendments to the Developmental Disabilities Act, encompassed services to persons with chronic emotional disorders and, therefore, states should be permitted to certify long term care facilities serving such clients as ICF/MR vendors.

In order to avoid confusion over the kind of care covered by the ICF/MR benefit, the Health Care Financing Administration (HCFA) published final regulations on May 28, 1986, that established an independent Medicaid definition of persons with conditions related to mental retardation. The rule became effective June 27, 1986.

COMMENTS AND QUESTIONS REGARDING THIS BULLETIN SHOULD BE DIRECTED TO: Frank L. Pierce, Director, Bureau of ICF/MR Administration & Management, Office of Mental Retardation, Room 302, Health & Welfare Bldg., Harrisburg, PA 17120; Telephone: 717-783-5314; Network: 8-443-5314.

APPLICATION

The new definition contained in 42 CFR 435.1009, of "related conditions" deletes autism from the list of categorically related conditions leaving just cerebral palsy and epilepsy.

Secondly, persons with "other conditions" must have impairments in either general intellectual functioning or adaptive behavior that are similar to those faced by mentally retarded persons and also must need services similar to those required by retarded persons.

However, even though "autism" is classified as a mental illness, many autistic individuals are functionally retarded and may require services provided by an ICF/MR to treat them. These individuals may continue to be cared for in the ICF/MR setting because such care is appropriate for their needs. Further clarification on the issue of ICF/MR services for autistic individuals is expected to be forthcoming from HCFA in the near future.

In addition, other individuals having mental illness and who also have other conditions specified in 42 CFR 435.1009 may also receive ICF/MR services provided the other eligibility criteria contained in Section 435.1009 are met.

A copy of the new definition adopted by HCFA is attached.

Attachment

or presence of free liquids in either a bulk or a containerized waste. The reserving of paragraph (d), which presents the Paint Filter Liquids Test requirement, was unintentional and is now being corrected. The Paint Filter Liquids Test has been in effect continuously since June 14, 1985, and remains in effect.

The amendatory language in paragraph 50 on page 28750 of the Federal Register is corrected by removing the reference to paragraph (d). Paragraph (d) of § 265.314 remains as added at page 18374 in the Federal Register published on April 30, 1985, (FR Doc. 85-10278).

Dated: May 13, 1986.

J.W. McGraw,

Acting Assistant Administrator.

Accordingly, in the Federal Register of July 15, 1985, (FR Doc. 83-13094), on page 28750, second column, paragraph 50, is corrected by changing the comma after the word "respectively" to a period, and by removing the words "and paragraph (d) is reserved."

For the convenience of the user, the text of § 265.314(d) is reprinted as follows:

§ 265.314 Special requirements for bulk and containerized liquids.

(d) To demonstrate the absence or presence of free liquids in either a containerized or a bulk waste, the following test must be used: Method 9095 (Paint Filter Liquids Test) as described in "Test Methods for Evaluating Solid Wastes, Physical/Chemical Methods." (EPA Publication No. SW-846).

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DEPARTMENT OF HEALTH AND HUMAN SERVICES

Health Care Financing Administration

42 CFR Part 435

(BERC-106-F)

Medicaid Program—Mental Retardation; Definition of "Persons With Related Conditions"

AGENCY: Health Care Financing Administration (HCFA), HHS.

ACTION: Final rule.

SUMMARY: This rule amends a definition in Medicaid regulations concerning intermediate care facilities for the mentally retarded (ICF/MR) and persons with related conditions. The definition of "persons with related

conditions" contained in our regulations was tied to the definition of developmental disability included in the Developmental Disabilities Assistance and Bill of Rights Act (DDABRA) as amended in 1978. The DDABRA, as amended, however, also included the mentally ill within the definition of developmental disability. The prior cross-reference in our regulations to the DDABRA definition resulted in confusion about the kind of care covered by the ICF/MR benefit. To avoid misunderstandings in the future, this rule establishes an independent Medicaid definition of persons with conditions related to mental retardation.

EFFECTIVE DATE: June 27, 1986.

FOR FURTHER INFORMATION CONTACT: Thomas Hoyer, (301) 594-9446.

