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**UCPA orientation-resource notebook
governmental activities**

PREPARED BY
UNITED CEREBRAL PALSY ASSOCIATIONS, INC.
GOVERNMENTAL ACTIVITIES OFFICE
WASHINGTON, D.C.

UCPA ORIENTATION - RESOURCE NOTEBOOK

A GOVERNMENTAL ACTIVITIES GUIDE FOR AFFILIATES
OF UNITED CEREBRAL PALSY ASSOCIATIONS, INC.

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OPERATION REVENUE

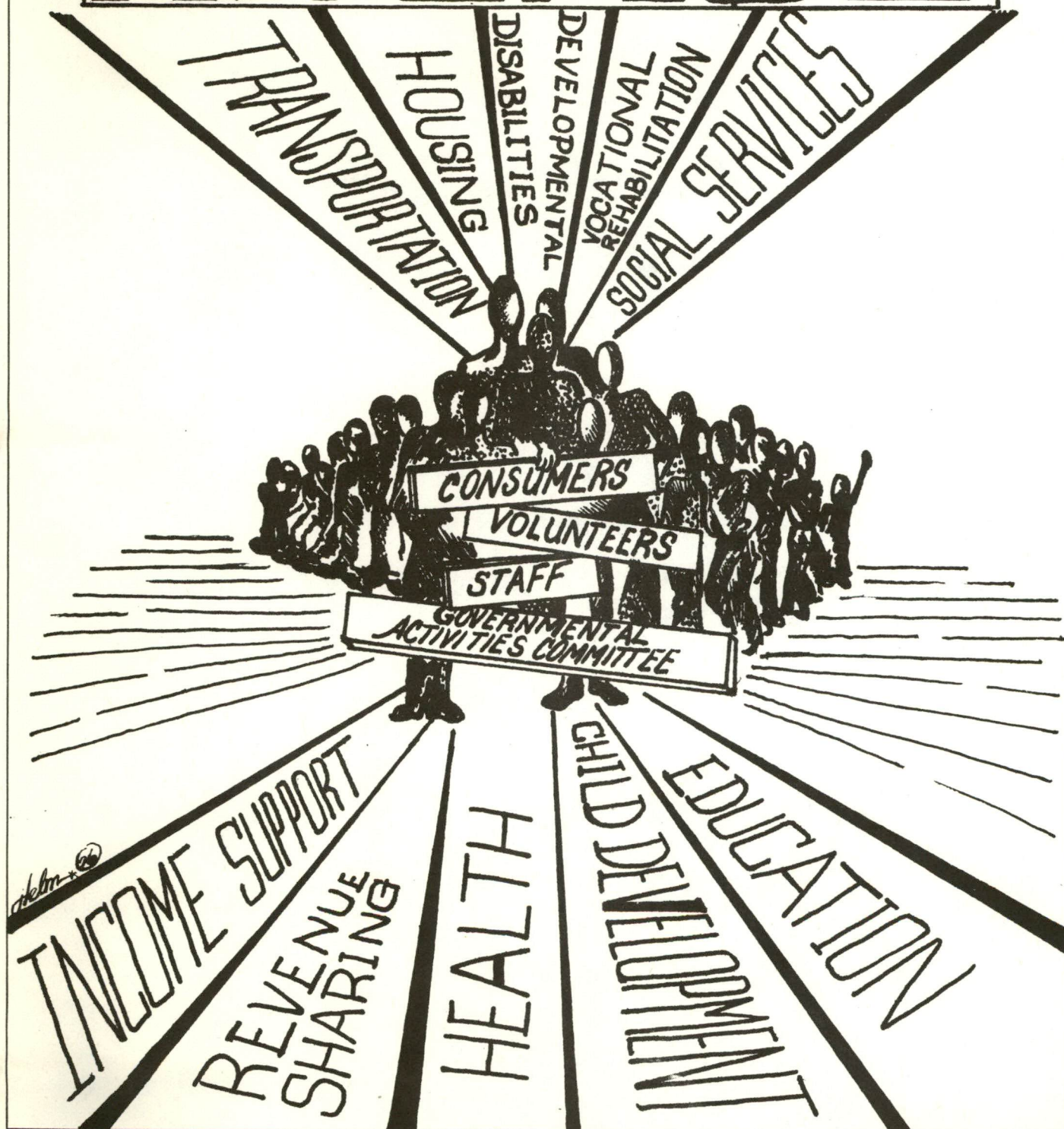




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INTRODUCTION

This is your Orientation and Resource Notebook which has been designed for you by the Staff of the UCPA Governmental Activities Office. It has been developed in response to numerous requests from Local and State affiliates for a basic reference guide to the federal legislative program.

MODEL AND ASSISTANCE

There is a wide diversity in the makeup, program and directions of our more than 300 affiliates across the nation. They are at different levels of development. In this notebook we have attempted to reach all of you in language that is simple and readily understandable regarding the Washington scene. You need to use this notebook as you would an introductory textbook, reading through it section by section quizing yourself at the end of each section to determine if you understand it.

The model of this notebook is one developed by Paula Hammer and Gary Richmond with the Developmental Disabilities Technical Assistance System in Chapel Hill, North Carolina. This program is funded by the Developmental Disabilities Office, Office for Human Development, U. S. Department of Health, Education and Welfare. Their notebook focused solely upon Developmental Disabilities. With their permission, we have used some of the DDTA's material in this notebook and expanded upon the model they developed to cover the legislative areas of primary importance to UCPA affiliates. We wish to express our appreciation to them for their assistance.

