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RWCA [Ryan White CARE Act] [2]

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A BILL

To extend and amend the Ryan White CARE Act programs under title XXVI of the Public Health Service Act, to improve access to health care and quality of care under such programs, and to provide for the development of increased capacity to provide health care and related support services to individuals and families with HIV disease, and for other purposes.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. SHORT TITLE.

This Act may be cited as the "Ryan White CARE Act Amendments of 2000".

SEC. 2. REFERENCES; TABLE OF CONTENTS.

(a) REFERENCES.—Whenever in this Act an amendment is expressed in terms of an amendment to a section or other provision, the reference shall be considered to be made to a section or other provision of the Public Health Service Act (42 U.S.C. 201 et seq.), unless another act is specified.

(b) TABLE OF CONTENTS.—The table of contents of this Act is as follows:

- | | |
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| Sec. 1. | Short title. |
| Sec. 2. | References; table of contents. |

TITLE I—AMENDMENTS TO HIV HEALTH CARE PROGRAM (TITLE XXVI OF THE PUBLIC HEALTH SERVICE ACT)

PART A—PURPOSE; AMENDMENTS TO PART A— EMERGENCY RELIEF GRANTS

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PART B—AMENDMENTS TO PART B—CARE GRANT PROGRAM

- Sec. 121. Consortia requirements concerning identification of need and allocation of resources.
- Sec. 122. Coordination with Medicaid and State Children's Health Insurance Program and with other service providers.
- Sec. 123. Quality management.
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- Sec. 128. Appropriations for treatment drug program.
- Sec. 129. Authorization of appropriations for HIV-related services for women and children.
- Sec. ~~128~~130. Repeal of requirement for completed Institute of Medicine report.

PART C—AMENDMENTS TO PART C—EARLY INTERVENTION SERVICES

- Sec. 141. Amendment of heading; repeal of formula grant program.
- Sec. 142. Capacity development grants.
- Sec. 143. Authorization of appropriations for categorical grants.
- Sec. ~~143~~144. Administrative expenses ceiling; quality management assessments

PART D—AMENDMENTS TO PART D—GENERAL PROVISIONS

- Sec. 151. Research involving women, infants, children, and youth.
- Sec. 152. ~~Authorization of appropriations for research grants.~~
- Sec. ~~153~~. Authorizations of appropriations for grants under parts A and B.
- Sec. ~~154~~. ~~Authorization of appropriations for grants to implement guidelines.~~

PART E—AMENDMENTS TO PART F—DEMONSTRATION AND TRAINING

- Sec. 161. Dental services; quality management; authorization of appropriations; and clarifying amendments.
- Sec. ~~162~~. ~~Capacity development grants.~~

TITLE II—OTHER PROVISIONS

- Sec. 201. Institute of Medicine study.

TITLE I—AMENDMENTS TO HIV HEALTH CARE PROGRAM

(TITLE XXVI OF THE PUBLIC HEALTH SERVICE ACT)

PART A—PURPOSE; AMENDMENTS TO PART A—

EMERGENCY RELIEF GRANTS

SEC. 101. SHORT TITLE; PURPOSE.

Title XXVI is amended by inserting before part A the following new section:

"SEC. 2600. SHORT TITLE; PURPOSE.

"(a) **SHORT TITLE.**—This title may be cited as the 'Ryan White CARE Act'.

"(b) **PURPOSE.**—It is the purpose of this title—

"(1) to provide emergency assistance to localities that are disproportionately affected by the Human Immunodeficiency Virus epidemic;

"(2) to make financial assistance available to States and other public or nonprofit private entities to provide for the development, organization, coordination, and operation of more effective and cost-efficient systems for the delivery of essential services to individuals with HIV disease and their families; and

"(3) to ensure, to the extent possible, that individuals and families with HIV disease receive a comprehensive continuum of essential medical and support services, including early intervention services."

SEC. 102. DUTIES OF PLANNING COUNCIL: RELOCATION OF PROVISION; AMENDMENTS CONCERNING FUNDING PRIORITIES, QUALITY ASSESSMENT.

Section 2602 (42 U.S.C. 300ff-12) is amended—

(1) in subsection (b)(4), by striking "shall—" and all that follows and inserting "shall have the responsibilities specified in subsection (d); and

(2) by adding at the end the following new subsections:

"(d) **DUTIES OF PLANNING COUNCIL.**—The planning council established under subsection (b) shall have the following duties:

"(1) **PRIORITIES FOR ALLOCATION OF FUNDS.**—The council shall establish priorities for the allocation of funds within the eligible area, including how best to meet each such priority and additional factors that a grantee should consider in allocating funds

under a grant, based on the following factors:

"(A) the size and demographic characteristics of the population with HIV disease (including the numbers of individuals with HIV disease in the area who are and who are not receiving HIV-related health services), as estimated on the basis of available epidemiologic data and using such recognized population-based assessment and modeling techniques as the Secretary may prescribe;

"(B) documented needs of the population with HIV disease (including needs of individuals who have been diagnosed with HIV disease but who are not currently receiving HIV-related health care services), with particular attention to disparities in health outcomes among affected subgroups (including women and including individuals with addictive disorders) within the eligible area;

"(C) demonstrated or probable cost and outcome effectiveness of proposed strategies and interventions, to the extent that data are reasonably available;

"(D) priorities of the communities with HIV disease for whom the services are intended, including priorities addressing the health and related support service needs of individuals not currently receiving such services;

"(E) strategies for making optimal use of financial assistance available under the State Medicaid plan under title XIX and the State Children's Health Insurance Program under title XXI of the Social Security Act to cover health care costs of eligible individuals and families with HIV disease; and

"(F) availability of other governmental and non-governmental resources; and

"(G) capacity development needs due to gaps in provision of HIV services in historically underserved low-income communities.

"(2) COMPREHENSIVE SERVICE DELIVERY PLAN.—The council shall develop a comprehensive plan for the organization and delivery of health and support services described in section 2604 that is compatible with any existing State or local plan

regarding the provision of such services to individuals with HIV disease.

"(3) **QUALITY MANAGEMENT PROGRAM.**—The council, directly or through contractual arrangements, shall implement a quality management program.

"(4) **ASSESSMENT OF FUND ALLOCATION EFFICIENCY.**—The council shall assess the efficiency of the administrative mechanism in rapidly allocating funds to the areas of greatest need within the eligible area.

"(5) **STATEWIDE STATEMENT OF NEED.**—The council shall participate in the development of the statewide coordinated statement of need initiated by the State public health agency responsible for administering grants under part B.

"(6) **COORDINATION WITH OTHER FEDERAL GRANTEES.**—The council shall coordinate with federal grantees providing HIV-related services within the eligible area.

"(7) **COMMUNITY PARTICIPATION.**—The council shall establish methods for obtaining input on community needs and priorities which may include public meetings, conducting focus groups, and convening ad-hoc panels.

"(e) **ADVICE ON ESTABLISHING ALLOCATION PRIORITIES.**—The Secretary, in consultation with eligible metropolitan areas and affected communities, shall provide advice and technical assistance to planning councils with respect to the process for establishing priorities for allocation of funds under subsection (d)(1)."

SEC. 103. QUALITY MANAGEMENT.

(a) **QUALITY MANAGEMENT PROGRAM DEFINED.**—Section 2676 (42 U.S.C. 300ff-76) is amended—

(1) by redesignating paragraph (12) as paragraph (13); and

(2) by inserting after paragraph (11) the following new paragraph:

"(12) **QUALITY MANAGEMENT PROGRAM.**—

"(A) **IN GENERAL.**—The term 'quality management program' means, with respect to a grant under which services are provided to individuals or families

under this title, a program under which, using such methods and criteria as the Secretary may establish,—

"(i) performance goals and measures are established regarding the effectiveness of the services provided under the grant with respect to the outcomes listed in subparagraph (B);

"(ii) an assessment is conducted of the effectiveness of the grant program concerned under this part with respect to such outcomes; and

"(iii) the results of the assessment are used to assist the grantee in determining whether modifications are needed in the grantee's operations and delivery of services under the grant program.

"(B) PROGRAM OUTCOMES TO BE ASSESSED.—The quality management program under subparagraph (A) shall be designed to assess the grant program from the standpoint of—

"(i) effectiveness in encouraging and ensuring timely access to appropriate health and support services by individuals diagnosed with HIV disease, including individuals not currently receiving HIV-related health services;

"(ii) quality of the services;

"(iii) health outcomes; and

"(iv) cost-effectiveness."

(b) QUALITY MANAGEMENT REQUIRED FOR ELIGIBILITY FOR GRANTS.—Section 2605(a) (42 U.S.C. 300ff-15(a)) is amended—

(1) by redesignating paragraphs (3) through (6) as paragraphs (4) through (7); and

(2) by inserting after paragraph (2) the following new paragraph:

"(3) that the planning council has satisfied (or, as appropriate with respect to requirements for a quality management program, will satisfy) all requirements under section 2602(d)."

(c) **CEILING ON FUNDS AVAILABLE FOR QUALITY MANAGEMENT.**—Section 2604 (42 U.S.C. 300ff-14) is amended by adding at the end the following new subsection:

"(g) **QUALITY MANAGEMENT.**—From amounts received under a grant awarded under this part, the chief elected official of an eligible area may use, for activities associated with its quality management program, no more than the lesser of—

"(1) 5 percent of amounts received under the grant; or

"(2) \$3,000,000."

SEC. 104. FUNDED ENTITIES REQUIRED TO HAVE HEALTH CARE REFERRAL RELATIONSHIPS.

Section 2604(b)(2) (42 U.S.C. 300ff-14(b)(2)) is amended—

(1) in subparagraph (A), by striking "Subject to subparagraph (B)" and inserting "Subject to subparagraphs (B) and (C)"; and

(2) by adding at the end the following new subparagraph:

"(C) **HEALTH CARE REFERRAL RELATIONSHIPS.**—In order to be eligible for financial assistance under paragraph (1), an entity shall maintain appropriate referral relationships, as defined by the Secretary, with entities in the area that constitute key points of access to the health care system for individuals with HIV disease (including all-emergency rooms, substance abuse treatment programs, detoxification centers, adult and juvenile detention facilities, sexually transmitted disease clinics, HIV counseling and testing sites, and family planning clinics) for the purpose of facilitating access to HIV-related services."

SEC. 105. SUPPORT SERVICES REQUIRED TO BE HEALTH CARE-RELATED.

(a) **IN GENERAL.**—Section 2604(b)(1) (42 U.S.C. 300ff-14(b)(1)) is amended—

(1) in the matter preceding subparagraph (A), by striking "HIV-related—" and inserting "HIV-related services, as follows:";

(2) in subparagraph (A)—

(A) by striking everything through "substance abuse treatment and" and

inserting the following:

"(A) OUTPATIENT HEALTH SERVICES.—Outpatient and ambulatory health services, including substance abuse treatment,"; and

(B) by striking "; and" and inserting a period;

(3) in subparagraph (B), by striking "(B) inpatient case management" and inserting "(C) INPATIENT CASE MANAGEMENT SERVICES.—Inpatient case management"; and

(4) by inserting after subparagraph (A) the following new subparagraph:

"(B) OUTPATIENT SUPPORT SERVICES.—Outpatient and ambulatory support services (including case management), to the extent that such services facilitate, enhance, support, or sustain the delivery, continuity, or benefits of health services for individuals and families with HIV disease."

(b) CONFORMING AMENDMENT TO APPLICATION REQUIREMENTS.—Section 2605(a) (42 U.S.C. 300ff-15(a)), as amended by section 103, is further amended—

(1) in paragraph (6), by striking "and" at the end;

(2) in paragraph (7), by striking the period and inserting "; and"; and

(3) by adding at the end the following new paragraph:

"(8) that the eligible area has procedures in place to ensure that services provided with funds received under this part meet the criteria specified in section 2604(b)(1)."

SEC. 106. USE OF GRANT FUNDS FOR EARLY INTERVENTION SERVICES.

(a) IN GENERAL.—Section 2604(b)(1) (42 U.S.C. 300ff-14(b)(1)), as amended by section 105, is further amended by adding at the end the following new subparagraph:

"(D) EARLY INTERVENTION SERVICES.—Early intervention services as described in section 2651(b)(2), with follow-through referral, provided for the purpose of facilitating access of individuals receiving the services to HIV-related health services, but only if the entity providing such services—

"(i)(I) is receiving funds under subparagraph (A) or (C), or

"(II) is an entity constituting a point of access to services, as described in paragraph (2)(C), that maintains a referral relationship with an entity described in subclause (I) and that is serving individuals at elevated risk of HIV disease); and

"(ii) demonstrates to the satisfaction of the chief elected official that no other Federal, State, or local funds are available for the early intervention services the entity will provide with funds received under this paragraph."

(b) CONFORMING AMENDMENTS TO APPLICATION REQUIREMENTS.—Section 2605(a)(1) (42 U.S.C. 300ff-15(a)(1)) is amended—

(1) in subparagraph (A), by striking "services to individuals with HIV disease" and inserting "services as described in section 2604(b)(1)"; and

(2) in subparagraph (B), by striking "services for individuals with HIV disease" and inserting "services as described in section 2604(b)(1)".

SEC. 107. CAPACITY DEVELOPMENT.