SUPPLEMENTARY INFORMATION:

I. Background

Section 1904 of the Social Security Act (Act) authorizes optional Medicaid coverage for services in intermediate care facilities (ICFs). ICFs are facilities that provide health-related care to individuals who do not need the degree of care commonly provided in hospitals or skilled nursing facilities, but who do require care and services, above the level of room and board, which can only be made available to them through institutional facilities. Section 1905(d) of the Act indicates that the term "intermediate care facility services" may include services in a public institution for the mentally retarded or "persons with related conditions" (ICF/MR). This statutory provision is reflected in current regulations at 42 CFR 435.1009 and 440.150.

Initial Medicaid regulations published in 1974 defined "persons with related conditions" by using a cross-reference to the definition of developmental disability in the Developmental Disabilities Services and Facilities Construction Act (DDSFCA), Pub. L. 91-517, enacted on October 30, 1970 (changed to the Developmental Disabilities Assistance and Bill of Rights Act in 1975, (DDABRA)). That definition of developmental disability used specific diagnoses to limit its scope to impairments closely related to mental retardation. The definition read "... a disability attributable to mental retardation, cerebral palsy, epilepsy, or another neurological condition of an individual found by the Secretary to be closely related to mental retardation or to require treatment similar to that required for mentally retarded individuals, whose disability originates before such individual attains age 18, which has continued or can be expected

to continue indefinitely, and which constitutes a substantial handicap to such individual."

Since 1970, the DDABRA definition of developmental disability has been amended twice. In 1975, Pub. L. 94-103 amended the definition to:

(1) Add autism to the list of specific conditions; dyslexia resulting from a disability otherwise specified in the definition was also added;

(2) Expand the reference to "other neurological conditions" to cover any conditions closely related to mental retardation by virtue of a similar impairment or a requirement for similar treatment; and

(3) Relate "substantial handicap" to the ability to function normally in society.

On October 1, 1978, an amendment to DDABRA, Pub. L. 95-602 revised the definition of developmental disability even further to read as follows:

"The term 'developmental disability' means a severe, chronic disability of a person which—

(1) Is attributable to a mental or physical impairment or combination of mental and physical impairments;

(2) Is manifested before the person attains age 22;

(3) Is likely to continue indefinitely;

(4) Results in substantial functional limitations in three or more of the following areas of major life activity:

(a) Self-care.
(b) Receptive and expressive language.

(c) Learning.
(d) Mobility.
(e) Self-direction.
(f) Capacity for independent living.
(g) Economic self-sufficiency.

(5) Reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care; treatment, or other services which are of lifelong or extended duration and are individually planned and coordinated."

This last amendment changed the focus of the definition from a categorical to a functional one. Thus, the definition no longer listed specific diagnoses that previously had been used to limit the definition to those impairments closely resembling mental retardation, but included any person with a mental or physical impairment that limits the person's functional ability in certain activities. Furthermore, the age by which a condition must manifest itself was changed from 18 to 22.

In 1974, Medicaid regulations were promulgated to implement the ICF/MR benefit under Medicaid. The DDABRA (then, DDSFCA) definition of "developmental disability" was adopted

Response: The potential for misunderstanding in this area was not immediately evident at the time, given the clear language in the statute concerning funding for institutions for mental diseases. Once the effect of the 1978 amendment to the DDABRA definition was assessed, HCFA began drafting a technical revision to correct the error. Upon consideration, we determined that a new definition of "persons with related conditions" was needed specifically for the Medicaid program and that public comment on such a definition was appropriate. Prior to publishing the proposed definition, HCFA met with representatives from the Administration on Developmental Disabilities and the National Institute for Mental Health to obtain advice on a Medicaid definition of "related conditions" and its relationship to Medicaid benefits for the mentally ill and programs under the aegis of the DDABRA. Careful consideration of the advice from these sources delayed issuance of the proposed regulation and the solicitation of public comment.

Comment: Two commenters indicated that the discussion in the preamble of the proposed rule did not adequately justify the reason for the new definition.

Response: We disagree and believe that sufficient justification for the definition was provided in the preamble of the NPRM. However, we have supplied additional explanation and discussion in this preamble.

Comment: A hospital program director stated that because 5 years have passed since the DDABRA definition of developmental disability changed, HCFA has set a precedent for covering the mentally ill under the ICF/MR provision and cannot exclude them now.

