

Correspondence – National Association for Retarded Citizens

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National Association for Retarded Citizens

SERVING RETARDED CHILDREN AND ADULTS

August 13, 1974

Governor Jimmy Carter
1974 Campaign Chairman
Democratic National Committee
P. O. Box 1524
Atlanta, Georgia 30301

Dear Governor Carter:

Thank you for your recent letter relative to the issues facing the people we serve through NARC. I have been in a rather constant state of travel of late, hence my somewhat tardy response.

I can think of no better way to describe our aims, goals, hopes and dreams for America's retarded citizens than to share with you our Five Year Plan, as hammered out by staff and volunteers and approved by our Board of Directors. It spells out what we hope for in the coming months and years and those legislative and administrative acts which further these goals have our support and appreciation. Those actions or lack of actions which frustrate the legitimate and natural aspirations of retarded Americans only require us to work harder to achieve our unselfish goals and objectives.

The present Administration has announced a goal by 1980 of reducing the institutionalized retarded population by one-third. The administrative and legislative support of this goal has been significantly lacking, particularly in the area of housing. We shall continue to endeavor to push for normalization of living arrangements for all "Retarded Citizens." (Please note name change.)

I am enclosing two of our recent publications "The Right to Choose" which highlights our needs in the housing area and "A Plan for Everyone" which emphasizes our concern for those in the underprivileged population where retardation has a very high incidence. There are issues in these two areas which can be addressed "in a serious and effective way by political candidates this year."

CAROL BURNETT,
NATIONAL HONORARY CHAIRMAN

MARION P. SMITH
PRESIDENT

PHILIP ROOS, Ph.D.,
EXECUTIVE DIRECTOR

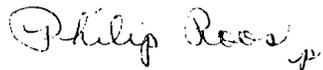
THE GREATER DALLAS-FORT WORTH METROPLEX

2709 AVENUE E EAST / P.O. BOX 6109 / ARLINGTON, TEXAS 76011 / (817) 261-4961

Governor Jimmy Carter
August 13, 1974
Page -2-

I do not have any present plans for a visit to Atlanta, but will certainly contact you should plans materialize. However, if, after reviewing the enclosures, you would want me to make a special trip to discuss the concerns of retarded citizens with you, please let me hear from you. Also, Jack Blackstone, Georgia Association for Retarded Children Executive Director, telephone (404) 761-5209 and Kermit Harrington, our NARC regional representative, telephone (404) 458-8024, are right in Atlanta and easily available to you.

Cordially,



Philip Roos, Ph.D.
Executive Director

PR:mp

Enclosures

cc: Mr. Marion P. Smith
Dr. Jack Blackstone
Mr. John Bowling
Mr. Bill McCahill
Dr. Brian McCann
Mr. Kermit Harrington

National Association for Retarded Citizens

SERVING RETARDED CHILDREN AND ADULTS

WILLIAM P. McCAHILL
DIRECTOR
GOVERNMENTAL AFFAIRS

August 22, 1974

Governor Jimmy Carter
1974 Campaign Chairman
Democratic National Committee
P.O. Box 1524
Atlanta, Georgia 30301

Dear Governor Carter:

In a follow-up to Dr. Roos' letter to you of August 13, 1974, copy attached, I am happy to supply you with NARC's views on a number of substantive legislative and administrative issues relative to mentally retarded citizens.

If you or your associates have any questions on the enclosures kindly feel free to contact this office.

Sincerely,



William P. McCahill
Director
Governmental Affairs

WPM/mkb

Enclosures

CC: Mr. Marion P. Smith
Dr. Jack Blackstone
Mr. John Bowling
Dr. Phil Roos
Dr. Brian McCann
Mr. Kermit Harrington

CAROL BURNETT,
NATIONAL HONORARY CHAIRMAN

MARION P. SMITH
PRESIDENT

PHILIP ROOS, Ph.D.,
EXECUTIVE DIRECTOR

GOVERNMENTAL AFFAIRS OFFICE

THE FEDERAL BUILDING • 1522 K STREET, N.W., SUITE 808 • WASHINGTON, D.C. 20005 • (202) 785-3388



FORMERLY THE NATIONAL ASSOCIATION FOR RETARDED CHILDREN

headquarters

National Association for Retarded Citizens

SERVING RETARDED CHILDREN AND ADULTS

August 13, 1974

Governor Jimmy Carter
1974 Campaign Chairman
Democratic National Committee
P. O. Box 1524
Atlanta, Georgia 30301

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CAPOL BURNETT
NATIONAL VICE CHAIRMAN

MARION P. SMITH
PRESIDENT

PHILIP ROOS, Ph.D.
EXECUTIVE DIRECTOR

THE GREATER DALLAS-FORT WORTH METROPLEX

2709 AVENUE E EAST, P. O. BOX 8109, ARLINGTON, TEXAS 76011 (817) 261-4981



FORMERLY THE NATIONAL ASSOCIATION FOR RETARDED CHILDREN

Mr. Bill McEntire

Governor Jimmy Carter
August 13, 1974
Page -2-

Paul
File

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Cordially,

Philip Roos
Philip Roos, Ph.D.
Executive Director

WRM
PR:mp

Enclosures

cc: Mr. Marion P. Smith
Dr. Jack Blackstone
Mr. John Bowling
Mr. Bill McCahill
Dr. Brian McCann
Mr. Kermit Harrington

RECEIVED AUG 15 1974

MENTAL RETARDATION RESEARCH

PROBLEM

The President's Committee on Mental Retardation announced three years ago that enough was known about the causes of mental retardation that the incidence of mental retardation could be reduced by one-half by using techniques available at that time. There are a variety of research and prevention programs funded and operated by the Federal Government to meet the goal of reducing the occurrence of mental retardation. In the area of research most of the funds and programs are housed in the National Institute for Child Health and Human Development in the National Institute of Health. One of the major roles of the Institute is to fund the existing twelve mental retardation research centers located throughout the country. In addition, the Institute funds programs, project grants and regular research grants and carries out other activities related to research in mental retardation. A tremendous investment was made about five years ago when these twelve mental retardation centers were built. Since that time, however, there has been little or no increase in the funds available to these centers and others interested in research work to carry out their planned activities. In the area of prevention the major programs in the mental retardation area include the Maternal and Child Health program and the Lead-based Paint Prevention program. Neither of these programs have grown substantially in recent years.

SOLUTION

Appropriations for mental retardation research in the National Institute for Child Health and Human Development must be greatly increased if we are to be able to make any meaningful inroads in the prevention of mental retardation. The same holds true for both the Maternal and Child Health program and the Lead-based Paint Prevention program. Both of these programs need greatly increased appropriations.

EDUCATION FOR THE HANDICAPPED

PROBLEM

Recent statistics issued by the Bureau of Education for the Handicapped in the U.S. Office of Education indicate that approximately 60% of all school age handicapped children are receiving inadequate educational services or no educational services at all. State and local school systems have been unable to meet the needs of these handicapped children due to the highly specialized services necessary that are generally more expensive than education for the so-called "normal" child. Since 1970, there have been a flurry of class action suits in the courts seeking full educational rights for all handicapped children. To date these suits have been successful in the states of Pennsylvania, Maryland, and the District of Columbia. These states are now forced by court order to provide a full educational opportunity for all their handicapped children. Other states have recently passed legislation which mandates that all handicapped children must receive public school education. This new activity has been forced on the states; there has been very little preplanning and the states have had great difficulty in locating the necessary financial resources to carry out these new commitments.