Section 2604(b)(1) (42 U.S.C. 300ff-14(b)(1)), as amended by sections 105 and 106, is further amended by adding at the end the following new subparagraph:

"(E) PRIMARY CARE SERVICES CAPACITY

DEVELOPMENT.—Assistance to entities to expand the capacity, preparedness, and expertise to deliver primary care services to individuals with HIV disease in historically underserved low-income communities, but only if—

"(i) the funds are used for—

"(I) establishment of core management functions (including financing and information systems and utilization review, planning, and evaluation activities);

"(II) establishment and enhancement of program development functions (including personnel and staff competencies

and service network development through contractual linkages with other providers of prevention and clinical services); or

"(III) addition of new services (including purchase of equipment and minor upgrading of facilities); and

"(ii) the funds are not used to purchase or improve land, or to purchase, construct, or permanently improve (other than minor remodeling) any building or other facility."

SEC. 107-108. ELIMINATION OF SUNSET ON EXPEDITED DISTRIBUTION REQUIREMENT.

Section 2603(a)(2) (42 U.S.C. 300ff-13(a)(2)) is amended by striking "for each of the fiscal years 1996 through 2000" and inserting "for a fiscal year".

PART B—AMENDMENTS TO PART B—CARE GRANT PROGRAM

SEC. 121. CONSORTIA REQUIREMENTS CONCERNING IDENTIFICATION OF NEED AND ALLOCATION OF RESOURCES.

(a) ESTIMATE OF SIZE AND DEMOGRAPHIC CHARACTERISTICS OF POPULATION WITH HIV DISEASE.—Section 2613(c)(1) (42 U.S.C. 300ff-23(c)(1)) is amended—

(1) by redesignating subparagraphs (B) through (E) as subparagraphs (C) through (F); and

(2) by adding after subparagraph (A) the following new subparagraph:

"(B) includes an assessment of the size and demographic characteristics of the population with HIV disease in the geographic area to be served (including the numbers of individuals with HIV disease who are and who are not receiving HIV-related health services), as estimated on the basis of available epidemiologic data and using such recognized population-based assessment and modeling techniques as the Secretary may prescribe;"

(b) INDIVIDUALS NOT YET RECEIVING CARE CONSIDERED IN PROGRAM

PLANNING AND RESOURCE ALLOCATION.—Section 2613(c)(1)(C) (42 U.S.C. 300ff-23(c)(1)(C)), as redesignated by subsection (a) of this section, is amended—

- (1) by striking "and" at the end of clause (iii);
- (2) by redesignating clause (iv) as clause (v); and
- (3) by inserting after clause (iii) the following new clause:

“(iv) assurances that, in planning its program and in allocating resources, the applicant will make appropriate provision for the health and related support service needs of individuals who have been diagnosed with HIV disease but who are not currently receiving such services;”.

(c) ADVICE ON MAKING ASSESSMENTS OF POPULATION AND NEED.—Section 2613(c) (42 U.S.C. 300ff-23(c)), as amended by subsections (a) and (b) of this section, is further amended by adding at the end the following new subsection:

“(f) **ADVICE ON MAKING ASSESSMENTS OF POPULATION AND NEED.**—The Secretary, in consultation with States and affected communities, shall provide advice and technical assistance to States and to consortia with respect to the process for making the assessments described in subparagraphs (B) and (C) of subsection (c)(1).”.

SEC. 122. COORDINATION WITH MEDICAID AND STATE CHILDREN'S HEALTH INSURANCE PROGRAM AND WITH OTHER SERVICE PROVIDERS.

(a) RESPONSIBILITY OF CONSORTIA TO CONSIDER AVAILABILITY OF MEDICAID AND STATE CHILDREN'S HEALTH INSURANCE PROGRAM BENEFITS AND TO COORDINATE WITH OTHER SERVICE PROVIDERS.—Section 2613(c)(1)(C) (42 U.S.C. 300ff-23(c)(1)(C)), as redesignated and amended by section 121, is further amended—

- (1) by redesignating clause (v) as clause (vii); and
- (2) by inserting after clause (iv) the following new clauses:

“(v) assurances that the consortium has considered strategies for making optimal use of financial assistance under the State Medicaid plan under title XIX and the State Children's Health Insurance Program under

title XXI of the Social Security Act to cover health care costs of eligible individuals and families with HIV disease;

"(vi) assurances that the consortium will coordinate with federal grantees providing HIV-related services within the eligible area; and".

(b) RESPONSIBILITY OF STATE TO CONSIDER AVAILABILITY OF MEDICAID AND STATE CHILDREN'S HEALTH INSURANCE PROGRAM BENEFITS.—Section 2617(b)(2)(B) (42 U.S.C. 300ff-27(b)(2)(B)) is amended by inserting before the semicolon " (including in particular services available to individuals and families with HIV disease pursuant to the State Medicaid plan under title XIX and pursuant to the State Children's Health Insurance Program under title XXI of the Social Security Act)".

SEC. 123. QUALITY MANAGEMENT.

(a) STATE REQUIREMENT FOR QUALITY MANAGEMENT.—Section 2617(b)(4)(C) (42 U.S.C. 300ff-27(b)(4)(C)) is amended to read as follows:

"(C) the State will provide for a quality management program, the assessment component of which is performed at least annually by independent peer review;"

(b) AVAILABILITY OF FUNDS FOR QUALITY MANAGEMENT.—

(1) AVAILABILITY OF GRANT FUNDS FOR PLANNING AND EVALUATION.—Section 2618(c)(3) (42 U.S.C. 300ff-28(c)(3)) is amended by inserting before the period " , including no more than \$3,000,000 for all activities associated with its quality management program".

(2) EXCEPTION TO COMBINED CEILING ON PLANNING AND ADMINISTRATION FUNDS FOR STATES WITH SMALL GRANTS.—Section 2618(c)(6) (42 U.S.C. 300ff-28(c)(6)) is amended to read as follows:

"(6) EXCEPTION.—Notwithstanding paragraph (5), a State whose grant under this part for a year does not exceed \$1,500,000 may use amounts not exceeding 20 percent of the grant for the purposes described in paragraphs (3) and (4) if—

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“(A) that portion of such amounts in excess of 15 percent of the grant is used for its quality management program; and

“(B) the State submits and the Secretary approves a plan (in such form and containing such information as the Secretary may prescribe) for use of funds for its quality management program.”.

SEC. 124. CONSORTIA REQUIRED TO HAVE HEALTH CARE REFERRAL RELATIONSHIPS.

Section 2613(c)(1) (42 U.S.C. 300ff-23(c)(1)), as amended by section 121, is further amended—

- (1) by redesignating subparagraphs (E) and (F) as subparagraphs (F) and (G); and
- (2) by inserting after subparagraph (D) the following new subparagraph:

“(E) provides assurances that the consortium maintains appropriate referral relationships, as defined by the Secretary, with entities in the area served that constitute key points of access to the health care system for individuals with HIV disease (including all-emergency rooms, substance abuse treatment programs, detoxification centers, adult and juvenile detention facilities, sexually transmitted disease clinics, HIV counseling and testing sites, and family planning clinics) for the purpose of facilitating access to HIV-related services.”.

SEC. 125. SUPPORT SERVICES REQUIRED TO BE HEALTH CARE-RELATED.

(a) GENERAL AUTHORITY TO USE GRANT FUNDS.—

(1) **IN GENERAL.**—Section 2612(1) (42 U.S.C. 300ff-22(1)) is amended by striking “for individuals with HIV disease” and inserting “, subject to the conditions and limitations that apply under such section”.

(2) **CONFORMING AMENDMENT TO STATE APPLICATION REQUIREMENT.**—Section 2617(b)(2) (42 U.S.C. 300ff-27(b)(2)) is amended—

(A) in subparagraph (B), by striking “and” at the end; and

(B) by adding at the end the following new subparagraph:

"(C) an assurance that the State has procedures in place to ensure that services provided with funds received under this section meet the criteria specified in section 2612."

(b) USE OF GRANT FUNDS BY CARE CONSORTIA.—

(1) IN GENERAL.—Section 2613(a) (42 U.S.C. 300ff-23(a)) is amended—

(A) in the matter preceding paragraph (1), by striking "an entity that—" and inserting "an entity that satisfies the conditions stated in paragraphs (1) and (2).";

(B) in paragraph (1),—

(i) by striking "is an association" and inserting "STRUCTURE OF CONSORTIUM.—The entity is an association";

(ii) by striking "; and" at the end and inserting a period; and

(iii) by inserting at the end of the paragraph "An entity or entities of the type described in this paragraph shall hereinafter be referred to in this title as a 'consortium' or 'consortia'.";

(C) in paragraph (2),—

(i) by striking "agrees to use" and inserting "AGREEMENT AS TO USE OF FUNDS.—The entity agrees to use";

(ii) by striking "may include—" and inserting "may include services described in subparagraphs (A) and (B).";

(iii) in subparagraph (A),—

(I) by striking "essential health services" and inserting "ESSENTIAL HEALTH SERVICES.—The consortium may provide essential health services,"; and

(II) by striking "; and" at the end and inserting a period; and

(iv) in subparagraph (B),—

(I) by striking "essential support services" and inserting "ESSENTIAL SUPPORT SERVICES.—The consortium may

provide essential support services,"; and

(II) by inserting at the end of the subparagraph, "The consortium may provide such support services only to the extent that they facilitate, enhance, support, or sustain the delivery, continuity, or benefits of health services that it provides under subparagraph (A)."; and

(D) by striking the matter following paragraph (2).

(2) CONFORMING AMENDMENT TO APPLICATION

REQUIREMENT.—Section 2613(b)(1) (42 U.S.C. 300ff-23(b)(1)) is amended—

(A) in subparagraph (B), by striking "and" at the end;

(B) in subparagraph (C), by striking the period and inserting "; and"; and

(C) by adding at the end the following new subparagraph:

"(D) the consortium has procedures in place to ensure that services provided with funds received under this section meet the criteria specified in subsection (a).".

SEC. 126. USE OF GRANT FUNDS FOR EARLY INTERVENTION SERVICES.

Section 2613(a)(2) (42 U.S.C. 300ff-23(a)(2)), as amended by section 125, is further amended—

(1) in the matter preceding subparagraph (A), by striking "subparagraphs (A) and (B)" and inserting "subparagraphs (A) through (C)"; and

(2) by adding at the end the following new subparagraph:

"(C) **EARLY INTERVENTION SERVICES.**—The consortium may provide early intervention services, as described in section 2651(b)(2), with follow-up referral, provided for the purpose of facilitating access of individuals receiving the services to HIV-related health services, but only if the entity providing such services—

"(i)(I) is receiving funds under subparagraph (A) or (C) of section

2604(b)(1), or

"(II) is an entity constituting a point of access to services, as described in section 2604(b)(2)(C), that maintains a referral relationship with an entity described in subclause (I) and that is serving individuals at elevated risk of HIV disease); and

"(ii) demonstrates to the State's satisfaction that no other Federal, State, or local funds are available for the early intervention services the entity will provide with funds received under this paragraph."

SEC. 127. USE OF GRANT FUNDS FOR CAPACITY DEVELOPMENT.

(a) **IN GENERAL.**—Section 2613(a)(2) (42 U.S.C. 300ff-23(a)(2)), as amended by sections 125 and 125, is further amended—

(1) in the matter preceding subparagraph (A), by striking "subparagraphs (A) through (C)" and inserting "subparagraphs (A) through (D)"; and

(2) by adding at the end the following new subparagraph:

"(D) **CAPACITY DEVELOPMENT.**—The consortium may assist entities to expand the capacity, preparedness, and expertise to deliver primary care services to individuals with HIV disease in historically underserved low-income communities, under the conditions stated in section 2604(b)(1)(E)."

(b) **CONFORMING AMENDMENT TO CONSORTIUM APPLICATION REQUIREMENT.**—Section 2613(c)(1)(C) (42 U.S.C. 300ff-23(b)(1)), as redesignated by section 121, and as amended by sections 121 and 122, is further amended—

(1) by redesignating clauses (ii) through (vii) as clauses (iii) through (viii); and

(2) by inserting after clause (i) the following new clause:

"(ii) assurances that capacity development needs due to gaps in provision of HIV services in historically underserved low-income communities will be addressed;"

SEC. 128. APPROPRIATIONS FOR TREATMENT DRUG PROGRAM.

Section 2618(b)(2)(H) (42 U.S.C. 300ff-28(b)(2)(H)) is amended—

(1) by redesignating clauses (i) and (ii) as subclauses (I) and (II), and indenting accordingly;

(2) in the material preceding subclause (I) (as so redesignated), by striking “for carrying out section 2616” and all that follows and inserting “for carrying out section 2616, such amount shall be allocated to the States in the following manner:

“(i) FORMULA ALLOCATION.—Of the portion defined in clause (ii), the Secretary shall allocate to a State an amount equal to the product of—”; and

(3) by adding at the end the following new clauses:

“(ii) PORTION ALLOCATED BY FORMULA.—The portion that shall be allocated as prescribed in clause (i) is the greater of—

“(I) 85 percent of the amount provided exclusively for carrying out section 2616 in that appropriations act; or

“(II) the amount so provided in P.L. 106-113.

“(iii) NEED-BASED ALLOCATION.—Any portion not allocated under clause (i) shall be allocated to States that demonstrate to the Secretary's satisfaction significant need for HIV-related treatments.”.

SEC. 129. AUTHORIZATION OF APPROPRIATIONS FOR HIV-RELATED SERVICES FOR WOMEN AND CHILDREN.

Section 2625(c)(2) (42 U.S.C. 300ff-33(c)(2)) is amended by striking “fiscal years 1996 through 2000” and inserting “fiscal years 2000 through 2005”.