Response: As detailed earlier in this preamble under the background discussion, the Medicaid statute places specific limits on coverage of care of the mentally ill to specified age groups and certain institutions. The Department cannot override the statutory restrictions when issuing program regulations; thus, HCFA's action or inaction cannot change that authority. HCFA is issuing the new definition of "persons with related conditions" to avoid future misunderstandings.

Comment: Two commenters indicated that 30 days was an insufficient amount of time to research the effect of the proposed definition. Another respondent requested that the comment period be extended 60 days.

Response: Commenters had 30 days after publication of our proposal to submit their comments. We do not agree that additional time for extensive research was needed because, as we

fully explained, these regulations reflect statutory intent. Additionally, States are currently implementing this provision.

Comment: One Congressman asked that we delay final action regarding the proposed definition until a policy and economic analysis can be conducted.

Response: A policy and economic analysis is conducted on all proposed regulations as required by section 1(b) of Executive Order 12291 and 5 U.S.C. 605(b). The results of the analysis were presented in the NPRM, and we believe additional analysis is not required.

2. Programmatic Effects of the Definition

Comment: The majority of commenters opposed the proposed regulations on the grounds that they will exclude mentally ill individuals from the definition of "persons with related conditions". They believe that this will result in the elimination of Medicaid coverage for children and adolescents who are emotionally disturbed or have other psychiatric conditions. One particular State had many respondents, including Members of Congress who were concerned that they would be unable to place or serve numerous children with chronic emotional/psychiatric disorders and that a significant amount of Federal funds would be lost upon adoption of the proposed definition.

Response: These comments reflect confusion about the settings for the services which Medicaid covers and the purpose of this rule. The term being defined, "persons with related conditions", is part of the Medicaid provision for intermediate care facility services for the mentally retarded and persons with related conditions (ICFs/MR) in section 1905(d) of the Act. As discussed earlier, coverage for inpatient psychiatric care for individuals under 21 is provided for under a separate provision. For this reason, we proposed to clarify this definition of "persons with related conditions" to prevent any confusion.

Comment: Two representatives from a private non-profit provider of residential and other services to mentally retarded and emotionally disturbed persons commented that emotionally disturbed individuals have substantial limitations in major life activities and benefit from training and habilitation programs. They added that these individuals are not in need of hospital or skilled nursing care, but rather ICF/MR services.

Response: We agree that emotionally disabled persons can benefit from individually developed care plans but do not support the contention that emotionally disturbed individuals, who

may have average or above average intelligence, generally should be placed in facilities which are designed for mentally retarded persons. Emotionally disturbed individuals who need institutionalization are usually best treated in a licensed psychiatric facility at the level of care (i.e. hospital, SNF or ICF) appropriate to their illness, rather than in a facility designed primarily for the care of mentally retarded persons. Also it is clear from the statutory limitations on funding of services in institutions for mental diseases, that Congress did not intend that services provided in those institutions be funded under the ICF/MR coverage provision.

Comment: Two respondents stated that the proposed definition discriminates against the mentally ill as a class while including individuals with cerebral palsy, epilepsy, autism, spina bifida, muscular dystrophy, deaf-blindness and severe learning disabilities.

Response: We do not believe that the proposed definition is discriminatory. Rather, as mentioned earlier, the Department cannot override statutory limitations. We think that this definition accurately implements statutory provisions (such as the definition of intermediate care facility services for the mentally retarded in section 1905(d) of the Act) and encourages treatment in appropriate settings. We chose to list two specific conditions as examples of "related conditions". It is important to note that this provision is applicable only to the definition of "intermediate care facility services for the mentally retarded or persons with related conditions" also defined in 42 CFR 435.1009 and 440.150(c). And, as discussed earlier, ICF/MR services may not include treatment of individuals who have a condition of mental illness only.

Comment: One official from a State human services department asserted that the proposed definition would reduce the number of individuals eligible to receive home and community-based services since they have already included the emotionally disturbed individuals being served by their ICFs/MR under a home and community-based waiver. Therefore, the commenter asserts that we are violating the intent of section 2176 of Pub. L. 97-35 (the Omnibus Budget Reconciliation Act of 1981).