SOLUTION

President Ford has just signed the Elementary and Secondary Education Act of 1974 (ESEA). Title VIB authorizes \$630 million for grants to states for educating handicapped children. This is a substantial increase over the FY 1974 authorization of \$47.5 million. It is critical that appropriations for education for the handicapped be passed at the full authorized level of \$630 million. This influx of new Federal dollars would greatly enhance the ability of the various states to begin implementing full educational opportunities for all children.

In addition to the Education for the Handicapped provisions contained in ESEA, there are currently pending two key pieces of legislation, S. 6 and H.R. 70, which would revolutionize the Federal Government's role in assisting states in funding educational programs for handicapped children. The Congress recognized the need of the passage of this legislation when it provided for only a one-year emergency authorization of Title VIB in the Elementary and Secondary Education Act. This one-year authorization was conceived as a stop-gap measure, pending passage of the more comprehensive S. 6 and H.R. 70. Passage of S. 6 and H.R. 70 is essential in the very near future to assure the states of the continued and expanded role of the Federal Government in the Education for the Handicapped.

SUPPLEMENTAL SECURITY INCOME

PROBLEM

Since the Supplemental Security Income program became effective on January 1, 1974, a great number of problems concerning this program have surfaced. This is particularly true of those segments of the program which deal with disabled individuals. Some of these problems have to do with the relationship between the SSI program and other Federal programs, such as the medicaid program. Other problems result from basic inequities in the SSI law itself. A few specific examples of the problems are:

1. Presumptive Disability

Many mentally retarded individuals who obviously meet the program disability criteria are having to go through a lengthy process to determine their disability before they become eligible for the program. This has led to delays of over six months before individuals actually begin receiving their SSI checks.

2. Definition of Institutions

The whole issue of eligibility of persons residing in institutions is extremely confusing and depends on many factors. Attached is a paper prepared by Dr. Elizabeth Boggs, member of the NARC's Governmental Affairs Committee and Chairman of the National Advisory Committee, which elaborates upon some of these factors.

3. One-third Reduction

Any disabled individual living in the household of another has his SSI payment reduced by one-third in lieu of the cost of room and board. This, at times, is detrimental to maintaining an individual in the community, wherein if he stays at home he loses benefits, and if he is institutionalized he may receive full benefits. There are many other problems surrounding institutions and problems dealing with SSI conflicts with other Federal programs.

SOLUTION

We know of no one quick solution to all these problems and therefore encourage the Congress to make a thorough and immediate review of the entire SSI situation as it relates to the disabled so that all these problems may be surfaced and acted upon expeditiously.

There are more than fifty bills currently pending in the Congress which would eliminate the majority of the above problems and they should be considered as soon as possible.

PROBLEM AREAS FOR THE DISABLED IN SSI - MEDICAID - SOCIAL SERVICES

Social Services should be promoted rather than limited for disabled persons who live at home, in community facilities or in "institutions." In facilities (such as group homes) which are properly not "institutions" (see problem # 1) - and hence not eligible for vendor payments under Title XIX, it should be legitimate to provide and pay for "social services" (counseling, training in activities of daily living, accessing of health care, transportation to other community facilities etc.) whether provided by the group home or by an independent agency. In the case of ICF's, "in reach" from an agency outside the facility should be fundable as a social service, outside the vendor payment. This is particularly important for protective services or advocacy or "ombudsmen."

A planned packaging of income maintenance payments with social service and medicaid can make prescriptive programming for individuals more nearly a reality. Non-medical living arrangements (whether short or long term, "social care" or congregate or "group") should be structured around the basic maintenance plus the service component with "outpatient" medical care as needed. For persons who are not recipients of income maintenance payments, a basic liability for board and lodging (as presumed for assistance payments) could be imposed, with the "service" component payable out of Title VI or IV A for persons who meet an eligibility test based either on a general income formula or on the "3 times SSI" test used for inpatient care under Medicaid.

To make the social services system work without distortion, changes should be made in SSI and Medicaid rules which (1) foster use of appropriate portions of the Life Safety Code (such as the rooming house portion) (2) permit state supplementation to reflect unskilled or non-medical services in congregate (non-medical) facilities (3) reduce discrimination against public facilities (4) narrow the definition of "institution" (5) allow state subsidies for non-medical services in community facilities without reducing SSI (6) protect disregard of earnings of residents in ICF's under Title XIX (7) define Medicaid indigency eligibility for disabled at 3 times SSI for outpatient as well as inpatient care (would be comparable to 133% of SSI plus state supplement).

Definition of an Institution:

Reference is made to Section 248.60 CFR 45 as amended by regulations made final in the Federal Register for January 17, 1974, page 2221. Also Section 233.60.

The definition in Section 248.60 (b) (1) covers four or more unrelated persons receiving any treatment or service beyond food and shelter. This definition is considerably more comprehensive than the popular (and Congressional concept) of "an institution" as evidenced in allusions to "needing institutional care." The term includes, for example, any "family care" or foster care, involving four or more residents, children etc. where any kind of unskilled personal assistance may be rendered; it also includes any group home and other special living arrangement in which some social supervision is provided but which does not take responsibility for the habilitation or treatment activities which may be rendered to the resident outside the home. It is confusing to talk of "deinstitutionalization," when in fact the person is being moved from one kind of an institution to another as defined above.

Contrast the above with the definition of "institution for the mentally retarded or persons with related conditions" in Section 248.60 (b) (10) which included reference to "24 hour supervision, coordination and integration of health or rehabilitative services ..."

The implications of the definition in (b) (1) become apparent when one notes that Congress defined an intermediate care facility as an institution for persons who "because of their physical or mental limitations or both require living accommodations and care which, as a practical matter, can be made available to them only through institutional facilities" and then went on to mandate the standards of safety and sanitation applicable to nursing homes, plus certain full time staffing. Under various amendments currently in effect, it is becoming increasingly difficult to secure either vendor payments or a combination of income maintenance plus either special needs supplements or social services add-ons, as needed, for those kinds of "community facilities" which are being espoused rhetorically, i.e. those which provide some social supervision and/or some assistance with activities of daily living, but which do not take 24 hour program responsibility.

It is recommended that the HEW definition of "institution" be narrowed to cover those facilities which provide either directly or by contract with other agencies the major on-going health or rehabilitative service required by the resident and which accept responsibility for 24 hour supervision.

It is further recommended that several new definitions of "community living arrangements" be developed which would cover the "group home" concept and in which "social supervision" is recognized either as an income maintenance cost (special need - or state supplementation increment) or as a separate social service cost. "Social supervision" should cover help with activities of daily living, parenting, self help skills training etc. in a setting which does not take full responsibility for 24 hour programming. Separate definitions should probably be developed for the following:

group care of children

residential treatment facilities for ambulant children

"group homes" for disabled children and adults.

APPENDIX II

DEFINITIONS OF CERTAIN TERMS USED IN THIS REPORT

Terms Relating to Residents

Age.—Age is defined as age at last birthday.

Resident.—A resident is a person who has been formally admitted to an establishment but not discharged. All such persons were included in the survey whether or not they were physically present at the time.