SEC. 128-130. REPEAL OF REQUIREMENT FOR COMPLETED INSTITUTE OF MEDICINE REPORT.

Section 2628 (42 U.S.C. 300ff-36) is repealed.

PART C—AMENDMENTS TO PART C—EARLY INTERVENTION SERVICES

SEC. 141. AMENDMENT OF HEADING; REPEAL OF FORMULA GRANT

PROGRAM.

(a) **AMENDMENT OF HEADING.**—The heading of part C is amended to read “EARLY INTERVENTION AND PRIMARY CARE SERVICES”.

(b) **REPEAL.**—Part C of title XXVI is amended—

(1) by repealing subpart I; and

(2) by redesignating subparts II and III as subparts I and II.

(c) **CONFORMING AMENDMENTS.**—

(1) Section 2661(a) (42 U.S.C. 300ff-61(a)) is amended—

(A) in the matter preceding paragraph (1), by striking the dash and inserting the text of paragraph (2); and

(B) by striking paragraphs (1) and (2).

(2) Section 2664 (42 U.S.C. 300ff-64) is amended—

(A) in subsection (e)(5), by striking “2642(b) or”;

(B) in subsection (f)(2), by striking “2642(b) or”; and

(C) by striking subsection (h).

SEC. 142. CAPACITY DEVELOPMENT GRANTS.

(a) **ALLOWING PLANNING AND DEVELOPMENT GRANT FOR CAPACITY DEVELOPMENT.**—Section 2654(c) (42 U.S.C. 300ff-54(c)) is amended—

(1) in paragraph (1), to read as follows:

“(1) **IN GENERAL.**—The Secretary may provide planning and development grants to public and nonprofit private entities for the purpose of—

“(A) enabling such entities to provide HIV early intervention services; or

“(B) assisting such entities to expand the capacity, preparedness, and expertise to deliver primary care services to individuals with HIV disease in historically underserved low-income communities, under the conditions stated in section 2604(b)(1)(E).”; and

(2) in each of paragraphs (2) and (3) by striking “paragraph (1)” and inserting “

paragraph (1)(A)".

(b) AMOUNT; DURATION.—Section 2654(c) (42 U.S.C. 300ff-54(c)), as amended by subsection (a), is further amended—

(1) by redesignating paragraph (4) as paragraph (5); and

(2) by inserting after paragraph (3) the following new paragraph:

"(4) AMOUNT AND DURATION OF GRANTS.—

"(A) EARLY INTERVENTION SERVICES.—A grant under paragraph (1)(A) may be made in an amount not to exceed \$50,000.

"(B) CAPACITY DEVELOPMENT.—

"(i) AMOUNT.—A grant under paragraph (1)(B) may be made in an amount not to exceed \$150,000; and

"(ii) DURATION.—The total duration of a grant under paragraph (1)(B), including any renewal, may not exceed three years."

(c) INCREASE IN LIMITATION.—Section 2654(c)(5) (42 U.S.C. 300ff-54(c)(5)), as redesignated by subsection (b), is amended by striking "1 percent" and inserting "10 percent".

SEC. 142-143. AUTHORIZATION OF APPROPRIATIONS FOR CATEGORICAL GRANTS.

Section 2655 (42 U.S.C. 300ff-55) is amended by striking "1996" and all that follows and inserting "2001 through 2005".

SEC. 143-144. ADMINISTRATIVE EXPENSES CEILING; QUALITY MANAGEMENT PROGRAM.

Section 2664(g) (42 U.S.C. 300ff-64(g)) is amended—

(1) in paragraph (3), to read as follows:

"(3) the applicant will not expend more than 10 percent of the grant for costs of administrative activities with respect to the grant;"

(2) in paragraph (4), by striking the period and inserting "; and"; and

(3) by adding at the end the following new paragraph:

"(5) the applicant will implement a quality management program."

PART D—AMENDMENTS TO PART D—GENERAL PROVISIONS

SEC. 151. RESEARCH INVOLVING WOMEN, INFANTS, CHILDREN, AND YOUTH.

(a) **ELIMINATION OF REQUIREMENT TO ENROLL SIGNIFICANT NUMBERS OF WOMEN AND CHILDREN.**—Section 2671(b) (42 U.S.C. 300ff-71(b)) is amended—

(1) by striking subparagraphs (C) and (D) of paragraph (1); and

(2) by striking paragraphs (3) and (4).

(b) **QUALITY MANAGEMENT; ADMINISTRATIVE EXPENSES CEILING.**—Section 2671(f) (42 U.S.C. 300ff-71(f)) is amended—

(1) by redesignating the caption and text as a new paragraph (1), and indenting accordingly;

(2) by inserting after "(f)" the following caption: "ADMINISTRATION.—"; and

(3) by adding at the end the following new paragraphs:

"(2) **QUALITY MANAGEMENT PROGRAM.**—A grantee shall implement a quality management program.

"(3) **ADMINISTRATIVE EXPENSES CEILING.**—The grantee shall not expend more than 10 percent of the grant for administrative expenses with respect to the grant, including all activities associated with its coordination activities under subsections (e) and (g) and under section 2675."

(c) **AUTHORIZATION OF APPROPRIATIONS.**—Section 2671(j) (42 U.S.C. 300ff-71(j)) is amended by striking "fiscal years 1996 through 2000" and inserting "fiscal years 2001 through 2005".

SEC. 152. ~~AUTHORIZATION OF APPROPRIATIONS FOR RESEARCH GRANTS.~~

~~Section 2673(c) (42 U.S.C. 300ff-73(c)) is amended by striking "1991 through 1995" and inserting "2001 through 2005".~~

~~SEC. 153. AUTHORIZATIONS OF APPROPRIATIONS FOR GRANTS UNDER PARTS~~

~~A AND B.~~

(a) IN GENERAL.—Section 2677 (42 U.S.C. 300ff-77) is amended—

(1) in subsection (a), by striking "fiscal years 1996 through 2000" and inserting "fiscal years 2001 through 2005"; and

(2) in subsection (b), by striking, each place it appears, "fiscal years 1997 through 2000" and inserting in each such place "fiscal years 2001 through 2005".

(b) REPEAL OF REQUIREMENT FOR COMPLETED REPORT.—Such section is further amended in subsection (b)(1) by striking the second sentence.

**~~SEC. 154. AUTHORIZATION OF APPROPRIATIONS FOR GRANTS TO
IMPLEMENT GUIDELINES.~~**

~~Section 2680(c) (42 U.S.C. 300ff-80(e)) is amended by striking "1991 through 1995" and inserting "2001 through 2005".~~

PART E—AMENDMENTS TO PART F—DEMONSTRATION AND TRAINING

**SEC. 161. DENTAL SERVICES; QUALITY MANAGEMENT; AUTHORIZATION OF
APPROPRIATIONS; AND CLARIFYING AMENDMENTS.**

(a) REDESIGNATION OF PROVISIONS.—Part F is amended—

(1) by striking "PART F—DEMONSTRATION AND TRAINING" and inserting "PART F—DEMONSTRATIONS, TRAINING, AND PROJECTS AND ACTIVITIES OF NATIONAL SIGNIFICANCE";

(2) by striking "Subpart II—AIDS Education and Training Centers" and inserting "Subpart II—Education, Training, and Certain Services";

(3) in the caption of section 2692, by striking "HIV/AIDS COMMUNITIES, SCHOOLS, AND CENTERS" and inserting "TRAINING AND SERVICE GRANTS"; and

(4) in the caption of section 2692(b), by striking "DENTAL SCHOOLS" and inserting "DENTAL SERVICES".

(b) SCOPE OF GRANTS FOR DENTAL SERVICES.—Section 2692(b) is further amended—

(1) in paragraph (1), by striking "and programs described in section 777(b)(4)(B)" and inserting "programs described in section 753(b)(4)(B), and entities satisfying the criteria stated in section 2652";

(2) in paragraph (2), to read as follows:

"(2) APPLICATION.—Any dental school, program described in section 753(b)(4)(B), or entity satisfying the criteria stated in section 2652 may submit an application for funding to provide oral health care to individuals with HIV disease.";

(3) in paragraph (3), to read as follows:

"(3) PREFERENCES IN MAKING GRANTS.—In making grants under this section, the Secretary shall give preference to an eligible entity that demonstrates, to the Secretary's satisfaction, a clear need for financial assistance for the purpose specified in paragraph (1), as indicated by—

"(A) the size of the population with HIV disease in the area served by the entity;

"(B) the rate of increase in HIV disease in that area; and

"(C) the unavailability or limited accessibility in that area of other providers of oral health care to individuals with HIV disease.".

(c) QUALITY MANAGEMENT.—

(1) SPECIAL PROJECTS OF NATIONAL SIGNIFICANCE.—Section 2691(f) (42 U.S.C. 300ff-10(f)) is amended—

(A) by striking "COORDINATION" and inserting "CONDITIONS";

(B) by inserting a dash after "submits evidence that";

(C) by moving "the proposed program" and all that follows to a new paragraph (1);

(D) in paragraph (1) (as so designated), by striking the period and inserting " ; and"; and

(E) by adding at the end the following new paragraph:

"(2) it has a quality management program."

(2) SCHOOLS; CENTERS.—Section 2692(a)(3) (42 U.S.C. 300ff-11(a)(3)) is amended by inserting before the period ", including an assurance that it has a quality management program".

(3) DENTAL SERVICES.—Section 2692(b), as amended by subsection (b), is further amended by adding at the end the following new paragraph:

"(5) QUALITY MANAGEMENT.—The Secretary may not make a grant under this subsection unless the application demonstrates that the applicant has a quality management program."

(d) AUTHORIZATIONS OF APPROPRIATIONS.—

(1) SCHOOLS; CENTERS.—Section 2692(c)(1) is amended by striking "fiscal years 1996 through 2000" and inserting "fiscal years 2001 through 2005".

(2) DENTAL SERVICES.—Section 2692(c)(2) is amended—

(A) in the caption, by striking "DENTAL SCHOOLS" and inserting "DENTAL SERVICES"; and

(B) by striking "fiscal years 1996 through 2000" and inserting "fiscal years 2001 through 2005".

~~SEC. 162. CAPACITY DEVELOPMENT GRANTS.~~

~~Part F of title XXVI is amended by inserting after subpart II the following new subpart:~~

~~"Subpart III—Primary Care Services Capacity Development Grants~~

~~"SEC. 2693. PRIMARY CARE SERVICES CAPACITY DEVELOPMENT GRANTS.~~

~~"(a) PROGRAM ESTABLISHED.—The Secretary shall establish and administer under this section a program of grants to public and nonprofit private entities, including community based organizations, for programs to develop or expand the capacity, preparedness, and expertise to deliver primary care services to individuals with HIV disease in historically underserved low income communities.~~

~~"(b) USES OF FUNDS.—~~

~~"(1) PERMITTED USES.—Grant funds received under this section may be used for capacity development activities including—~~

~~"(A) establishment and enhancement of core management functions (including financing and information systems and utilization review, planning, and evaluation activities);~~

~~"(B) establishment and enhancement of program development functions (including personnel and staff competencies and service network development through contractual linkages with other providers of prevention and clinical services); and~~

~~"(C) addition of new services (including purchase of equipment and minor upgrading of facilities).~~

~~"(2) IMPERMISSIBLE USES.—Grant funds may not be used to purchase or improve land, or to purchase, construct, or permanently improve (other than minor remodeling) any building or other facility.~~

~~"(c) SELECTION CRITERIA.—~~

~~"(1) IN GENERAL.—The Secretary shall award grants under subsection (a) based on—~~

~~"(A) the need within the geographical community to be served for the development of additional long-term capacity to deliver primary care services to individuals with HIV disease;~~

~~"(B) the applicant's demonstrated ability to develop or expand within two years the capacity and expertise to deliver primary care services to individuals with HIV disease; and~~

~~"(C) the applicant's demonstrated capacity to establish, with entities constituting key points of access to the health care system for individuals with HIV disease, as described in section 2604(b)(2)(C), effective service coordination relationships which include provision of primary care services at the sites where~~

~~such entities are located.~~

~~"(2) PREFERENCE.—In awarding grants under this section, the Secretary shall give preference to—~~

~~"(A) public or nonprofit private entities that—~~

~~"(i) are located in historically underserved low income communities where there currently exists substantially insufficient HIV related health care; and~~

~~"(ii) are capable of providing or ensuring access to primary care services for residents of such communities; and~~

~~"(B) public or nonprofit private entities that—~~

~~"(i) are currently providing HIV care services; and~~

~~"(ii) are affiliated with local community based providers of health and social services that do not have significant capacity to provide HIV related services.~~

~~"(3) INTEGRATION INTO STATEWIDE PLAN.—In order to be eligible for a grant under this section, an applicant must—~~

~~"(A) demonstrate that the proposed program is consistent with the Statewide coordinated statement of need for each State that includes part or all of the geographical community to be served;~~

~~"(B) agree to participate in the ongoing revision process for each such statement of need; and~~

~~"(C) demonstrate that it has a quality management program.~~

~~"(d) FUNDING.—There are authorized to be appropriated to carry out this section such sums as may be necessary for each of fiscal years 2001 through 2005."~~

TITLE II—OTHER PROVISIONS

SEC. 201. INSTITUTE OF MEDICINE STUDY.