Response: Section 2176 enacted section 1915(c) of the Act. The intent of Section 2176 is to offer home and community-based services as an alternative to nursing home care which otherwise would have been reimbursed under the State Medicaid Plan. The new

Response: We do not agree and have not adopted this suggestion. We do not believe that this addition would strengthen the statement but rather would create additional confusion. The reason for the exclusion of mental illness from this definition is the statutory restriction related to payment for services in institutions for mental diseases. There is no comparable restriction relating to other types of illnesses.

Comment: One hospital program director asserted that including individuals with autism, which is categorized as a mental illness, directly conflicts with the decision to exclude other mental illnesses from the definition.

Response: We had planned to continue to include autism as a related condition because it has been specifically identified in the developmental disability definition since the 1975 amendments. Since it is classified as a mental illness, however, we have deleted this specific diagnosis from the final regulations. Despite this approach, many autistic individuals are functionally retarded and may require the services provided by an ICF/MR to treat them. These individuals may continue to be cared for in this setting since such care is appropriate for them.

Comment: The National Mental Health Association indicated that economic self-sufficiency should be included as a criterion because it is a substantial functional limitation and should be one of the factors in determining those individuals who may need and should be eligible for care in ICFs/MR.

Response: Although both programs are geared toward providing services which assist an individual in reaching the maximum level of functioning, the Medicaid definition of persons with related conditions is applicable only to the services provided by an ICF/MR whereas the DDABRA and its definition of developmental disabilities is applicable to a host of other categories of service such as education, vocational rehabilitation, and alternative community living arrangements, in which economic sufficiency is generally an integral part of the service system. Based on the need for which an ICF/MR is designed (health-related care in an institutional setting), we do not believe economic self-sufficiency is an appropriate criterion for defining ICF/MR services. Moreover, all Medicaid recipients have, by definition, economic difficulties that make them unable to meet their medical costs without assistance.

IV. Impact Analysis

We have determined that this final rule does not meet the criteria for a major rule as defined by section 1(b) of Executive Order 12291. That is, this rule would not have an annual effect on the economy of \$100 million or more; or result in a major increase in costs or prices for consumers, government agencies, industry, or a geographic region; or have significant adverse effects on competition, employment, investment, productivity, innovation, or on the ability of United States-based enterprises to compete with foreign-based enterprises in domestic or import markets.

This final rule corrects a regulation drafting error which unintentionally appeared to cross-reference the 1978 DDABRA definition of developmental disability for use in defining persons with related conditions. The new definition of this term reflects in regulations the policies States now generally follow in connection with ICF/MR benefits. The rule will, therefore, have little, if any, fiscal impact on program operations and does not meet the criteria for a major rule under Executive Order 12291.

For these reasons, the Secretary also certifies, pursuant to section 605(b) of title 5, United States Code, enacted by the Regulatory Flexibility Act (Pub. L. 96-354) that the regulations will not have a significant economic impact on a substantial number of small entities.

Recordkeeping and Reporting Requirements

This final rule does not contain information collection requirements. Therefore, a review by the Office of Management and Budget (OMB) as specified under section 3504(h) of the Paperwork Reduction Act of 1980 is not necessary.

List of Subjects in 42 CFR Part 435

Aid to families with dependent children, Grant programs—health, Medicaid, Supplemental Security Income (SSI).

PART 435—ELIGIBILITY IN THE STATES, DISTRICT OF COLUMBIA AND THE NORTHERN MARIANA ISLANDS

42 CFR Part 435 is amended as set forth below:

The authority citation for Part 435 continues to read as follows:

Authority: Sec. 1102 of the Social Security Act (42 U.S.C. 1302).

Section 435.1009 is amended by revising the definition of "Persons with related conditions" to read as follows:

§ 435.1009 Definitions relating to institutional status.

"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.

(Catalog of Federal Domestic Assistance Program No. 13.714, Medical Assistance Program)

Dated: March 25, 1986.

Henry R. Desmarais,
 Acting Administrator, Health Care Financing Administration.

Approved: April 29, 1986.

Otis R. Bowen,

Secretary.

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FEDERAL EMERGENCY MANAGEMENT AGENCY

44 CFR Part 67

Final Flood Elevation Determinations; California et al.

AGENCY: Federal Emergency Management Agency

ACTION: Final rule.

SUMMARY: Final base (100-year) flood elevations are determined for the communities listed below.

The base (100-year) flood elevations are the basis for the flood plain management measures that the community is required to either adopt or