Classification of Homes by Type of Service

For purposes of stratification of the universe prior to selection of a sample, the homes on the MFI have been classified as nursing care homes, personal care homes with nursing, and personal care homes. The classification scheme for type of service was based on the following four criteria:

1. The number of persons receiving nursing care during the "past 7 days." Nursing care is defined as the provision of one or more of the following services:

Taking of temperature-pulse-respiration or blood pressure

Full bed bath

Application of dressing or bandages

Catheterization

Intravenous injection

Intramuscular injection

Nasal feeding

Irrigation

Bowel and bladder retraining

Hypodermic injection

Oxygen therapy

Enema

2. The presence or absence of nurses on the staff.
3. Whether or not the institution provides administration of medications or supervision over self-administered medications.
4. The number of activities for daily living for which the institution offers assistance. These include provisions of rub and massage, help with tub bath or shower, help with dressing,

correspondence, or shopping; help with walking or getting about; and help with feeding.

The type of service provided by a home might have changed during the 2-year interval between the 1967 MFI survey (used as the basic sampling universe) and the RPS-3. To produce reliable statistics by type of service from the RPS-3, the homes were reclassified by type of service on the basis of the data collected in RPS-3. This classification procedure is essentially the same as the MFI scheme. The three types of service classes delineated for RPS-3 are defined as follows:

Nursing care home.—Home in which 50 percent or more of the residents received nursing care during the week before the survey and in which a registered nurse (RN) or licensed practical nurse (LPN) was employed at least 35 hours or more per week.

Personal care home with nursing.—Home in which either (a) some but less than 50 percent of the residents received nursing care during the week before the survey and at least one full-time RN or LPN was employed or (b) some of the residents received nursing care during the week before the survey, no RN or LPN was employed, and at least one of the following conditions was met:

The institution provided administration of medicine or supervision over self-administered medicines.

The institution provided assistance with three or more activities for daily living.

Personal care home.—Home in which one or more of the following criteria were met: (a) some of the residents received nursing care during the week before the survey, no full-time RN or LPN was employed, the institution did not provide administration of medicine or supervision over self-administered medicines, and the institution provided assistance with one or two activities for daily living; or (b) none of the residents received nursing care during the week before the survey, at least one full-time RN or LPN was employed, and at least one of the following conditions was met:

Table IV. Classification of institutions by type of service

Classification variables	Classification criteria													
	50 percent or more					Some but less than 50 percent				None				
Percent of total residents who received nursing care during the week prior to day of survey														
Number of registered or licensed practical nurses	1+	None				1+	None			0+				
Does the institution provide: (a) Administration of medicine or treatments according to doctor's orders or (b) Supervision over self-administered medicine?	...	Yes	No			...	Yes	No		Yes	No			
Does the institution offer assistance with three activities or more for daily living?	Yes	No		Yes	No		...	Yes	No	
Does the institution offer assistance with one or two activities for daily living?	Yes	No	Yes	No	Yes	No
Does the institution offer room and/or board as its only service?	Yes	Yes	Yes
Institution ¹	Nc	Pcn	Pcn	Pc	D	Pcn	Pcn	Pcn	Pc	D	Pc	Pc	D	B

¹Nc=Nursing care home
Pcn=Personal care with nursing home
Pc=Personal care home
D=Domestic care home (out of scope)
B=Boarding or rooming house (out of scope)

The institution provided administration of medicine or supervision over self-administered medicines.

The institution provided assistance with three or more activities for daily living.

Institutions which provided assistance with one or two activities for daily living or offered room and board as the only service were classified as out of scope of the RPS-3. Table IV shows in detail the scheme for classifying institutions according to type of service.

From CHRONIC CONDITIONS AND IMPAIRMENTS OF NURSING HOME RESIDENTS: United States 1969
DHEW Publication No. (HRA) 74-1707

U.S. DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE
Public Health Service

Health Resources Administration
National Center for Health Statistics
Rockville, Md. December 1973

Data from the NATIONAL HEALTH SURVEY

Series 12
Number 22

Over Definition of "health and remedial care"

Congress is legitimately concerned that elderly and infirm persons not be housed in institutions which do not meet appropriate life safety codes. Unfortunately, this has resulted in overkill.

It is important to recognize that:

- 1) Not everyone who may need "intermediate care" requires the same level of fire safety as is called for in nursing homes for the infirm. This fact has been recognized by the exceptions to the institutional life safety code authorized in respect to facilities housing 15 or less retarded persons, alcoholics or drug abusers who are capable of self preservation under the intermediate care standards. (Section 249.12 (a) (5) (i))
- 2) Most persons who are developmentally disabled and do not need "institutional care" do not need the "institutional life safety code" either.
- 3) It should be possible to protect persons in community facilities or "special living arrangements" which are "home like" or normalized, by invoking the Lodging or Rooming House sections of the residential occupancy requirements of the Code.
- 4) Not everyone who needs some "service" beyond board and lodging (e.g. some help with activities of daily living) needs the full panoply of service properly included in the new intermediate care standards.
- 5) There are levels of personal care or domiciliary or congregate care which are legitimate for some persons and which it should be possible for those persons to purchase with their SSI plus state supplemental dollars without loss of SSI. This was in fact recognized in July of 1973 by Secretarial agreements that the states could specify up to five levels of payments (supplemental) based on "living arrangements", to include congregate care.
- 6) The final regulations issued November 29, 1974, to implement Section 249 D of P.L. 92-603, went counter to this recognition because it defined "medical or remedial care" as "any care or service beyond room and board" provided because of the residents physical or mental condition. (Section 233.145 (c) (2) (i)) This provision is no longer directly applicable other than in Puerto Rico, etc., but the regulation is considered to set a precedent for regulations yet to be issued to interpret

Section 14 of P.L. 93-233. These new regulations must be issued by SSA rather than APA. There is a need to get a policy change on this so that facilities which provide only assistance with activities of daily living to residents who need it, or only social supervision, are not required to gear up to full ICF status to the disadvantage of residents and the taxpayer alike.

A suggested amendment to Section 1616 (e) is attached. If the same end could be achieved by regulation, it would suffice.

(1) payments made or to be made during such fiscal year from such Trust Fund under part A of title XVIII of such Act with respect to individuals who are qualified railroad retirement beneficiaries (as defined in section 226(c) of such Act) and who are not, and upon filing application for monthly insurance benefits under section 202 of such Act would not be, entitled to such benefits if service as an employee (as defined in the Railroad Retirement Act of 1937) after December 31, 1936, had been included in the term "employment" as defined in the Social Security Act,

(2) the additional administrative expenses resulting or expected to result therefrom, and

(3) any loss of interest to such Trust Fund resulting from the payment of such amounts.

in order to place such Trust Fund in the same position at the end of such fiscal year in which it would have been if the individuals described in paragraph (1) had not been entitled to benefits under part A of title XVIII of the Social Security Act.

(c) (1) The amendments made by the preceding provisions of this section shall apply to the calendar year 1966 or to any subsequent calendar year, but only if the requirement in paragraph (2) has been met with respect to such calendar year.

(2) The requirement referred to in paragraph (1) shall be deemed to have been met with respect to any calendar year if, as of the October 1 immediately preceding such calendar year, the Railroad Retirement Tax Act provides that the maximum amount of monthly compensation taxable under such Act during all months of such calendar year will be an amount equal to one-twelfth of the maximum wages which the Federal Insurance Contributions Act provides may be counted for such calendar year.