(a) IN GENERAL.—The Secretary shall request that the Institute of Medicine, by two

years after enactment of this Act, conduct a study of the financing and delivery of HIV services for low-income, uninsured, and under-insured individuals with HIV disease under the Ryan White CARE Act, and submit to the appropriate committees of the Congress a report summarizing the results of the study and including any conclusions and recommendations.

(b) **FACTORS.**—The study described in subsection (a) shall consider—

(1) the effectiveness and efficiency of service delivery (including the quality of services, health outcomes, and cost-effectiveness) within the context of a changing health care and therapeutic environment as well as the changing epidemiology of the epidemic;

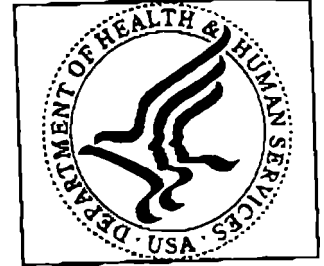
(2) existing and needed epidemiological data and other analytic tools for resource planning and allocation decisions; and

(3) other factors deemed relevant to assessing an individual's or community's ability to gain and sustain access to quality HIV services (including access to substance abuse treatment for persons with addictive disorders).

(c) **FUNDING.**—The Secretary is authorized to use amounts appropriated under section 2677(a) to carry out the provisions of this section.

Office of HIV/AIDS Policy

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Office of the Secretary
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TO:

Michael

FAX:

FROM: Deborah von Zinkernagel
Deputy Director for Policy

(This fax contains 2 page(s) + cover)

*I haven't edited
it yet*

If there are any problems with this transmission, please call Terrie Alvarez at (202) 690-5560

**U.S. Department of Health and Human Services (HHS)
Recommendations for the Reauthorization of the Ryan White CARE Act**

Although much has been accomplished since passage of the CARE Act in 1990, serious challenges remain as the epidemic spreads among underserved populations and outpatient treatment costs continue their dramatic increase. To meet these challenges, HHS is recommending several legislative changes that require the implementation of methods for identifying and reaching HIV-positive individuals (especially persons not currently receiving care), establish increasingly accountable service networks, and increase the service capacity of providers in underserved and rural communities. [Our bill refers to rural communities in connection with the Dental Reimbursement program, but not in connection with capacity development.]

Increase Access to Care for Vulnerable Populations

- ~~Work~~ HHS should work with title I planning councils, States, and experts in the field to develop and implement activities including: estimate the number of HIV-infected individuals in the region covered by the grant (including persons not currently receiving HIV-related health care, specifically including women and including persons with addictive disorders); conduct needs assessment activities among communities not in care in order to establish service needs; and, ~~direct application of~~ apply such estimates and needs assessment information in planning for services.
- ~~Enact~~ Recipients of funds under titles I and II should develop strategies for using Medicaid and State Children's Health Insurance Programs funds to cover HIV-related health care costs of eligible individuals when allocating funds at a local and State level.
- ~~Establish~~ Fund recipients should establish referral relationships key points of entry between Ryan White providers and important medical care sites, key points of access to the health care system, for example, ERs, emergency rooms, family planning clinics, substance abuse facilities, detention centers, housing projects, and others.
- Allow funding use of titles I and II funds for Early Intervention Services (counseling/testing and referral) at key points of entry and among Ryan White service programs for purposes of identifying persons needing care and bringing more persons them into care.
- Expand eligibility of the Dental Reimbursement Program to include community health centers in order to expand services to smaller metropolitan and rural areas. [Do you want to mention changing this from cost-reimbursement to competitive grant?]

Assess and Improve Quality of Services

- Work with title I Planning Councils, States, and experts in the field to develop and implement a Quality Management program for all grantees in order to: assess effectiveness of strategies for improving access to care among persons not in care; establish standards of care that are used as benchmarks for measuring effectiveness of social support and clinical service

programs; and establish mechanisms to assess population-based health outcomes for purposes of assessing and improving overall program effectiveness, especially among underserved communities.

- Provide additional resources to grantees for Quality Management Programs.
- ~~Create linkages between social~~ Social support services funded under the Act should be in support of ~~and health providers services~~ in order to establish a more seamless continuum of social support and health services.

Capacity and Infrastructure Development ["Infrastructure" suggests building construction and similar major renovations]

- Support ~~title I-EMA~~ and State activities ~~under titles I and II~~ related to assessing needs for and implementing capacity development activities for low-income, historically underserved communities.
- Expand title III planning grants activities to include capacity development grants of \$150,000 over 3 years to enhance the delivery and benefits of HIV primary care services to low-income, historically underserved communities.
- Capacity Development activities include: core management functions, program integration and professional development, purchase of equipment, and minor modification of ~~space facilities~~.

Funding and Demonstration Projects

- Fund a study of the delivery and financing of HIV services among low-income, under and uninsured persons conducted by the National Academy of Science/Institute of Medicine Study.
- The purpose of study is to examine key factors associated with the financing and delivery of HIV services in relation to the existing public (e.g., Medicaid, Medicare) and private health services, general demographics (race/ethnicity, poverty, age, urban/rural, etc) and co-morbidities (substance abuse, mental health, homelessness) of community members, regional variations in the funding and costs of delivery services, and available epidemiologic tools and data sets necessary for local and national planning and allocation decisions.

Other Recommendations

- Continue the title IV relationship with research programs but remove requirements related to enrollments in clinical trials.
- ~~Modify Increase~~ title III ~~administrative cap~~ and establish title IV administrative caps.

A- RW

HIV/AIDS Services

Policy Studies

Overview || Guiding Principles || Program Review Activities and Policy Studies

HAB commissioned a series of indepth policy studies to further inform the reauthorization discussion. These studies focused on the experience of vulnerable populations (e.g., minority women, children, and substance users) in accessing needed services and care; the changing nature of health care delivery and finance systems for HIV services and their relationship with CARE Act-funded programs; and the role and structure of Title I, II, III and IV programs within communities. Each study was focused on identifying recommendations for improvements in the CARE Act that could improve access and the quality of care, as well as to improve efficiency and economy in the operation of the program, and finally, to more effectively coordinate and integrate care delivery systems among different payers.

Overview of Policy Studies

When the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act was initially authorized in 1990, lack of public infrastructure and capacity to provide services for affected persons, particularly low-income and uninsured/underinsured people with HIV/AIDS, posed profound challenges to communities throughout the country. Since that time, the CARE Act has established a critically needed planning process and infrastructure to develop and sustain essential health and social services for persons living with HIV/AIDS. These services have improved the lives of thousands of poor, uninsured/underinsured men, women, children, youth and families throughout the United States. And their effectiveness has been borne out by the reduction in HIV morbidity and mortality among the most impoverished communities.

Although substantial gains have been made, challenges remain in meeting the care and support needs of historically underserved populations, including minorities, women, families, substance users and people with mental illness. And these continuing disparities represent new challenges for the CARE Act in its second decade.

Guiding Principles

As the CARE Act entered a second reauthorization cycle last year, HRSA's HIV/AIDS Bureau (HAB) conducted a comprehensive assessment of disparities in access to services and care. This assessment was based on the policy framework established by HAB Associate Administrator, Dr. Joseph O'Neill, who identified four principles to guide the Bureau's mission. These include: 1) changes in demographics; 2) access to emerging therapies; 3) changes in health care financing; and 4) program accountability.

During a year-long review of the role and structure of CARE Act services, HAB explored various changes, issues and needs affecting HIV service delivery, using these principles as a lens by which to identify and assess current and future challenges in caring for uninsured and underinsured people with HIV/AIDS. HAB examined these issues in light of the following questions:

- How can HRSA strengthen CARE Act-funded programs to ensure that all persons with HIV/AIDS, regardless of race, co-morbidity, geographic location or income, have access to needed health and support services?
- How can HRSA ensure that CARE Act services meet current standards of quality HIV care?

- How can HRSA and CARE Act grantees help providers maintain fiscal and administrative viability within rapidly evolving health delivery and social welfare systems, while creating opportunities for new providers to care for affected and underserved populations?
- How can HRSA improve its ability and that of CARE Act grantees to monitor and evaluate services, becoming more accountable to Congress, State agencies and, most importantly, people with HIV/AIDS who depend on these services for their survival?

Program Review Activities and Policy Studies

Under the guidance of Dr. John Palenicek, Director of the Bureau's Office of Policy and Program Development (OPPD), staff engaged in extensive consultation with constituents, community members and people living with HIV/AIDS. This includes collaborating with HRSA's AIDS Advisory Committee to sponsor a series of public hearings to solicit broad feedback in preparation for reauthorization. During the past year, OPPD staff undertook a comprehensive evaluation of current program activities to understand the dynamic of HIV care within an evolving system of health care finance and delivery. And they initiated a series of targeted policy studies to more fully understand the factors that affect access to care and ability to remain in care for poor, low-income and traditionally underserved populations.

Topics selected for these studies include the following:

- The experience of vulnerable populations (e.g., minority women, families and children, and substance users) in accessing needed services and care;
- The changing nature of health care delivery and finance systems for HIV services and their relationship with CARE Act-funded programs; and
- The role and structure of Title I, II, III and IV programs within communities.

These files are available for viewing or downloading in Adobe Acrobat (.pdf) format.



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The goal of these studies is to expand on current knowledge and to generate findings that can inform future policy directions or suggest administrative or legislative changes for the reauthorized CARE Act. Results of these studies will be presented in a series of policy briefs--*Directions in HIV Service Delivery & Care*--to help grantees and CARE Act providers render more effective services to people with HIV/AIDS. Findings and recommendations will also help inform HRSA's administrative procedures, technical assistance and training activities, improve service delivery, and enhance inter-governmental relationships between Federal agencies and among Federal, State and local jurisdictions.

These studies are especially relevant for CARE Act providers because they focus on populations and issues that--although difficult to address--offer the greatest potential for significantly improving outcomes for the Nation's most underserved populations. HRSA grantees are encouraged to read these reports and to incorporate findings and recommendations into their ongoing planning and program activities. HRSA welcomes feedback from readers on the usefulness of these monographs for their work. Send comments to: jgrantling@hrsa.gov.

FAX TRANSMISSION
DEMOCRATIC OFFICE OF
THE UNITED STATES SENATE
COMMITTEE ON HEALTH, EDUCATION, LABOR, AND PENSIONS

To: Michael

FROM: Scott

FAX #: 456-2439

DATE: 2/17 TOTAL PAGES (INCLUDING COVER) 6

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COMMENTS:



Memorandum

To: Stephanie Robinson, Minority Staff
Senate HELP Committee

From: Miguelina Maldonado, Director, Government Relations and Public Policy
Javier G. Salazar, Federal Affairs Manager

Date: February 16, 2000

Re: Recommended Language on Health Disparities in the Ryan White CARE Act Reauthorization of 2000

Thank you for allowing the National Minority AIDS Council the opportunity to submit the following recommendations. Each of these are intended to provide concrete ways the Ryan White CARE Act can be modified to ensure that the existing disparities in health outcomes for individuals from disproportionately impacted ethnic and racial minority populations, and subpopulations e.g. substance users, women, gay men of color, and youth are reduced and ultimately eliminated.

It is our strong belief that these measures are necessary to truly make the CARE Act responsive to the needs of individuals and communities around the nation that are underserved and severely impacted by HIV/AIDS.

APPLICABLE ACROSS ALL TITLES

1. Ensure That Highly Impacted Individuals Are Brought In To Care Through Outreach, Case Finding, And Early Intervention.

In statute:

Allow funds to be used for early intervention services including case finding and HIV counseling and testing to identify HIV positive individuals and link them to health care and support services. Also allow funds to co-locate said early intervention services in sites that serve as key points of access for individuals with HIV disease, including emergency rooms, substance abuse treatment programs, detoxification centers, and family planning and STD clinics. Priority should be given to identifying individuals from disproportionately impacted ethnic and racial minority populations, and subpopulations (substance users, women, gay men of color, youth, homeless individuals and individuals recently released from correctional facilities) for the purposes of early diagnosis and linkage to health care and support services.

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NMAC Memo

Page Two

2. Improve the Quality and Effectiveness of Care and Services.**In statute:**

Require grantees to develop and implement programs of quality management that include assessments of a) the effectiveness in ensuring timely access to appropriate health and support services by individuals diagnosed with HIV disease including those not currently receiving HIV-related services, b) the programs ability to reduce existing disparities in health outcomes in individuals from disproportionately impacted ethnic and racial minority population, and subpopulations (substance users, women, gay men of color, and youth.), and c) efforts to integrate and collocate services for disproportionately impacted and underserved populations and subpopulations (substance users, women, gay men of color, youth, homeless individuals and individuals recently released from correctional facilities)

3. Ensure That The Needs Of Highly Impacted Populations Are Addressed By The Planning And Funding Allocation Process.**In statute**

Direct the Secretary to implement mechanisms at the federal department and agency level to assess and address the disparities in health outcomes with particular attention to disparities related to gender, race and ethnicity.

(A portion of the following paragraph is already in the statute in Section 2621 Coordination. The underlined section is our addition.)

Require that the Secretary implement a formal mechanism to ensure that HRSA, CDC, and SAMHSA coordinate the planning and implementation of a complete continuum of HIV-related services for individuals with HIV disease and those at risk for such disease with priority given to integration and co-location of services for underserved and highly impacted populations (including substance users, women, gay men of color, youth, homeless individuals, individuals recently released from correctional facilities and individuals experiencing co-morbid conditions such as STDs, TB, mental illness, and Hepatitis C.)

**NMAC Memo****Page Three****In statute:**

Require as a condition of grant award beginning in 2002 that existing disparities in HIV-related health outcomes experienced by women, youth, substance users, homeless individuals, and ethnic and racial minority populations are assessed and addressed by grantees in the planning, prioritization, funding allocation and services coordination and reporting processes and mechanisms currently in place within the CARE Act. These processes and mechanisms include assurances and agreements in the grant applications for all Titles, Title I planning councils, Title II consortia and Statewide Coordinated Statement of Need, and Title IV assurances and agreements regarding the provision of health care, support services, and linkages to research.

4. Ensure That The Needs Of Women Are Met Through Health And Support Services.**In statute:**

Require that all CARE Act funded programs serving women diagnosed with HIV disease integrate high-quality gynecological care as part of the delivery of primary care services.

Require that all CARE Act funded programs serving women diagnosed with HIV disease and their families provide a continuum of family focused services to facilitate access to and continuity of HIV-related health care and a full range of supportive services, including the co-location of pediatric and adult HIV primary care, case management services, transportation, childcare, nutritional, psycho-social support, mental health and substance abuse services.

In report language:

Ensure that all CARE Act funded programs serving women integrate women-focused services across the life cycle and address the special needs of women through a continuum of HIV-related health and supportive services that include trauma, domestic violence, mental health, and substance abuse services.

**NMAC Memo****Page Four****5. Building Capacity in Underserved areas.****In statute:**

Make multi-year funding available to entities or organizations to develop capacity and infrastructure for the delivery of HIV/AIDS health care and support services in underserved geographic areas and communities with large numbers of ethnic and minority populations and subpopulations (substance users, women, gay men of color, youth, homeless individuals and individuals recently released from correctional facilities). Priority should be given to minority led and managed entities or organizations with a history of serving ethnic and minority populations and subpopulations (substance users, women, gay men of color, youth, homeless individuals and individuals recently released from correctional facilities).

Title I**1. Ensuring Effective Representation and Participation on Planning Councils****In statute:**

Include in the list of members required on the planning council organizations serving or representatives serving incarcerated populations and homeless persons.

Make financial support available through technical assistance or other mechanisms and require that grantees make every effort, and document that effort, to ensure effective participation of planning council members from disproportionately affected and historically underserved groups, individuals living with HIV, consumers, and subpopulations (substance users, women, gay men of color, youth, homeless individuals and individuals recently released from correctional facilities) through on-going training and mentoring on needs assessment, planning, prioritization, gap analysis, decision-making processes and all of the specific requirements of the CARE Act. Assistance such as reimbursement for transportation and childcare must also be provided to facilitate consistent participation.

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NMAC Memo
Page Five

Title II-ADAP

In report language:

Direct the Secretary to ensure that outreach activities targeted to ethnic and racial minority populations and subpopulations that are eligible but underserved by the ADAP program are undertaken to ensure access to HIV therapies, medication, diagnostic testing and monitoring.

SPNS

In statute:

Make available additional funding for grants for the continuation of evidence-based service delivery models in order to transition such programs in to mainstream CARE Act funding cycles to ensure the continued availability and continuity of services. As a condition of funding, SPNS programs should be required to demonstrate on-going coordination with local planning bodies and other CARE Act services.

**POSSIBLE QUESTIONS ON THE RYAN WHITE CARE ACT PROGRAM
WHICH MAY BE ASKED DURING THE HEARING**

- 1) Does the formulary contained in Title I meet the needs of people with HIV, or should it be changed? If so, to what? Should the 50/50 formula and supplemental funding ratio be changed? What would be the effects of changing it?
- 2) Is a hold harmless provision needed? Why should there be one if the number of people living with HIV in a city is lower now than before?
- 3) What data collection and analysis needs to be done that is currently not being done, and do the Ryan White grantees have the capacity to collect and analyze this data? How does HRSA work to make data reporting requirements consistent across programs and with other federal programs that require similar data collection?
- 4) Given that not every state has HIV reporting, why will the CARE Act require applicants to estimate the number of individuals with HIV in a service area, and how accurate will these estimates be? Does the federal government already have a formula/model developed, which can accurately determine the number of HIV infections in any given jurisdiction?
- 5) If we do have a model already developed that can estimate the number of HIV infections in a specific area, then why has CDC been pushing the concept of name reporting so hard? Isn't one of the purposes of name reporting to help us "plan" for the infection?
- 6) One version of draft legislation would require grantees to determine the effectiveness of programs and services. Are grantees not currently required to do this? If not, why not? If so, how is this done? What is currently being done to ensure that services are being provided effectively, efficiently, and are what the clients need? Are proposed quality management requirements going to place an undue burden on grantees without providing the support necessary to ensure that their quality management plans are feasible? What is HRSA doing to ensure quality of care? What is HRSA doing to help its grantees determine unmet need?
- 7) Currently, HRSA must set aside 1% of Ryan White monies to support the Department's evaluation program, as is every other program within HHS. How does this 1% set-aside affect the CARE program from evaluating its own programs? Does any of this money get returned to HRSA and to Ryan White programs in particular? Is this the best way for Ryan White to evaluate itself?

- 8) Currently, HRSA taps 1% of the Ryan White funding for technical assistance activities. Explain what this money is used for and how grantees are able to benefit from it. Is technical assistance competitively bid, and if so, on average, how many applicants are there? How do these programs help communities of color? Should technical assistance programs be nationally or regionally based?
- 9) Discuss efforts at ensuring that racial and ethnic minorities, especially those with HIV, are on the local planning councils. What specific efforts are undertaken to ensure adequate representation of service clients on the planning councils?
- 10) How many times has HRSA restricted an entity's funding based on lack of representation on planning councils?
- 11) What efforts have been implemented to ensure that services being provided are actually related to the care and treatment of people with HIV, and not what many would consider a "luxury", such as dog walking, acupuncture, etc.? What mechanisms are in place to ensure that services being provided are only that necessary to treat a person with HIV?
- 12) A version of draft legislation contains a provision that requires recipients of grant funds to certify that referral systems are in place with the major providers of ancillary services (emergency room, substance abuse clinics, etc.). Does this mean that in most localities such systems are not already in place and if so, why not? How have these requirements been met in the past? Why is this change needed now?
- 13) A version of draft legislation is requesting authority to implement a new grant program focusing on technical assistance. Why is this technical assistance not currently being provided? Why is there a need for this new grant program? Why can't HRSA provide the technical assistance anticipated under the requested grant program?
- 14) What effect would 2-year funding cycles have on the grantees? Does the Administration support this?
- 15) Why are Title I and II grant periods not consistent?
- 16) How are Special Projects of National Significance focus areas determined?
- 17) If AIDS deaths keep declining, why do we need to keep adding more money to the Ryan White program? Shouldn't cost be declining as well?
- 18) The decline in AIDS deaths is not equal among all racial/ethnic groups. What is the Ryan White program doing to ensure that all racial/ethnic groups have equal access to the services being provided under Ryan White?

- 18) Why shouldn't the Ryan White program only provide services to U.S. citizens? Why shouldn't we ask clients to prove that they are U.S. citizens before obtaining services?
- 19) It appears as if the services provided by the various Titles overlap in terms of client base and services provided. What mechanisms are in place to ensure that programs coordinate their efforts at the local level? As importantly, what programs are in place to ensure that programs are coordinated within HRSA?
- 20) What mechanisms are in place to ensure that the drugs purchased under the ADAP program are obtained at the lowest possible cost?
- 21) Each state determines its own formulary of what drugs can be purchased with ADAP funds. What is the best way to ensure that clients in one state have the same access to treatment drugs under the program as clients in every other state? Should there be a national formulary that States are required to use?
- 22) What progress has been made to include individuals with HIV under Medicaid coverage?
- 23) What mechanism/safeguards are in place to ensure that Ryan White is the payer of last resort?
- 24) Current, states can purchase drugs for the Ryan White program in bulk through the Public Health Service. Is a similar program in place for other medical items as well (needles, syringes, other medical supplies)? If not, would this help reduce the cost of the program?
- 25) How does the CARE Act monitor its CBC (Minority AIDS Initiative) funds? How have these funds augmented services for people of color living with HIV?
- 26) How does the CARE Act programs link to the health planning efforts of the CDC funded Community Planning Groups? To NIDA's State funded programs? To the SAMHSA block grants?
- 27) How does the CARE Act help new minority CBO's access CARE Act funding?
- 28) What is HRSA doing to receive feedback from recipients of CARE Act programs – people living with HIV?
- 29) What is HRSA doing to ensure that Clinical Guidelines are being followed by all of its providers?
- 30) What is HRSA doing to ensure that its providers are appropriately linked to Medicaid?

- 31) What benefit does HRSA receive from its cooperative agreements with national advocacy organizations such as NASTAD, NAPWA, and AIDS Action Council?
- 32) Why is HRSA interested in an international agenda?
- 33) What is HRSA doing to ensure that the staff works together across programs with its federal partners at CDC, SAMHSA, OMH, NIH, etc.?
- 34) How does HRSA coordinate its efforts with the Office of HIV/AIDS Policy in HHS? With the White House Office of National AIDS Policy?

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Cities Advocating Emergency AIDS Relief Coalition

Advocating for CARE Act Title I & Title III

Policy Position Paper: Ryan White CARE Act Reauthorization

June 1999

CITIES ADVOCATING EMERGENCY AIDS RELIEF COALITION

Policy Position Paper : Ryan White CARE Act Reauthorization

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Overview of Policy Positions

Cities Advocating Emergency AIDS Relief (CAEAR) is a national coalition that advocates for sound public health policies and resources related to the critical health care and supportive service needs of people living with HIV disease in the United States.

The Coalition is a national representative organization focusing on the needs of individuals and programs dependent on resources from Title I and Title III of the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act. The CARE Act, first passed by Congress in 1990, was reauthorized in 1996 for five years through September 30, 2000.

CAEAR Coalition members are people living with HIV disease and their coalitions, CARE Act grantees, community health clinics, community health advocates, public health departments, and Title I planning council representatives, and Title III grantees throughout the United States

The CAEAR Coalition has prepared this document to inform the Members of Congress, the Administration, and the public about key policy perspectives from consumers of HIV/AIDS services, HIV/AIDS service providers, and concerned citizens who are affiliated with Ryan White CARE Act Title I and Title III. The Coalition has received input from hundreds of individuals through its own regular membership meetings, planning council surveys, and special meetings of CAEAR members in December of 1998 and May 1999, which focused entirely on CARE Act reauthorization issues.

The CAEAR Coalition's policy recommendations on CARE Act reauthorization center on the key questions and their answers, as presented below briefly. Expanded discussion of these questions can be found in the attached document.

1. Should the CARE Act be reauthorized by the 106th Congress and signed into law by the President in order to ensure continued access to comprehensive primary care, HIV treatments, and supportive services for people living with HIV disease in the United States?

Answer: YES. The services provided by the CARE Act continue to be urgently needed by low-income, uninsured, and underinsured individuals living with HIV/AIDS. The federal CARE Act resources are critical to localities in their efforts to establish and maintain comprehensive medical and supportive systems of care.

2. Does the existing structure of the CARE Act continue to provide comprehensive and coordinated medical and supportive care to people living with HIV/AIDS?

Answer: YES. Title I of the CARE Act has expanded from the original 16 cities hardest hit by the AIDS epidemic to now include 51 emergency eligible metropolitan areas. The resources ensure that the basic infrastructure for comprehensive medical and supportive services exist in localities most heavily impacted by the HIV/AIDS epidemic. Title III grants to existing community-based health centers ensure that individuals have access to high quality HIV primary health care at sites that are familiar to them and located within their communities. Increasingly new Title III sites are located in geographically isolated areas and are the only local access points to quality HIV care.

3. Is it possible to improve the design of the current formula used to distribute emergency funding under Title I of the Ryan White CARE Act?

Answer: YES. The CAEAR Coalition proposes the replacement of the 10-year weighted AIDS case band with the CDC living AIDS case data report corrected for late reporting as the primary data set used to distribute Title I formula funding. The Coalition continues to believe that dramatic shifts in funding should be avoided by the retention of a hold harmless provision. The CAEAR Coalition will promote a hold harmless provision that limits the formula reductions to any EMA to no more than 2 percent a year for a maximum of 10 percent over five years (a doubling of the existing 1 percent per year limit on formula reductions).

4. Should the 50/50 ratio between Title I formula and supplemental funding be maintained?

Answer: YES. The formula funding continues to direct funds to communities most heavily impacted by the AIDS epidemic. In addition, to this essential purpose, the supplemental funds simultaneously seek, by means of competitive grants, to direct funds to those Title I areas which are using Title I funding in the most creative and efficient manner and face particularly severe needs.

5. Should the federal government continue to provide direct Title III grants to public and community-based health centers to improve access to HIV early intervention medical and related supportive care—with special emphasis on underserved and geographically isolated communities?

Answer: YES. Title III grants provide an ability to the federal administration to target grants to those underserved and heavily impacted areas in desperate need of enhanced access to high quality HIV primary medical care and essential supportive services. Increasingly Title III grants are targeted outside of urban areas—focusing on geographically isolated communities that have been traditionally underserved.

6. Question: Have the administrative caps on CARE Act resources effectively targeted resources to essential medical and supportive services to people living with HIV/AIDS?