Sec. 121. * * *

(b) No payment may be made to any State under title I, IV, X, XIV, or XVI of the Social Security Act with respect to aid or assistance in the form of medical or any other type of remedial care for any period for which such State receives payments under title XIX of such Act, or for any period after December 31, 1969. After the date of enactment of the Social Security Amendments of 1972, Federal matching shall not be available for any portion of any payment by any State under title I, X, XIV, or XVI, or part A of title IV, of the Social Security Act for or on account of any medical or any other type of remedial care provided by an institution to any individual as an inpatient thereof, in the case of any State which has a plan approved under title XIX of such Act, if such care is (or could be) provided under a State plan approved under title XIX of such Act by an institution certified under such title XIX.¹

Evaluation and Report

Sec. 206. The Secretary shall submit to the President for transmission to the Congress before July 1, 1969, a full report of the administration of the provisions of section 532 of the Social Security Act (as added by section 205 of this Act), together with an evaluation of the

¹ P.L. 92-603, sec. 210D, added the last sentence of section 121. The Social Security Amendments of 1972 were enacted October 30, 1972.

* compare with Section 14 of P.L. 93-233 which added Section 1616

program establishment of and modification of

**Part 4—Miscellaneous
Health Study**

Sec. 231. (a) is authorized, under the Mental Health Act, pediatrics and other program of research facilities for diagnosis of treating, curative illnesses.

(b) Such grants only on condition or if more than one condition that shall undertake and conduct study of all aspects to in subsection (c)

(c) As used in nongovernmental representatives of other professional field of mental health

(d) There are ending June 30, grants to help in section; and the making of such study to complete the research and from the date reports with the several States, a final report shall

Sec. 301. * * *

(e) If an individual section 223 of the of an application old-age insurance Act (if applicable in such section column on the amount of the amount

Section 233.145 of Part 233, Chapter II, Title 45 of the Code of Federal Regulations is amended to add paragraph (c) as follows:

§ 233.145 Expiration of medical assistance programs under titles I, IV-A, X, XIV, and XVI of the Social Security Act.

(c) (1) Under the provisions of section 249D of Public Law 92-603, enacted October 30, 1972, Federal matching is not available for any portion of any payment

by any State under titles I, IV-A, X, XIV, or XVI of the Social Security Act for or on account of any medical or any other type of remedial care provided by an institution to any individual as an inpatient thereof, in the case of any State which has a plan approved under title XIX of such Act, if such care is (or could be) provided, under a State plan approved under title XIX of such Act, by an institution certified under such title XIX. The effective date of this proposed provision will be the date of publication of the final regulation in the FEDERAL REGISTER.

(2) For purposes of this paragraph.

(i) An institution (see § 233.60(b)(1) of this chapter) is considered to provide medical or remedial care if it provides any care or service beyond room and board because of the physical or mental condition (or both) of its inpatients;

(ii) An inpatient is an individual who is living in an institution which provides medical or remedial care and who is receiving care or service beyond room and board because of his physical or mental condition (or both).

(iii) Federal financial participation is not available for any portion of the payment for care of an inpatient. It is immaterial whether such payment is made as a vendor payment or as a money payment or other cash assistance payment. It is also immaterial whether the payment is divided into components, such as separate amounts or payments for room and board, and for care or services beyond room and board, or whether the payment is considered to meet "basic" needs or "special" needs. If, however, a money payment (or protective payment) is made to an individual who is living in an institution, and such payment does not exceed a reasonable rate for room, board and laundry for individuals not living in their own homes, and no additional payment is made for such individual's care in the institution, Federal financial participation is available in the money payment (or protective payment) since the individual may spend the funds at his discretion and obtain room and board at the place of his choice.

SUGGESTED TECHNICAL AMENDMENTS TO THE SOCIAL SECURITY ACT

Section 1616 (e)

Add:

"Such payments shall not be reduced with respect to an individual who is ambulatory or mobile non-ambulatory who is appropriately placed in an institution which provides only social supervision, or help with activities of daily living or occasional or incidental medical or remedial care, or some combination thereof, if the institution (or distinct party thereof) has 15 beds or less, has only residents certified by a physician as not in need of regular nursing services, and meets the Lodging or Rooming Houses section of the residential occupancy requirements of the Life Safety Code of the National Fire Protection Association (23rd edition, 1973 or equivalent).

Section 1861 (j) (13)

Change: "21st edition, 1967 'to read'-- 23rd edition, 1973"

REASON: The intention of Congress to preclude public assistance payments supporting persons in substandard institutions has given rise to language which is inadvertently working at cross purposes to "deinstitutionalization." The excessively broad HEW definition of "medical or remedial care" in CFR 45 para. 233.145 is preventing SSI from reaching legitimate recipients in group homes and like facilities.



January 11, 1974

MEDICAL SERVICES
ADMINISTRATION

Our Reference - SRS-MSA-P&S

POLICY INFORMATION MEMO NO. 74-9

FOR MSA ASSOCIATE REGIONAL COMMISSIONERS

SUBJECT: Interpretation of P.L. 92-603, Section 249D, Limitation on Institutional Care (45 CFR 233.145)

Questions have been raised regarding 1.) the relevance of Sec. 249D since January 1, 1974, when the adult cash assistance programs were replaced by SSI, and 2.) the types of institutions which are affected.

1.) Public Law 93-233, signed by the President on December 31, 1973, contains a provision (Sec. 14) which would reduce the SSI payment dollar for dollar for any State supplementary payment or vendor payment made for care in an institution which could be financed under title XIX if the institution met Medicaid standards. This in effect extends Sec. 249D so that it is enforceable after the adult cash assistance programs have been replaced by the Federal SSI program.

2.) Only those institutions which provide care which is, or could be, included under title XIX are affected. Social care institutions, such as child care facilities, are not affected, since their primary purpose is not to provide medical or remedial care, but to provide social care. The same is true of maternity homes where, customarily, prenatal, delivery and postnatal care are provided outside the facility. The fact that a social care institution might have a nurse on its staff to attend to minor medical problems or emergencies would not alter the essential character of the institution.

With regard to personal care homes, it is not possible to make a categorical statement since the term covers a wide variety of facilities. Those homes which accept only those recipients who neither need nor receive health-related services of any sort are not affected by 249D. However, in cases where the facility is found to be providing care which in general resembles or is similar to that provided under Medicaid, the restrictions of Sec. 249D hold.

Discrimination against Public Institutions which are not "Medical"

Persons in public facilities which are either "medical" or "intermediate care facilities" are eligible for vendor payments under Title XIX if the State includes all such options in its state plan. However, persons in public institutions which do not meet these requirements are ineligible for SSI etc. Redefining "institutions" would make it possible to use SSI plus state supplementation in publically sponsored "community facilities" which are not "institutions." This would permit supervised group living or public housing as well as state and local government sponsored group homes, as part of the public-private continuum. However, it would be timely to make a more fundamental reform which is long overdue as a matter of social policy: recognize comparable institutions and facilities whether under public or private auspices, according to the same definitions and standards. Failure to do this results in distortions of the system by which states move eligible persons from public to private facilities according to criteria of cost rather than client benefit, or in which states rent or sell their facilities to private corporations or agencies, thus losing some measure of control over the direction in which resources will develop.

Failure to protect for maintenance under Medicaid.

Section 1109 of the Social Security Act requires that any amount disregarded for one individual under any state plan for assistance or medicaid shall not be taken into account for any other individual. It was assumed that any amount disregarded for income maintenance purposes would also be disregarded for medicaid purposes for the same individual. With the enactment of SSI, however, states are being allowed to completely disallow for medicaid purposes the earned income disregards for the disabled which are part of SSI. Thus persons in intermediate care facilities who are engaging in trial work or sheltered work activities are not allowed to retain any of their pay which would increase their disposable income beyond the \$25 which a non-working beneficiary receives under SSI as spending money. This is proving a deterrent to employment by such disabled persons.