Answer: YES. The administrative cap for Title I grantees should remain at 5 percent per year. The administrative cap for the directly funded Title III programs should be increased to 10 percent from their current level of 7.5 percent to correspond to the similar 10 percent cap on individual contractors in Title I. The revised CARE Act should clarify that the costs related to data collection, quality improvement, quality assurance and evaluation/analysis of CARE Act programs are not required to be covered by the administrative cap. Additional resources should be provided to grantees to conduct these essential functions.

7. Question: Local decision-making and control over resources define Title I of the CARE Act. Does the current design continue to provide appropriate access to essential HIV/AIDS medical care and treatment without federal mandates?

Answer: YES. Local decision making works. Planning Councils establish comprehensive continua of care to address local needs by setting Title I service priorities, allocating resources to each priority, and evaluating the efficiency with which resources are distributed and contracts managed. Local planning council membership is mandated to mirror the diversity and demographics of the local epidemic while including representation from key health care stakeholders. The needs assessment processes, managed by these planning councils, are informed by community input from clients, providers, grantees, and concerned citizens. This input creates a local plan that is responsive to the specific needs of individuals living with HIV/AIDS in the local areas.

8. Should the current U.S. Public Health Service guidelines on HIV care and the prophylaxis of opportunistic infections be used as a minimum standard for medical care and treatment provided by CARE Act funded providers with assurances that both providers and consumers are informed of the rapid and ongoing developments in the clinical management of HIV-disease?

Answer: YES. Treatment guidelines define a minimum standard of care for HIV disease among various populations. They also help to support health care professionals and consumers in the decision-making processes related to the clinical management of HIV disease. To increase provider knowledge and expand access to the highest quality HIV care among CARE Act providers, CAEAR believes the Secretary should be directed to create a mechanism that ensures that updates to the PHS guidelines are actively communicated to all CARE Act funded health care providers.

9. Should the Office of the Secretary of Health and Human Services ensure that resources appropriated by Congress to ensure appropriate data collection, analysis, and evaluation of CARE Act funded services be allocated to the Health

Resources and Services Administration (HRSA) so that the appropriate level of staff and resources can be targeted to this purpose?

Answer: YES. Many of the essential data collection, analysis, evaluation, and technical assistance functions could be carried out in a more timely and appropriate manner by the Health Services and Resources Administration (HRSA) if the agency had full access to the percentage allocated for that purpose from CARE Act appropriations. The Secretary should be directed to provide the full one- percent of CARE Act funding for data collection and evaluation to HRSA. The Secretary should also be directed to evaluate the utility, cost, and feasibility of developing a widely available, client-level, reporting system as a possible source of useful data.

10. Question: Beyond the establishment of a continuum of quality HIV health care and supportive services, the success of the CARE Act is determined by the extent to which Americans living with HIV disease have access to and benefit from these services. Can existing methods used by CARE Act grantees be improved to eliminate access barriers to HIV health care and support services for specific target populations?

Answer: YES. CAEAR supports a more formal approach to addressing these problems. The Secretary should explicitly instruct Title I and Title III grantees to engage in the identification and implementation of new and creative solutions to the challenge of disparate outcomes. Specifically, the Secretary should direct all Title I planning councils and grantees, as a part of the existing needs assessment processes, to measure health outcome disparities among individuals living with HIV/AIDS and to identify the target populations in their local communities that continue, despite existing efforts, to suffer significant HIV-related health outcome disparities. Further, Title I grantees, Title I planning councils, and Title III grantees should be directed to continue to create and enhance strategies to address health outcome disparities.

11. HIV comprehensive systems of care are designed to provide broad access to medical and supportive services. Despite the best efforts of local communities, is there a need for additional targeted federal allocations serving hard-to-reach populations disproportionately affected by the HIV/AIDS epidemic and for better coordination at the federal level?

Answer: YES. CAEAR supports the specific, targeted allocation of new resources to improve access to services and high quality HIV medical care, treatment and supportive services to underserved, hard-to-reach populations. CAEAR supports national initiatives, with local flexibility, as long as the allocations continue to flow through the existing Titles of the CARE Act and are not used to supplant other HIV/AIDS resources.

The Case for CARE Act Reauthorization

Why the CARE Act is so urgently needed

The Ryan White CARE Act expires on September 30, 2000. The HIV/ AIDS health care and related supportive services provided through the CARE Act are critically important and will continue to be to tens of thousands of people living with HIV/AIDS in the United States. Therefore Congress should reauthorize the CARE Act before September 2000 in order to ensure continued access to these critically important systems of care and life-saving services.

Impact

**688,200
Individuals have
been diagnosed
with AIDS in the
United States
(12/31/1998)**

**417,357 have died
(12/31/1998)**

**An estimated
40,000 new
infections occur
each year**

**600,000 to
900,000
Individuals are
estimated to be
living with HIV/
AIDS in the U.S.
today**

The HIV/AIDS epidemic in the U.S. must be viewed as part of a worldwide pandemic that continues to devastate the public health systems in many countries and ends the lives of millions worldwide. Through December 1998, 688,200 individuals in the U.S. had been diagnosed with AIDS, the end stage of HIV disease. Of this number, 417,357 have already died. The Centers for Disease Control and Prevention (CDC) estimates that over 40,000 Americans become infected with HIV annually and that today an estimated 600,000-900,000 Americans are living with HIV disease, including AIDS.

Communities Affected

The HIV epidemic in America is far from over. Since the CARE Act began in 1991, the number of American communities eligible for emergency assistance under Title I has grown from 16 to an astounding 51. As the HIV epidemic continues its relentless expansion, communities of color, African American women, Latinas, and gay and bisexual men are being disproportionately impacted. While continuing to significantly impact white gay and bisexual men, HIV infections since 1995 have increased most rapidly within communities of color. And today fully two thirds of Title I and Title III clients are people of color.

Increasingly, the newly infected are likely to be of color, heterosexual, poor, women, youth, substance users, the elderly, and homeless or marginally housed persons. Some of these factors further complicate HIV service delivery and strain already overburdened community-based and local public health care systems. As we approach the millennium, it is critical for us to recognize that no community is immune from this disease, and that we must care for each community if we are to stop the progress of HIV and preserve the nation's health care systems.

Still No Cure

The improved clinical management of HIV disease and the widespread use of combination anti-retroviral therapies have resulted in dramatic reductions in HIV-related opportunistic infections and deaths. However, the number of people becoming newly infected with HIV has remained relatively stable. Consequently more people than ever are in need of care. There is no respite in sight from the pressing health emergency facing America.

HAART stands for Highly Active Anti- Retroviral Therapy

In 1996, community members and medical researchers were optimistic that newly available highly active anti-retroviral therapies (HAART) would soon lead to eradication of the virus and perhaps even a cure for HIV disease. This euphoria led many to declare the AIDS crisis over, a prediction that has proven to be woefully incorrect.

Unfortunately, it is now clear that while these new treatments have restored the health of many individuals living with advanced HIV disease, and are largely responsible for the dramatic national reductions in AIDS-related deaths, they are not a cure. Clinical trial data presented by John Bartlett, MD from Johns Hopkins Medical Center, has demonstrated that for approximately half of those individuals in care with extensive, prior, anti-retroviral experience, the available HIV treatments have failed to be fully effective.

For those who have achieved benefits, the new treatments have increased the complexity and cost of their care. Many individuals are requiring more frequent and longer medical visits after the initiation of anti-retroviral therapy. A 1998 CAEAR survey found the average length of medical visits increased 65 percent between 1995-97, and the average cost of medical care rose 89.3 percent. HIV anti-retroviral treatments involve demanding and complicated dosing schedules and routines and are sometimes accompanied by serious side effects. These are truly challenging regimens, even for the most conscientious of patients who recognize that prevention of resistance to these medications depends on adhering to these regimens.

Despite these challenges, the success of early access to outpatient medical care, treatment, and support services is undeniable. The Centers for Disease Control and Prevention (CDC) National Center for Health Statistics (NCHS) recently released data showing the inpatient hospitalization rates for HIV-infected patients continues to decline. In 1997, the nation saw a 30 percent decline in HIV/AIDS related

As the national death rates from HIV-related illnesses have dropped (47 percent nationally in 1998), the number of people living with HIV/AIDS has increased

hospitalizations (71,000 fewer) than in 1995. This reduction in hospitalizations combined with an overall reduction in the lengths of stay for those who are hospitalized contributed to a reduction of 900,000 total days of hospital care. The hundreds of millions of dollars in cost savings these reductions represent are due to the community-based outpatient support provided through Title I and Title III of the CARE Act. To sustain these results, supportive services such as treatment adherence programs and ongoing education about anti-HIV medications have grown in importance.

The advent of HAART has altered what constitutes an appropriate array of primary health care and supportive services for many people living with HIV disease. In 1998, the U.S. Public Health Service issued guidelines for the use of these anti-HIV medications. For many recipients there has been a dramatic shift from palliative, end stage care and prophylactic treatment of opportunistic infections, to the active treatment of HIV infection. With diagnostic tests now available to monitor HIV disease progression, care providers and their patients create care plans based on a more scientific understanding of HIV treatment.

The flexibility of the local planning process required under Title I, and the community-based strengths incorporated into the design of Title III, have allowed many communities to quickly and efficiently adapt to emerging treatment strategies and to provide increasingly high quality and cost effective HIV care and supportive services. As a result, many people with HIV disease are living longer, more productive and healthier lives. Care created by the Ryan White CARE Act must continue to stabilize individuals and family units thrown into crisis by HIV/AIDS, and resources for the Act must be expanded to meet the growing and evolving need.

The next chapter presents the Coalition's specific policy positions along with discussion of the key issues that need to be considered during reauthorization of the CARE Act.

The CAEAR Coalition's CARE Act Reauthorization Policy Recommendations

Key questions, answers, and justifications

Beginning in the spring of 1998, the CAEAR Coalition engaged in an intensive review of the current and future key strategic issues facing people with HIV/AIDS, their communities, and the public health systems that respond to their health and life needs.

In national meetings in September 1998, December 1998, and May 1999, the Coalition's membership focused on the key issues related to reauthorization of the CARE Act.

We intend for these positions to outline the key areas of interest to the Title I and Title III communities. They will also provide a basis for the many policy discussions that will occur along the successful path to reauthorization of the CARE Act.

Coordinating Care through the CARE Act

Does the existing structure of the CARE Act continue to provide comprehensive and coordinated medical and supportive care to people living with HIV/AIDS?	Yes.
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The CAEAR Coalition supports maintaining the current structure of the CARE Act intact within a reauthorized Act.

The existing structure of the CARE Act provides a comprehensive structure and dynamic approach to the planning and delivery of HIV primary care and supportive services to people living with HIV disease.

The CARE Act was originally structured with four titles targeting different systems of care and Part F, including a Special Project of National Significance (SPNS) component. Part F was expanded to include the AIDS Education and Training Centers Program (AETCs) and the AIDS Dental Reimbursement Program during the last reauthorization in 1996.

Title I of the CARE Act

Title I of the CARE Act originally distributed federal resources to 16 eligible metropolitan areas (EMAs) in the United States identified as emergency epicenters of the HIV/AIDS epidemic. These areas had private and public health care infrastructures that were collapsing under the magnitude, volume, and severity of the HIV epidemic in their areas.

Because of the expanding U.S. HIV/AIDS epidemic, 16 Title I areas in 1991 has grown to 51 areas in 1999

About 74 percent of all people with AIDS in the U.S. reside in Title I areas

By fiscal year 1999, Title I had expanded to include 51 EMAs hardest hit by the HIV/AIDS epidemic – a sad reminder of the continuing emergency in the United States. These 51 Title I EMAs are home to about 74 percent of all individuals diagnosed with AIDS in the United States. These areas are predominantly urban, and they serve as magnets for individuals from surrounding suburban and rural areas in need of HIV specialty care. The result is increasing caseloads in Title I EMAs, which in turn puts even more pressure on funding and services, and a continued danger of collapsing private and public systems of health care.

Title I funding provides critical HIV primary care and supportive services to persons living with HIV/AIDS most in need. Title I funded HIV health care and essential supportive services include but are not limited to:

- primary health care
- sub-specialty medical care (for example: obstetrics and gynecology, neurology)

- dental care
- medications
- treatment education
- laboratory tests
- home health care
- mental health care
- substance abuse treatment/counseling
- comprehensive medical case management/benefits counseling
- assessment for work entry/re-entry
- legal services
- transitional housing
- food and nutritional services
- transportation to care services

The CARE Act requires the establishment of a local HIV health services planning council in each of the Title I communities. The purpose of these planning councils is to conduct needs assessments and prepare comprehensive plans for the delivery of HIV services for low-income, uninsured, and underinsured individuals living with HIV disease in their areas. Councils set annual priorities for services and allocate the Title I resources available to provide them. In addition, councils are responsible for assessing the efficiency with which Title I funds are made available to the community. These features assure local responsibility for addressing a local problem and are a model for federal initiatives. The planning council process represents a welcome departure from top-down models of health care planning and service delivery that often fail to address local service needs.

In 1998, Title III served over 96,000 people living with HIV disease

Over half of Title III providers are located in rural and geographically isolated communities

Over two-thirds of patients served by Title III are people of color and one-third are women

Title III of the CARE Act

As of early 1999, Title III of the CARE Act provides direct federal grants to 181 community-based and public health centers in 43 states, the District of Columbia, and Puerto Rico to provide comprehensive, early intervention HIV/AIDS health care to historically under-served communities, families, and individuals living with HIV disease in urban and rural areas. Title III is intended to establish or enhance the HIV-specific service capacity of already existing public health service programs. Title III allows clients to receive a continuum of HIV primary care from the same community-based organizations that provide them with other kinds of medical care and allows for the creation of innovative systems of care. Building the capacity within existing community health services is both cost-effective and an efficient use of available resources. This is a model for public health programs of the future.

One of the several goals of the Title III program is to provide HIV primary care to hard-to-reach individuals and geographically isolated communities who have HIV care needs. Over two-thirds of patients served by Title III are people of color and over one-third of these patients are women. Clearly, Title III plays a critical role in efforts to increase the early diagnosis and treatment of HIV disease within the African American and Latino communities, as well as other underserved and disproportionately affected communities. Title III grantees are mandated to allocate at least 50 percent of funds to health care services. In 1998, Title III grantees actually allocated 74 percent of their grants to primary medical care and medications.

Ensuring Access to Early Intervention HIV Services for People Living with HIV/AIDS

By providing Title III grants directly from the federal government to community providers, Title III ensures a rapid clinical response to ever-changing treatment practices and addresses inadequacies in primary care and supportive services to poor areas, smaller cities, and rural communities. Approximately 23 percent of Title III programs are the only outpatient HIV health care program available in their area. In 1998, Title III served over 96,000 people living with HIV disease. Over 50 percent of Title III providers are located in rural and geographically isolated communities outside Title I areas.

The Title I Formula and Supplemental Funding Distribution

Is it possible to improve the design of the current formula used to distribute emergency funding under Title I of the Ryan White CARE Act?	Yes.
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At the outset, the CAEAR Coalition wishes to emphasize that no Title I community receives adequate federal resources to fully meet the needs of people living with HIV/AIDS. To provide such resources in support of local efforts to establish comprehensive HIV/AIDS systems of care is clearly the paramount goal of Title I. The CAEAR Coalition will continue to advocate for increases in Title I resources to more adequately address the increasing needs of Title I clients. In order to sustain and expand these systems of care, the Title I formula should seek, to the extent possible, to fairly distribute the burden of unmet need among Title I areas while protecting existing systems of care from destabilization.

The current Title I formula is based on the number of AIDS cases diagnosed over the ten years immediately preceding the current year, with each year, further away from the current year, given a lower weight in determining awards. This is the so-called ten-year weighted case band, designed as a surrogate measure for the burden of the AIDS epidemic on the systems of health care in areas eligible for Title I funding.

The ten-year band was established, prior to combination therapy, to more accurately reflect those living with AIDS. However, combination therapy (also referred to as HAART) has dramatically lengthened the life spans of some clients receiving these treatments, calling into question the extent to which the band will continue to serve its purpose. In addition, it is clear that not every person living with AIDS in a particular Title I community utilizes Title I funding every year, and that the current formula does not capture the significant number of HIV positive individuals—not AIDS diagnosed—who do receive Title I services in a given year.

Therefore, the current Title I formula, established during the prior reauthorization of the Ryan White CARE Act, is an imperfect, but useful mechanism for providing federal resources to communities endeavoring to develop comprehensive systems of medical and supportive services for people living with HIV/AIDS.

Because the ten-year band was projected to redirect resources away from some Title I communities towards others, a so-called “hold harmless” provision was inserted into the Title I formula. This provision does not prevent reductions in a Title I area’s formula funding. However, it does ensure that such reductions are phased in over time. This “phased in reduction” provision guaranteed that no Title I community would lose more than one percent per year in formula funding for a total potential loss of five percent, relative to a Fiscal Year 1995 baseline, over the lifetime of the five-year authorization. The intent of this provision was to provide a mechanism to prevent the rapid destabilization of existing health care systems even as the new formula might direct resources to emerging areas.

Recommendation

The CAEAR Coalition recommends that the current formula be updated. The new formula should be based on the cumulative estimate of living AIDS cases (corrected for late reporting) as reported by the Centers for Disease Control and Prevention

(CDC). The Coalition believes this measure is simpler, more direct, and more accurate than the ten-year weighted case band contained in the current Title I formula.

The CAEAR Coalition believes that the phased in formula reduction or hold harmless provision continues to be a necessary mechanism in the Title I formula in order to prevent the rapid destabilization of existing health care systems, even as the formula responds quickly and flexibly to changes in the epidemic. In order to accelerate a more even distribution of unmet need, the Coalition recommends that the redirection of resources permitted in the new reauthorization be increased from one percent to two percent per year, with a maximum reduction of ten percent in formula funding for any eligible metropolitan area from an FY 2000 baseline over the lifetime of the authorization.

Additionally, the CAEAR Coalition calls to the attention of the Congress that, as new HIV prevalence data becomes available, such data may provide, in part, a better basis for allocating some Title I resources. These data are currently not available, and mindful of the changes quickly wrought in this epidemic from the advent of combination therapy, the Coalition believes that it would be imprudent to endorse the use of such data at this time.

Maintaining the 50/50 Ratio of Title I Formula to Supplemental

CAEAR strongly believes that the current structure of Title I of the Ryan White CARE Act, including both formula and supplemental portions, should be maintained. The formula half of Title I continues to direct funds to the communities most heavily impacted by the AIDS epidemic. The supplemental half does the same, but simultaneously seeks, by means of competitive grants, to direct funds to those Title I areas that use Title I funding in the most creative and efficient manner and face particularly severe needs. The Coalition supports continuing the competitive element of the supplemental award to assure that a substantial portion of CARE Act funds are awarded on the basis of merit.

Measuring the Severity of Need in Title I EMAs

In reauthorizing the CARE Act in 1996, the Congress acknowledged the many significant co-morbid factors that contribute to the complexity of providing HIV health and supportive services. These co-morbid conditions include substance abuse, tuberculosis, mental illness, homelessness, and sexually transmitted diseases. The Secretary of Health and Human Services was authorized to use severe need as a factor in the distribution of the supplemental portion of Title I resources.

Recommendation

The CAEAR Coalition affirms the importance of using co-morbid factors in assessing the need for Title I resources. However, the Coalition is troubled by the inability of the Department of Health and Human Services to develop a uniform set of criteria against which to measure the many severe needs of Title I areas as required by the

1996 reauthorization statute. The absence of this set of criteria has made a national comparison of statistics across localities impossible.

CAEAR believes that in addition to the factors currently used to determine severe need, the Secretary of HHS may consider the inclusion of factors such as: the HIV Cost and Services Utilization Study (HCSUS), the cost of providing care, which may include the cost of transportation to and from care, the density of HIV in the population, the rate of poverty in the EMA, the prevalence of Hepatitis B and Hepatitis C, the need for the development of infrastructure in areas of increasing need for AIDS services, and the need to ensure access to comprehensive care in geographically isolated areas. These measures of need should be standard, equivalent, and applied consistently across all Title I areas. Because of the increasing impact of these co-morbid conditions on the ability of Title I EMAs to provide care, the Coalition believes that, to reflect the increasing impact, the weight of severity of need should be increased to one-third of the points used to award Title I supplemental grants.

The Coalition acknowledges that, because it is difficult to find local data that are comparable across Title I areas, there are concerns about the feasibility of developing an appropriate and uniform set of criteria against which to measure the severity of needs in local communities. The Coalition, therefore, calls on the Congress to require the Secretary to convene by 2001 a panel of experts to examine the feasibility of developing such criteria, as outlined above, that can be used to measure the severity of these needs consistently across localities. The Secretary shall create, test, refine, and implement such criteria by FY 2002, or if no uniform set of criteria can be developed, the Secretary shall report to Congress at that time on the barriers that prohibit implementation.

Pending the development of such criteria, the Department should continue to base its consideration of severe need on a detailed description and qualitative analysis contained in the supplemental application, which may include any local prevalence data gathered and analyzed by the eligible area.

Distributing Targeted Resources through Title III Grants

Should the federal government continue to provide direct Title III grants to public and community-based health centers to improve access to HIV early intervention medical and related supportive care—with special emphasis on underserved and geographically isolated communities?	Yes.
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The CARE Act should continue to target and directly fund community-based and public health care centers to provide HIV early intervention medical and supportive services to people living with HIV disease. Title III grants provide an ability to the federal administration to target grants to those underserved and heavily impacted areas in desperate need of enhanced access to high quality HIV primary medical care and essential supportive services. Increasingly Title III grants are targeted outside of urban areas—focusing on geographically isolated communities that have been traditionally underserved.

CAEAR continues to support the CARE Act provision that authorizes Title III HIV early intervention grantees to allocate at least 50 percent of each grant for primary care services. Title III programs should also continue to provide free services to individuals with incomes at or below 100 percent of the federal poverty level (FPL), with a sliding scale fee for individuals above that level (capped at specific amounts for 101%-200% FPL, 201%-300% FPL, and over 300% FPL).

The CAEAR Coalition supports the continuation of these provisions within Title III of the CARE Act.

Containing Administrative Costs by way of Caps for Title I and Title III

Have the administrative caps on CARE Act resources effectively targeted resources to essential medical and supportive services to people living with HIV/AIDS? Yes.

Title I and Title III CARE Act grantees have historically maximized federal dollars for primary care and related supportive services by limiting the amount of administrative costs. These caps have rarely compensated for the costs of doing business, but have maintained the CARE Act as a model of efficiency and cost effectiveness.

Title I grantees are limited to 5 percent of their grant amount for basic grants administration, including funding distribution, grants monitoring, and fiscal management. In addition, the CARE Act mandates flexible administrative caps, up to a maximum of 10 percent, for individual contractors at the local level who receive grants from the local government entity. This differential in percentages was created intentionally by the Congress, recognizing that grantees overseeing an entire Title I allocation often would be applying the percentage to millions of dollars, while

individual agencies would most likely be applying the percentage to thousands of dollars.

Federal administrators and Title I planning councils, however, are increasingly requiring in-depth evaluation of health outcomes, quality assurance, quality improvement, and data collection and analysis. These important functions are resource intensive and consequently require additional sources of support.

Title III grantees are local community health centers, hospital outpatient care programs, health departments and other community-based organizations which in size are more similar to the individual contractors under Title I, but face some of the same demands as the larger government grantees under Title I for evaluating health outcomes, quality assurance, quality improvements, and data collection and analysis. Administrative expenses for these directly funded Title III grantees, however, have been capped at 7.5 percent.

The CAEAR Coalition strongly recommends that the 5 percent administrative cap for Title I be maintained with the continuation of the flexible, 10 percent administrative cap for Title I individual contractors. Under Title 26 of the Public Health Service Act, the Department of Health and Human Services is allocated for evaluation purposes one percent of total CARE Act funding. From that allocation, the Department should provide funding to Title I and Title III grantees for the evaluation and analysis functions, separate from the administrative cap.

The anomaly of the 7.5 percent cap on Title III grantees should be corrected by raising the administrative cap to 10 percent. The Title III administrative cap should be increased to reflect that, in size, Title III grantees more closely resemble Title I individual contractors than Title I grantees and also to reflect the limited availability of discretionary resources.

Local Planning and Decision Making

Local decision-making and control over resources define Title I of the CARE Act. Does the current design continue to provide appropriate access to essential HIV/AIDS medical care and treatment without federal mandates? Yes.

Local decision making is the cornerstone upon which Title I of the CARE Act is based. The CARE Act mandates the establishment of a planning council within each Title I eligible metropolitan area. The planning council is responsible for conducting a

Local decision making is the cornerstone upon which the CARE Act is based

needs assessment at the local level that reviews all health care resources in that area to determine continuing unmet need. Planning councils establish comprehensive continua of care to address local needs by setting Title I service priorities, allocating resources to each priority, and evaluating the efficiency with which resources are distributed and contracts managed. Local planning councils are comprised of consumers, health care providers, community leaders, local representatives of CARE Act Title II, Title III, and Title IV, other CARE Act grantees, mental health providers, substance abuse providers, Medicaid representatives, local and state government representatives, and other interested parties.

The CAEAR Coalition believes local decision making is the critical component responsible for the success of Title I of the CARE Act. This manner of planning for and enhancing comprehensive continua of HIV care stands as a model for effective, dynamic, and responsive health care and supportive service delivery for other national, state, and local initiatives. Local decision making ensures a rapid disbursement of funds, community involvement, and grantee accountability. It continues to be the best and most responsive system to identify and remedy gaps in services and barriers to access at the local level. The CAEAR Coalition supports outreach efforts at the local level to encourage local participation in the planning process that accurately reflects the demographics of the local HIV/AIDS epidemic.

Ensuring Effective Planning to Address Local Needs

The current provision that at least 25 percent of each local planning council be comprised of individuals living with HIV disease has improved the input of CARE Act consumers to the planning process. Title I has a long-standing commitment to setting a high priority for HIV health care and increasing access to HIV services. Each planning council is routinely required to engage in data collection and analysis, strategic planning, and cost-benefit analysis. Parliamentary procedures are often used to negotiate numerous policy issues as the council works towards a consensus of the local stakeholders.

Finally, internal procedures can be complicated, such as the mandated grievance processes required by the CARE Act. Many of these complex issues may not be well understood by all planning council members. Planning councils work most effectively when they are knowledgeable of and familiar with both internal and external governing and planning procedures utilized to accomplish their critical work.

The CAEAR Coalition believes that the Health Resources and Services Administration (HRSA) should provide technical assistance to planning councils as they continue to strengthen the available training for all people who serve on Title I planning councils. This will ensure that the parliamentary and planning processes are continually enhanced by the expertise and life experiences of its members.