In a recent policy statement by the AAMD it is recognized that a person who is in a residential facility has an obligation to make some contribution to his board costs if he is earning, either by work in the institution or on the outside. However, the AAMD guidelines recommend that the amount recovered for maintenance should not exceed 75% of the earned income (plus any unearned income subject to the reservation of SSI spending money).

Because there may be an earnings disregard of up to about \$112 a month (assuming earnings under \$140 which is the disability test), it is clear that a complete disregard where the person is being provided with board and lodging would be unreasonable. However, no differential between worker and non-worker appears equally inequitable, and is certainly counterproductive. Coordination is also indicated with the standards now being written by the Labor Department Wages and Hours division to implement the court decision in Souder v. Brennan.

It is suggested that where an individual in an ICF has prospects of moving to a less restrictive alternative, policies should encourage the accumulation of earned income up to the resources limit under SSI (\$1500). There is really no reason why this policy cannot be implemented for all working residents.

- (1) for payment to Puerto Rico shall not exceed \$50,000,000,¹
 (2) for payment to the Virgin Islands shall not exceed \$1,000,000,¹
 and
 (3) for payment to Guam shall not exceed \$900,000.

(d) Notwithstanding the provisions of section 502(a) and 512(a) of this Act, and the provisions of sections 421, 503(1), and 504(1) of this Act as amended by the Social Security Amendments of 1957, and until such time as the Congress may by appropriation or other law otherwise provide, the Secretary shall, in lieu of the initial allotment specified in such sections, allot such smaller amounts to Guam, American Samoa, and the Trust Territory of the Pacific Islands as he may deem appropriate.

Amounts Disregarded Not To Be Taken Into Account in Determining Eligibility of Other Individuals

Sec. 1109. Any amount which is disregarded (or set aside for future needs) in determining the eligibility of and amount of the aid or assistance for any individual under a State plan approved under title I, X, XIV, XVI, or XIX, or part A of title IV, shall not be taken into consideration in determining the eligibility of and amount of aid or assistance for any other individual under a State plan approved under any other of such titles.

Cooperative Research or Demonstration Projects

Sec. 1110. (a) There are hereby authorized to be appropriated for the fiscal year ending June 30, 1957, \$5,000,000 and for each fiscal year thereafter such sums as the Congress may determine for (1) making grants to States and public and other nonprofit organizations and agencies for payment part of the cost of research or demonstration projects such as those relating to the prevention and reduction of dependency, or which will aid in effecting coordination of planning between private and public welfare agencies or which will help improve the administration and effectiveness of programs carried on or assisted under the Social Security Act and programs related thereto, and (2) making contracts or jointly financed cooperative arrangements with States and public and other organizations and agencies for the conduct of research or demonstration projects relating to such matters.

(b) No contract or jointly financed cooperative arrangement shall be entered into, and no grant shall be made, under subsection (a), until the Secretary obtains the advice and recommendations of specialists who are competent to evaluate the proposed project as to soundness of their design, the possibilities of securing productive results, the adequacy of resources to conduct the proposed research or demonstrations, and their relationship to other similar research or demonstrations already completed or in process.

(c) Grants and payments under contracts or cooperative arrangements under subsection (a) may be made either in advance or by way of reimbursement, as may be determined by the Secretary; and shall be made in such installments and on such conditions as the Secretary finds necessary to carry out the purposes of this section.

Public Assistance Payments to Legal Representatives

Sec. 1111. For purposes of title I, X, XIV, and XVI, and Part A of title IV, payments on behalf of an individual, made to another person who has been judicially appointed, under the law of the State in which such individual resides, as legal representative of such individual for the purpose of receiving and managing such payments (whether or not he is such individual's legal representative for other purposes), shall be regarded as money payments to such individual.

Medical Care Guides and Reports for Public Assistance and Medical Assistance

Sec. 1112. In order to assist the States to extend the scope and content, and improve the quality, of medical care and medical services for which payments are made to or on behalf of needy and low-income individuals under this Act and in order to promote better public understanding about medical care and medical assistance for needy and low-income individuals, the Secretary shall develop and revise from time to time guides or recommended standards as to the level, content, and quality of medical care and medical services for the use of the States in evaluating and improving their public assistance medical care programs and their programs of medical assistance; shall secure periodic reports from the States on items included in, and the quantity of, medical care and medical services for which expenditures under such programs are made; and shall from time to time publish data secured from these reports and other information necessary to carry out the purposes of this section.

Assistance for United States Citizens Returned From Foreign Countries

Sec. 1113. (a) (1) The Secretary is authorized to provide temporary assistance to citizens of the United States and to dependents of citizens of the United States, if they (A) are identified by the Department of State as having returned, or been brought, from a foreign country to the United States because of the destitution of the citizen of the United States or the illness of such citizen or any of his dependents or because of war, threat of war, invasion, or similar crisis, and (B) are without available resources.

(2) Except in such cases or classes of cases as are set forth in regulations of the Secretary, provision shall be made for reimbursement to the United States by the recipients of the temporary assistance to cover the cost thereof.

(3) The Secretary may provide assistance under paragraph (1)

¹P.L. 82-603, sec. 271(a), inserted "\$30,000,000" in lieu of "\$20,000,000". Applicable to fiscal years beginning after June 30, 1971.

State subsidies not routed through SSI Supplementation

Section 1612 (b) (of the Social Security Act) defines excludable income for SSI recipients. Section 416.1109 describes medical and social services as excludable, when furnished by a "third party" payor or a public or private agency. However, state subsidies to private agencies, whether as grants or purchase of service payments, are being counted as income to the residents of group homes and other facilities in those states where such facilities have been fostered by public policy and where such subsidies have been made available to supplement the basic medicaid or public assistance grant. The issue arises both in "institutional" (i.e. intermediate care) and "congregate care" or "special living arrangement" settings. Carried to its logical conclusion it could render moot all charitable or United Fund contributions to such agencies.

Section 1612 (b) (6) applies to "assistance based on need ... provided by a state or political subdivision." There should be provision for excluding value of contributions or public subsidies which are equally applicable to all residents, i.e. universal benefits.

Related to the above is a need to clarify the use of Title VI funds to pay for social services provided in a group home or in an ICF which are not appropriately covered by the SSI plus state supplement or by the Title XIX vendor payment. In the former case such social services may be rendered by staff of the facility. In the latter it may appropriately be rendered by "in reach" agencies which supplement the services provided by the facility itself. Examples of the latter would be protective ombudsman services, legal services, adult education, etc. The ICF regulations already presuppose that rehabilitation and education services will be provided outside the vendor payment, why not social services to the extent they are not an integral part of the resident or "in-patient" package?

"Notch" in definition of medical indigency for SSI recipients

The idea of medical indigency is to cover for medical costs those persons above the assistance level whose income is nevertheless sufficiently low to make them vulnerable to extra expenses such as those for medical care. This is approached in two ways:

(1) making eligible those whose income exceeds the cash assistance level but does not exceed some higher specified level.

(2) taking account of "spend down" effects - i.e. covering an individual or family when their medical expenses leave them with a net which comes within the assistance range (or the medically indigent range).

In enacting the SSI program the Congress and administration sought to establish minimum maintenance levels for aged, blind, and disabled persons which were not only nearer to a "decent" minimum standard of living than had previously been achieved but also took some account of the likely special needs and unusual costs of persons who are less likely to be able to use all the economies which a fully vigorous younger person can seek. Thus levels have been established which in general exceed the levels for two persons under AFDC or the level to which AFDC might be extrapolated for one person. However, under Section 1903 (f) (1) (B) (i) states may not set the upper limit of medical indigency at a level more than 133 1/3% above the AFDC payment level. This limit applies to aged, blind and disabled individuals and couples as well.

Tying the SSI group to AFDC defeats one of the objectives of SSI - to achieve more nearly equitable levels throughout the country. It also produces notches in that it is quite possible for a disabled person who has income from social security which exceeds SSI to lose his medicaid eligibility even though his income level is comparable to another such person whose income includes some SSI.

Although it is politically impossible to mandate that states at least make their SSI eligibles also medicaid eligible, it is politically quite feasible to provide states with the option to include among their medically indigent population those whose incomes exceed the SSI levels by a specified percentage. However, the law would have to be amended to permit the tying of medical indigency for the aged, blind, and disabled to the SSI levels. One suggested solution is attached.

Another suggested solution would be to set the limit at a gross income of three times federal SSI levels, as was recently done for inpatient care of aged, blind, and disabled. (P.L. 93-233)

Representative Payees

The Social Security Administration has had long experience with representative payee selection and supervision under social security. This problem is becoming more acute with the addition of the SSI caseload, for several reasons in addition to sheer numbers.

1. The SSI population is, by definition, poor and hence even more vulnerable than the Social Security beneficiary group.
2. When the SSI recipient is institutionalized he loses all SSI except \$25 per month spending money; hence he does not bring income to the institution through this route. An SSA beneficiary, by contrast, usually brings some additional funding, particularly to a public institution. Administrators of facilities are now claiming that the costs of administering the spending money for patients cannot be absorbed by them; this has led to consideration of the possibility of paying payees.

Paying providers to administer the personal spending money of residents or patients in residential facilities raises issues of conflict of interest. Moreover, experience under SSA with representative payments in institutions does not generally inspire confidence in that system.

We would prefer to see citizen advocates recruited for this responsibility both as to community placed and institutionalized beneficiaries. It is quite possible that the services of the advocates themselves would be contributed. However, there are costs associated with the recruitment, selection, and orientation advocates to act as payees which would have to be covered.

The following passage from a memo from the Commissioner of SSA to the Assistant Secretary for Human Development is encouraging and should be pursued.

"The problem of obtaining adequate payees for social security beneficiaries, particularly old-age recipients, has been a vexing one for some time. When there is no interested relative or other interested party, the search for a payee is sometimes difficult and arduous. Also, in many cases, payees not closely related to the beneficiary manifest little or no interest in the beneficiaries. One alternative under consideration is a legislative proposal to authorize the purchase of payee services.

"Such a provision would enable the Social Security Administration to purchase representative payee services from community or social organizations when other payees cannot be located. Development of the specifications for such a proposal has been slowed because of the lack of information which could serve as a basis for developing a legislative proposal (e.g., cost, number affected, and amount of payee fee). The possibility of a pilot study to obtain this information is now being explored."

TEHCNICAL AMENDMENT TO SOCIAL SECURITY ACT

Section 1903 (f) (3)

add

" For purposes of paragraph (1)(B) , in the case of an individual, or individual and eligible spouse or essential person, who is receiving supplemental security income or a state supplemental payment (other than as an inpatient in a medical institution receiving reimbursement under Title XIX) the "highest amount which would ordinarily be paid " shall be the amount of supplemental security income plus any state supplementary payment under section 1616 which would be payable to a similarly situated individual, or individual and spouse or essential person, without any income and resources "

REASON: Clause 1903 (f)(1)(B)(i) ties the standard for medical indigency of the aged blind and disabled to the State's AFDC payment levels. The effect of this is to set "medical indigency" below SSI payment levels in some instances. In particular this means that disabled and aged individuals who have social security benefits slightly in excess of SSI levels may be excluded from medicaid, even though similar persons with similar incomes part of which is derived from SSI may be medicaid eligible. The State is prevented by federal rule (as presently interpreted) from correcting such inequity.

HOUSING

PROBLEM

The concept of "de-institutionalization," which has now gained nearly universal acceptance and which has been formally embraced by the Federal government, places an increasing burden on community services and programs. The Federal government has pledged itself to decrease by one-third the number of persons living in institutions for the mentally retarded but considerably less attention has been focused on translating this goal into reality. If people are not to be simply "dumped" into an unprepared community, housing specially designed to meet their needs must be developed now. The need is several-fold: firstly, for financing of bricks and mortar homes and apartments and other congregate living arrangements; secondly, for architectural designs which are accessible for persons with handicaps; and thirdly, for community planning capacities to assure that the network of homes and residences are close to needed work, educational and recreational facilities.

SOLUTION

The Senate and House have recently completed work on the Housing and Community Development Act of 1974, which would provide several different sources of planning and development monies for housing for mentally retarded persons -- the most promising of these sources appear to be a revised section 23. If the President signs the bill, the initiative for making the section 23 program an operating entity will fall to the Appropriations Committee, which should appropriate the full authorization under this section as well as under the community development sections of the bill.

RECEIVED AUG 14 1974

UNITED STATES GOVERNMENT

DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE

SOCIAL AND REHABILITATION SERVICE
Rehabilitation Services Administration

Memorandum

*Paul
S...*

NUMBER 11

TO : Administrators and Professional Staffs, DD

DATE: August 1, 1974

FROM : Division of Developmental Disabilities *MR*

SUBJECT: For Your Information

RESOLUTION CLARIFYING THE TERM "DEINSTITUTIONALIZATION"

In response to requests from State Councils and others to clarify what is meant by the term "deinstitutionalization" in the context of HEW objectives of the Developmental Disabilities field, the National Advisory Council at its meeting on June 11, 1974, adopted the following statement:

"Deinstitutionalization" is a federally coined term used to characterize one of the Mental Retardation goals expressed by President Nixon in November of 1971. The goal was to reduce by one-third, nationally, the census of the State MR institutions. This was the estimate of the number of residents who were inappropriately placed there.

The principle of deinstitutionalization is considered to apply to all developmentally disabled persons who might require long-term care.

The National Advisory Council and the Division of Developmental Disabilities take the position that effective deinstitutionalization requires a simultaneous development of community alternatives as well as institutional reform.

Deinstitutionalization *encompasses three interrelated processes: (1) prevention of admission by finding and developing alternative community methods of care and training; (2) return to the community of all residents who can be prepared through programs of habilitation and training to function adequately in appropriate local settings; and (3) establishment and maintenance of a responsive residential environment which protects human and civil rights and which contributes to the expeditious return of the individual to community living which is as nearly normal as possible. The success of deinstitutionalization is dependent upon the availability of an array of quality community programs and services.



RESOLUTION CLARIFYING THE TERM "DEINSTITUTIONALIZATION" - continued

Community alternatives have sometimes been construed to mean only community-based residential programs. This is incomplete. Community alternatives must be responsive to the full range of needs of families to prevent crisis, and to deal with crisis. Examples include public education, education of professionals who advise placement, a variety of kinds of respite care, family training in habilitation skills, and effective counseling.

Institutional reform *involves a modification or improvement in attitudes, philosophies, policies, effective utilization of all available resources, and increased financing to provide adequate programs to motivate and assist individuals to reach their maximum level of functioning in the least restrictive environment possible. Institutional reform will occur only through an increased effort on the part of all professional, nonprofessional, and lay persons concerned with the developmentally disabled.

*These elaborations are adapted from "Position Statement by the National Association of Superintendents of Public Residential Facilities for the Mentally Retarded," May 1974, published by President's Committee on Mental Retardation.