**Title III currently
allocates 74
percent of funding
for health care
and medications**

Ensuring Access to Essential Services for People Living with HIV/AIDS

The CARE Act provides a vital continuum of care for people with HIV and AIDS. Title I has a long-standing commitments to setting a high priority for HIV health care and increasing access to HIV services. Title I areas regularly allocate over 60 percent of their funding to health care services including medications; Title III, mandated to allocate at least 50 percent of funds to health care services actually allocates 74 percent of funding for health care and medications.

This commitment to primary health care services at the local level will continue with the emergence of more effective treatments for HIV itself, as well as HIV-related opportunistic infections. In addition to health care, CARE Act clients receive essential support services that help link them to and maintain them in medical care. Some examples include case management, food and nutrition services, transportation, housing assistance, and treatment education. Growing requests for assistance from people physically and mentally able to re-enter or train to enter the work force are indicative of altered needs.

Suggestions that a mandated set of core services be implemented are unwarranted. The identification of a core set of services is by definition an outgrowth of good local planning and should not be mandated from the federal level. Regionally specific continua of care are currently planned for and then implemented through the local processes. In each instance, these continua of care are designed to respond to local identified gaps in services and address the unmet needs of local clients.

The CAEAR Coalition opposes the establishment at the federal level of a core set of Title I services, percentage set-asides for specific services, or limiting the amount of funding that can be allocated at the local level for an approved service.

Assuring Quality of Care through CARE Act Funded Providers

Should the current U.S. Public Health Service guidelines on HIV care and the prophylaxis of opportunistic infections be used as a minimum standard for medical care and treatment provided by CARE Act funded providers with assurances that both providers and consumers are informed of the rapid and ongoing developments in the clinical management of HIV disease?

Yes.

CARE Act providers have worked to assure that they provide the highest quality community-based HIV primary care and supportive services. With the development of effective anti-retroviral treatments, CARE Act funded programs have emerged as important mechanisms for the dissemination of high quality HIV-specific treatment practices.

In 1996, the Department of Health and Human Services and the Henry J. Kaiser Family Foundation convened the Panel on Clinical Practices for the Treatment of HIV Infection. This panel has produced guidelines for the use of anti-retroviral agents in HIV-infected adults and adolescents. Other panels have produced treatment guidelines for prophylaxis of HIV-related opportunistic infections, treating HIV-positive pregnant women, and treating children under 13 years of age. These guidelines are all designed to inform health care providers of the standard of care for HIV disease and the treatment and prophylaxis of HIV-related opportunistic infections. Given a swiftly evolving HIV treatment environment, and owing to the amount of time required for federal guidelines to be updated, the guidelines tend to be outdated to some degree upon their dissemination.

In effect, treatment guidelines define a standard of care for HIV disease among various populations. They also help to support health care professionals and consumers in the decision-making processes related to the clinical management of HIV disease. The CAEAR Coalition supports the use of these federal guidelines as a minimum standard for CARE Act funded HIV health care providers and recognizes that resources are necessary to provide the standard of care to patients seeking care for HIV disease.

The CAEAR Coalition believes all people living with HIV are entitled to high quality HIV health care provided by knowledgeable health care professionals. The Coalition supports a sufficient authorization for each Title of the CARE Act to assure that CARE Act funded providers of HIV primary care are able to employ, as a minimum standard for medical care and treatment, the most current versions of the U.S. Public Health Service (PHS) guidelines on HIV treatments and prophylaxis for HIV-related opportunistic infections. Further, the CAEAR Coalition believes that the Secretary should be directed to create a mechanism that ensures that updates to the PHS guidelines are actively communicated to all CARE Act funded health care providers.

Improving the Data Collection, Analysis, and Evaluation Process at HRSA

Should the Office of the Secretary of HHS ensure that resources appropriated by Congress to ensure appropriate data collection, analysis, and evaluation of CARE Act funded services be allocated to the Health Resources and Services Administration (HRSA) so that the appropriate level of staff and resources can be targeted to this purpose? Yes.

Congress affirmed the importance of data collection, analysis, and evaluation when it stipulated that one- percent of the annual CARE Act appropriation be used for data collection and evaluation at the Health Resources and Services Administration (HRSA). To be responsive to the growing complexity of the HIV/AIDS epidemic, planning requires reliable data on changing trends and outcomes at both the national and local levels. The Coalition remains concerned that the Department of Health and Human Services has not allocated the full funding for these data management functions to HRSA.

The HIV/AIDS Bureau (HAB) at HRSA does not receive the resources from the Office of the Secretary that are Congressionally appropriated for data collection and evaluation. Because of inadequate resources at the HAB level, there is insufficient staff devoted to the data collection and evaluation efforts at HRSA. This has resulted in data reports that are incomplete or unresponsive to the key planning and evaluation questions being faced by communities, thereby hampering local efforts to make fully informed decisions.

The Secretary should be directed to provide the full one- percent of CARE Act funding for data collection and evaluation to HRSA. Further, the CAEAR Coalition believes the Secretary should be directed to evaluate the utility, cost, and feasibility of developing a widely available, client-level, reporting system as a possible source of useful data.

Improving Access to CARE Act Programs for the Underserved

Beyond the establishment of a continuum of quality HIV health care and supportive services, the success of the CARE Act is determined by the extent to which Americans living with HIV disease have access to and benefit from these services. Can existing methods used by CARE Act grantees be improved to eliminate access barriers to HIV health care and support services for specific target populations? Yes.

Historic inequalities, the impact of co-morbid conditions on people living with HIV disease, the shifting demographics of individuals in need of care, and evolving HIV treatment options continually challenge local planning bodies to assess the effectiveness of outreach to connect targeted populations to the care system. Outreach efforts used to connect people living with HIV disease with available services must continuously be evaluated to assess their effectiveness with emerging populations in need of care and treatment. Successful and innovative approaches to outreach efforts should be shared at the earliest possible moment by the HIV/AIDS Bureau of the Health Resources and Services Administration (HRSA) with other federal programs that serve the same populations.

Addressing Health Outcome Disparities

An important responsibility of local planning bodies and grantees is the identification, reduction, and elimination of barriers to existing health care, and to the extent possible, eliminating existing health outcome and quality of life disparities experienced by historically underserved populations.

In 1998, the National Medical Association found that overall in the nation African Americans were most likely to receive their first treatment for HIV-related conditions when they required hospitalization and that a significant number of African Americans discover they are living with AIDS within one month of their death. In addition, studies have identified significant health outcome disparities between whites and African Americans, Latinos, and youth living with HIV disease. These health outcome disparities suggest that the existing health care system is often challenged to reach and provide quality services to many of those most in need.

Years of grappling with these challenges have forced the realization that standardization of services may not, in and of itself, guarantee uniform outcomes for

Significant numbers of African Americans discover they are living with AIDS within one month of their deaths

affected populations. Similarly, providing services in a culturally specific setting does not always resolve the access and quality of care concerns inherent in the disparities between racial, ethnic, and gender groups.

The CAEAR Coalition will continue to work at the national level to reduce and eliminate, whenever possible, health outcome disparities between specific populations at risk for or living with HIV disease. The Coalition is also aware that there are myriad reasons for disparities in health outcomes between various target populations. The CARE Act, as important as it is, cannot be expected to resolve broad health care disparities that are the responsibility of the larger public health system and society as a whole. Title I grantees, Title I planning councils, and Title III providers have great expertise and understanding of their local communities and can be agents for change.

The CAEAR Coalition supports a more formal approach to addressing these problems. CAEAR believes that the Secretary of Health and Human Services should explicitly instruct Title I and Title III grantees to engage in the identification and implementation of new and creative solutions to the challenge of disparate outcomes.

Specifically, the Secretary should direct all Title I planning councils and grantees, as a part of existing needs assessment processes, to identify the target populations in their local communities that continue, despite existing efforts, to suffer significant HIV-related health outcome disparities. Further, the Secretary should direct Title I grantees, Title I planning councils, and Title III grantees to continue to create and enhance strategies to address health outcome disparities. Additional funding should be authorized to allow the Department of HHS to provide Title I grantees, Title I planning councils, and Title III grantees the additional resources required to identify such disparities and implement plans to address them.

Finally, the Secretary should be directed to evaluate the success of grantees in identifying health outcome disparities and implementing plans to address health outcomes disparities, and beginning in fiscal year 2003, use such evaluation, as one measure, in determining Title I supplemental awards and Title III grants.

Targeting Resources to Hard-to-Reach Populations and Coordinating Federal Efforts

HIV comprehensive systems of care are designed to provide broad access to medical and supportive services. Despite the best efforts of local communities, is there a need for additional targeted federal allocations serving hard-to-reach populations disproportionately affected by the HIV/AIDS epidemic and for better coordination at the federal level? Yes.

The FY 1999 Congressional Black Caucus HIV/AIDS Initiative was instrumental in focusing the nation's attention on the disproportionate impact of HIV disease in the African American community and the associated disparities in health outcomes. While the CAEAR Coalition strongly believes that local planning and implementation are the most appropriate mechanism to resolve access and quality of care issues for specific populations, targeted allocations are needed that provide additional resources to address broad national inequalities between racial, ethnic, and gender groups. At the same time, the CAEAR Coalition affirms that different geographic locations may confront different challenges and utilize unique strategies to reach the disenfranchised and underserved populations in their communities.

The CAEAR Coalition supports specific targeted allocations of new resources to improve access to services and high quality care to underserved, hard-to-reach populations. CAEAR supports national initiatives, with local flexibility, as long as the allocations continue to flow through the existing Titles of the CARE Act and not used to supplant other HIV/AIDS resources.

Coordination of the CARE Act with Other Federal Programs

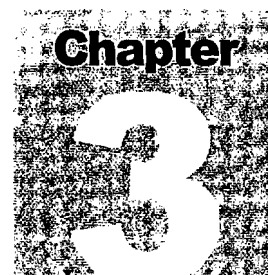
The federal government addresses the expansion of the HIV epidemic through multiple and concurrent initiatives. Efforts include medical research (National Institutes of Health), prevention and education (Centers for Disease Control and Prevention), housing (Housing and Urban Development), substance abuse (Substance Abuse and Mental Health Services Administration), among others such as the Veterans Administration and the Indian Health Service. The CAEAR Coalition believes that federal HIV/AIDS initiatives housed in various agencies of government need to be better coordinated with the CARE Act.

One example of such coordination relates to job training and work readiness issues that have emerged for people living with HIV disease whose health has been stabilized by effective treatments

The CAEAR Coalition strongly believes that CARE Act providers and consumers should be informed about and integrated into existing federal and state employment programs for people with disabilities. The CARE Act providers should serve as a link between training programs and people living with HIV disease who are able to participate in such programs.

The depth and breadth of the federal government's commitment to fighting HIV/AIDS is extensive. Coordinating the numerous HIV/AIDS programs is an enormous undertaking that must be improved if the nation is to receive the full benefits from the cross-pollination of useful information and emerging technologies. The CAEAR Coalition understands that such wide-ranging interdepartmental coordination requires the cooperation and commitment of the White House Office of National AIDS Policy (ONAP) to implement such coordination across federal agencies. The CAEAR Coalition has requested that the President and ONAP create an interdepartmental plan of action with specific goals and time lines to better coordinate the critically important work of the federal government in the HIV/AIDS epidemic.

The CAEAR Coalition asks that the Congress request that the Administration establish a more formal and consistent interdepartmental funding and programmatic coordination plan for HIV/AIDS initiatives across the federal government.



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**Title I Eligible Metropolitan
Areas (51 as of FY 1999)**

Atlanta GA	Newark NJ
Austin TX	Norfolk VA
Baltimore MD	Oakland CA
Bergen-Passaic NJ	Orange County CA
Boston MA/NH	Orlando FL
Caguas PR	Philadelphia PA/NJ
Chicago IL	Phoenix AZ
Cleveland-Lorain-Elyria OH	Ponce PR
Dallas TX	Portland OR
Denver CO	Riverside-San Bernardino CA
Detroit MI	Sacramento CA
Dutchess County NY	St. Louis MO/KS
Ft. Lauderdale FL	San Antonio TX
Ft. Worth-Arlington TX	San Diego CA
Hartford CT	San Francisco CA
Houston TX	San Jose CA
Jacksonville FL	San Juan PR
Jersey City/Hudson County NJ	Santa Rosa-Petaluma CA
Kansas City MO	Seattle WA
Las Vegas NV	Tampa-St. Petersburg FL
Los Angeles CA	Vineland-Millville-Bridgeton NJ
Miami FL	Washington DC/MD/WV
Middlesex/Somerset/Hunterdon NJ	West Palm Beach FL
Minneapolis-St. Paul MN	
Nassau-Suffolk NY	
New Haven Fairfield CT	

New Orleans LA
New York NY

**Title III Grantees by States
(45 as of June 1999)**

Alaska
Alabama
Arkansas
Arizona
California
Colorado
Connecticut
Delaware
District of Columbia
Florida
Georgia
Idaho
Illinois
Indiana
Iowa
Kansas
Kentucky
Louisiana
Maine
Maryland
Massachusetts
Michigan
Mississippi

Missouri
Montana
Nebraska
Nevada
New Jersey
New Mexico
New York
North Carolina
Ohio
Oklahoma
Oregon
Pennsylvania
Puerto Rico
Rhode Island
South Carolina
Tennessee
Texas
Utah
Vermont
Virginia
Washington
Wisconsin