* * * * *

COMPREHENSIVE EMPLOYMENT AND TRAINING ACT OF 1973 (P.L. 93-203)

PROBLEM

This Act has worked reasonably well in providing training opportunities for mentally retarded citizens through the Manpower Revenue Sharing arrangements with prime contractors. The "problem" has been the absence of a definition of "mentally retarded persons" as a category to be served, leading some jurisdictions to assume that in the absence of specific mention, the retarded are excluded. Just this week we had such a query from Oregon. If poor and retarded workers aren't "disadvantaged" under this Act, then nobody is.

SOLUTION

A solution would be to amend the Act so that the mentally retarded are included among categorical listings of clients to be served. In addition, as new Special Revenue Sharing legislation is authorized, the mentally retarded as a group to be served should be so identified, if not in the actual Act, then in the Committee Report which indicates the will of the Congress sometimes better than the legal jargon of some legislation.

In addition, the sums available to the U.S. Department of Labor for special national programs could and should be increased to make possible additional programs such as the present NARC OJT Project with the Labor Department which is training retarded men and women more efficiently and at much less cost than many other special programs, but the cutback in national funds prohibits expansion of the program and maintaining the momentum of earlier grants in this special area.

NATIONAL HEALTH INSURANCE

PROBLEM

Securing adequate health insurance protection for mentally retarded citizens has been and remains a very serious problem with which the National Association for Retarded Citizens has long been concerned. All too often, the six million retarded persons in the United States are unable to obtain coverage because private insurers categorically exclude persons with certain conditions, diagnoses or genetic disorders. Such practices discriminate against those most severely at risk of incurring costly medical and health-related expenditures.

Where coverage is available, it often fails to adequately protect against the catastrophic consequences of chronic disability. As a result, persons suffering from serious disability are today left with crushing burdens after the benefits of the system have been exhausted. In the case of chronic impairments which originate early in life, such as mental retardation, the cumulative financial effect on the individual and his family are devastating.

The catastrophic consequences of mental retardation more often than not take the form of the need for long-term institutional care, typically in an institution for the mentally retarded classified as an intermediate care facility (ICF). ICF services are currently available as an optional item of service under the Medicaid program. However, this program affects only persons who live in states which have opted to cover ICF care and whose family income falls below a state-established minimum, and who, in addition, meet certain categorical requirements (membership in a one-parent family, for example). The population which remains ineligible includes persons who are poor but from intact families, persons with incomes bordering the poverty line, and persons from middle-class families which may be forced to financial dependency as a consequence of supporting a family member in an institution.

SOLUTION

We believe that a well-designed national health insurance program could successfully address all of the issues identified above. In order to do so, the insurance plan must have the following features:

- universal coverage, including all mentally retarded citizens;
- benefits for long-term institutional care, including intermediate care facilities, with no length of stay limitations;

- universally required protection against the catastrophic financial consequences of medical, rehabilitative, and health-related expenses with the government financing the cost of premiums for low income persons and families, and with a \$1,000 maximum annual per person limit on liability;
- reform of the Medicaid program to mandate coverage of ICF care and to eliminate categorical eligibility requirements.

I have attached a copy of NARC's testimony on national health insurance before the Ways and Means Committee, which will provide greater detail on the points made above.

TESTIMONY
ON
NATIONAL HEALTH INSURANCE

Respectfully Submitted to:
THE COMMITTEE ON WAYS AND MEANS
OF THE
U. S. HOUSE OF REPRESENTATIVES

Presented by:
THE NATIONAL ASSOCIATION FOR RETARDED CITIZENS

Witness:
Dr. Elizabeth Boggs
Governmental Affairs Committee
Friday, June 14, 1974

Mr. Chairman:

It is a great pleasure to appear before you and the members of your Committee. The National Association for Retarded Citizens welcomes these hearings and the serious consideration being given by the Committee to the enactment of national health insurance this year. Securing adequate health insurance protection for mentally retarded citizens has been and remains a very serious problem with which this Association is deeply involved. All too often, the six million mentally retarded persons in the United States are unable to obtain coverage because of the categorical exclusion by private insurers of certain conditions and diagnoses. We believe the time has long come to end these practices, which discriminate against those most severely at risk.

We firmly maintain that mentally retarded persons should obtain health care through normal channels available to all citizens, such as health insurance. This health insurance coverage must be tailored to meet the general health needs of mentally retarded persons as well as diagnostic and medical treatment needs specific to the condition of mental retardation.

COVERAGE

We recommend a national health insurance program with universal coverage, including all mentally retarded citizens. In this connection, we have some concern with a system where an individual's eligibility is determined by his work status or his membership in a particular population. The greatest caution must be exercised

to assure continuity of coverage when a person moves from one group to another. For example, an adult disabled child who moves out of the parental home or a mentally retarded person who changes his sheltered workshop employment status must be protected by an automatic mechanism which prevents lapses in coverage.

BENEFIT STRUCTURE

The National Association for Retarded Citizens recommends that a comprehensive benefits package be enacted, as detailed in this statement for the record. None of the bills before you provide the scope of benefits which we believe are essential for mentally retarded persons. The benefits we have proposed in this statement would assure coverage for general medical and health-related care as well as specialized services which are necessitated by the condition of mental retardation and where liability for such care would otherwise be vested in the individual or his family.

Preventive Services:

The National Association for Retarded Citizens places very great emphasis on preventive services. It is estimated that the prevalence of mental retardation in our country could be reduced by one-half if American citizens only availed themselves of existing preventive technologies and services. In November of 1971, President Nixon pledged his personal commitment to halving the incidence of mental retardation by the close of the century. In doing so, the President noted that this is a realistic goal well within the reach of our society.

Genetic counseling for families at risk, family planning, prenatal and postnatal care, and comprehensive early childhood diagnosis and intervention must be covered under national health insurance. These services are of critical importance in reducing mental retardation caused by prematurity and other factors.

In addition, we believe that a number of critical preventive services should be made more widely available through the public health service delivery system. Immunizations against measles and rubella, screening for carriers of Tay-Sachs disease and other genetically transmitted conditions which contribute to mental retardation, and testing for lead and heavy metals and the presence of other environmental toxins are all examples of procedures which may be more cost-effectively performed through such delivery systems. In addition to the reduced expenditures associated with mass delivery of services, the public health system is more effectively equipped to perform the outreach and health education functions which are such a necessary concomitant to preventive care.

Clinics and projects funded under the Maternal and Child Health programs authorized in the Title V of the Social Security Act currently provide a limited number of these services to an even more limited section of our national population. In many ways, their most valuable contribution has been the demonstration that such services are indeed effective in alleviating an adverse rate of prematurity, infant mortality and morbidity. In addition, they have performed an outstanding service in organizing and coordinating the necessary professional resources in one setting. If we are to

develop the capacity to insure the availability of preventive care, adequate insurance coverage is only a first, though indispensable step. We see a new role for the Title V formula grant program in assuring a more planful distribution of resources through which these preventive services can be available. We strongly urge the Committee to expand the current Title V program to provide start-up support and perhaps an on-going subsidy for a truly national network of preventive care resources.

Long-Term Care

We are pleased to note that H.R. 13870, the bill introduced by Chairman Mills, addresses at least partially the critical issue of long term care for disabled citizens. It is of vital importance that long term care - one of the most devastating financial responsibilities which a family can experience - be covered under national health insurance. We are fully cognizant of the fiscal implications of such a move, but must nevertheless insist on the urgent need to provide some protection to families at economic risk. As an interim measure, we recommend that long-term care (both residential and non-residential) for children under age 22 be included in the basic benefit package, since the period of eligibility for insurance coverage in this instance will perforce be limited to the attainment of their majority.

COST-SHARING

Cost-sharing is increasingly regarded as an effective lever for inducing more appropriate patterns of utilization of health services. The National Association for Retarded Citizens, however,

is not convinced that the case for cost-sharing has been satisfactorily made. It is not at all clear that cost-sharing is as influential a factor in beneficiary decision-making as its boosters proclaim. In addition, we are very concerned that the maximum annual liability for all forms of cost-sharing - premiums, deductibles, and co-payments - be set at a level which will not prove so restrictive that access to necessary care is prevented or discouraged.

In addition, we believe that it is disastrous to establish any cost-sharing for preventive services. In the case of preventive services, incentives for securing increased utilization must be sought. It is estimated that one-half of all mental retardation is preventable; the health and social costs averted through such prevention is enormous. The cost/benefits of preventive services available under the maternal and infant care program under Title V of the Social Security Act (Maternal and Child Health) have already been demonstrated.

We, therefore, strongly recommend that deductibles and co-payments not be applied to family planning services, genetic counseling, prenatal care, well-child care, and annual physical examinations. It is imperative that the structure of cost-sharing under national health insurance actively encourage public participation in preventive care.

CATASTROPHIC COVERAGE

We believe that protection against the catastrophic consequences of prolonged illness or chronic disability is one of the most pressing issues before this Committee. Private insurers have heretofore

been unwilling to assume the risks associated with catastrophic coverage; as a result, persons suffering from serious illness or disability are today left with crushing burdens after the benefits of the system have been exhausted. In the case of chronic impairments which originate early in life, such as mental retardation, cerebral palsy, epilepsy, and autism, the cumulative financial and social effect on the individual and his family can be devastating. The catastrophic consequences of mental retardation more often than not take the form of the need for long-term care, typically in an institution for the mentally retarded classified as an intermediate care facility. It is absolutely vital that catastrophic coverage for intermediate care facility services be available under national health insurance.

No person or family not already in poverty should find itself forced to financial dependency as a consequence of catastrophic illness or disability. The financial risks associated with prolonged illness or severe chronic disability must be distributed through a social insurance program.

Insurance coverage against catastrophic medical, rehabilitative, and health-related expenses should be universally required, with the government financing the cost of premiums for low-income persons and families. Catastrophic expenditures should be defined as a maximum annual liability, related to income, beyond which necessary medical, rehabilitative, and health-related expenses cannot be met without major alteration in the individual's or family's standard of living.

We suggest a \$1000 annual per person limit on liability or a \$1500 per annum per family limit prior to catastrophic coverage.

PROVISIONS FOR LOW-INCOME PERSONS

We believe that the enactment of national health insurance provides the opportunity for reform of the current financing structure for health care for low-income persons. The inequities of the present Medicaid program are notorious and must be eliminated.

Ideally, health care for low-income persons should be financed through the same insurance program available to other income groups, with the proviso that deductibles, premiums, and co-payments be related inversely to income and eliminated entirely for the lowest income groups, with the government paying this cost directly.

If the Committee follows this course, however, it is critical that the present Medicaid-eligible population be held harmless against any loss in coverage resulting from a national health insurance program with less broad coverage than is currently available under the state plan for medical assistance in the individual's home state.

Reliance on health insurance as the financing mechanism for low-income persons requires that the benefits and coverage under national health insurance be sufficiently comprehensive to assure that no needy person must forego necessary medical, rehabilitative, or health-related care for lack of financial resources.

If the scope of benefits under national health insurance proves inadequate to provide this assurance, the Medicaid program must

be retained but with substantial reforms:

- The income test for eligibility must be standardized throughout the nation;
- Categorical requirements for eligibility must be eliminated;
- Non-income-producing assets and resources should not be considered in determining eligibility; and
- Covered services must be uniform for all states, and must be expanded to cover intermediate care facility services as a mandatory item of service.

Regardless of whether the health needs of low-income persons are met through health insurance alone or through a combination of insurance and Medicaid, the critical functions of case finding, case management, referral resource inventory, transportation, and follow-up services must continue to be available to low-income persons. National health insurance cannot stand alone, but must be buttressed by an organized case management system. Otherwise, substantial numbers of low-income persons will be unable, as a practical matter, to avail themselves of covered services or benefits. Indeed, these support services should be available universally, through the public health delivery system and the social services program.

This concludes my formal testimony. I am most appreciative of this opportunity to share the views of the National Association for Retarded Citizens with the Committee on Ways and Means.

APPENDIX A

BENEFIT PACKAGE

We recommend the following benefits structure:

Physician's services, including annual physical examination

Inpatient hospital services

Laboratory and X-ray services

Physical rehabilitation services

Outpatient and inpatient physical therapy and speech therapy services

Audiology services

Podiatrist services

Clinical psychology services where required for diagnosis and evaluation of mental development or as a necessary adjunct to a physician's services.

Long-term care services:

Skilled nursing and intermediate care facility services

Home health services

No spell of illness requirements. No limitation on length of stay for children under age 22

All medical and health-related services provided in skilled or intermediate care facilities.

Prescription drugs

Medical appliances, supplies, and assistive devices

Ambulance services where medically indicated

Well-child care¹ to age 18:

Early and periodic screening, diagnosis, and treatment

Dental services

Hearing services

Vision services, including eye-glasses

¹We are very pleased to note that the definition of Well-Child Care in H.R. 13870 makes reference to "screening for intellectual development."

Appendix A (cont'd.)

Preventive services:

Family planning
Genetic counseling
Comprehensive prenatal and maternal care
Postnatal care, including care of premature infants
Annual physical examination for adults

We note that H.R. 13870 prohibits payments for items and services "which are not reasonable and necessary for the treatment of congenital defects, illness or injury or to improve the functioning of a malformed body member ..." (Part A, Section 2011 (a) (2) (A)). We are concerned that some mentally retarded persons would be excluded from services under this phraseology; for example, persons whose mental retardation is occasioned by post-natal environmental influences such as lead paint poisoning.

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SOCIAL SERVICES

PROBLEM

The Social Services programs funded under Titles IV-A and VI of the Social Security Act have been the focus of much attention and controversy over the last several years. The imposition of a \$2.5 billion ceiling on expenditures by the Congress and the issuance of several sets of restrictive regulations by HEW have been responses to the burgeoning and diffuse program of services implemented under these two titles. The current statutory basis for the program, as well as the implementing regulations currently in effect, are satisfying to none of the major interested parties: Congress, HEW, the States, professional groups, and consumer advocates such as NARC.

SOLUTION

The Social Services Coalition, of which NARC is an active member, has devoted many months to developing new legislation acceptable to all interested parties. Negotiations with HEW have reached a critical stage, and it is expected that sufficient agreement will soon be reached so that the legislation may be introduced in Congress.

The current draft of the legislation contains several sections of great importance to NARC:

- inclusion of services "designed to meet the special needs of the mentally retarded;" and
- inclusions of services directed at "preventing or reducing the more intensive forms of institutionalization."

When the legislation is introduced and providing, of course, that such legislation retains language similar to that discussed above, the Congress should move to quickly secure passage.



PLAN FOR EVERYONE

The involvement of low income and minority members.



National Association for Retarded Citizens

Five Year Plan



The Right to Choose

Achieving Residential Alternatives in the Community.