OBJECTIVE

The objective of this notebook is to familiarize you with the federal legislative program, how it works, its output, where you can have input and how you can best access the monies for a particular program. It is a broad and complex picture and even experienced and dedicated people have need for such a reference guide to refresh their memories and fill in the gaps in their knowledge.

INDEPTH INFORMATION

The description of programs contained in this notebook provides a general introduction. Detailed information is contained in the Analysis papers prepared by the UCPA Governmental Activities Office. Likewise, timely and specific program reporting is made in our monthly newsletter, Word From Washington. Subject indices for both the newsletter and special analysis papers are available by writing the UCPA Washington Office.



UPDATE STRATEGY

Finally, we see this notebook as an ongoing, working document and resource guide. As such, we have developed it in a loose leaf binder so that it can be kept up to date. Periodically, as information changes and the focus of interest shifts, we will send to you update pages to be inserted into the notebook and also instruct you as to what pages should be removed.

FEEDBACK

There is one additional obligation we would like to pass on to you. Please make critical evaluations of The Orientation and Resource Notebook, as you use it, especially concerning what is included and excluded. Please communicate constructive criticisms to us. This is your notebook and should respond to your needs.



UNITED CEREBRAL PALSY ASSOCIATIONS, INC.

LEGISLATIVE

POLICY STATEMENT

ON

NATIONAL HEALTH, EDUCATION AND WELFARE ISSUES

FOREWORD

Educating the public and public officials in the human rights and legislative needs of the handicapped is part of UCPA's total program of service. A clear understanding of present and proposed legislation is, consequently, essential if we are to encourage, support, or oppose that which will affect those we represent and serve. Counselling and advising other agencies as well as governmental agencies is becoming a larger part of our work of strong advocacy for the cerebral palsied, and broad understanding is needed for this.

The following Policy Statement allows a flexible response to the changing pattern of public and private roles in service delivery. It also provides a framework for action at federal, state, and local levels.



UNITED CEREBRAL PALSY ASSOCIATIONS, INC.

LEGISLATIVE

POLICY STATEMENT

ON

NATIONAL HEALTH, EDUCATION AND WELFARE ISSUES

I. A BILL OF RIGHTS FOR THE HANDICAPPED

A Bill of Rights for the handicapped was adopted in the Spring of 1973. The Bill is a composite of decisions reached by many special task forces. It will change as the needs of the handicapped become clear and change.

A. Basic Premise

"We hold these Truths to be self-evident, that all men are created equal, that they are endowed by their Creator with certain unalienable Rights, and that among these are Life, Liberty, and the Pursuit of Happiness....."

The individual's rights begin with the inherent right to be born with as great a capacity to grow and develop fully as his mother can give him. This is followed by ensuring this birthright through services which protect both the embryonic environment and the individual's entry to the world.

Those who fail to achieve this birthright, or who are handicapped by other causes, have the right to be assured the means of achieving maximum growth and development. They also have the right to enjoy the dignity, respect, and opportunities accorded all men by the freedoms and privileges in the Constitution of the United States.

Society must provide, preserve, and protect the means whereby the handicapped can obtain the rights of first-class citizenship from earliest infancy throughout life. These means form a particular "Bill of Rights for the Handicapped."

B. The Specific Rights

1. PREVENTION OF DISABILITY insofar as possible through early detection of abnormalities in infancy, immediate and continuing family guidance, and comprehensive habilitative services until maximum potential is achieved.



2. HEALTH SERVICES AND MEDICAL CARE for protecting the individual's general well-being, and such additional special services as are required because of his handicap.
3. EDUCATION to the fullest extent to which the individual is intellectually capable, provided through the regular channels of American education.
4. TRAINING for vocational and avocational pursuits as dictated by his talents and capabilities.
5. WORK at any occupation for which the individual is qualified and prepared.
6. AN INCOME sufficient to maintain a lifestyle comparable to non-handicapped peers.
7. LIVE HOW AND WHERE HE CHOOSES and enjoy residential accommodations which meet his needs if he cannot function in conventional housing.
8. BARRIER-FREE PUBLIC FACILITIES, including buildings, mass or subsidized alternative transportation services, and social, recreational and entertainment facilities.
9. FUNCTION INDEPENDENTLY in any way in which he is able to act on his own and to obtain the assistance he may need to assure mobility, communication, and daily living activities.
10. PETITION social institutions and the courts to gain such opportunities as may be enjoyed by others but denied the handicapped because of oversight, public apathy, or discrimination.

II. UCPA POLICY APPROACH

UCPA has developed an approach for ensuring and delivering the rights given above for the Bill of Rights for the Handicapped. The intent of this approach is implementation at federal, state and local levels, either by federal law, by state or local option, or a combination thereof.

A. Disabilities Prevention (Right No. 1)

A comprehensive prevention program should include the following five points:

1. A registry of high-risk babies and mothers.



2. A suitable health-care delivery system that will insure good prenatal care, including income-maintenance during the last trimester of pregnancy.

3. UCPA support for all programs of genetic counselling, nutrition, family planning and community education because the incidence of cerebral palsy is related to maternal malnutrition, the increased number of pregnancies, the undue frequency of pregnancies, genetic factors, smoking, the mother's age and infections. The aim is to give the community an understanding of the aims and importance of these services.

4. A broad spectrum of services designed to stimulate the physical, intellectual and emotional growth and development of high-risk infants less than two years old.

5. A program of early detection, adequate treatment and elimination of environmental poisons from children's play and living areas because eating lead and other heavy metals is one of the causes of brain damage. Adequate appropriations are urged for both immediate and long-range programs.

B. Health Services and Medical Care (Right No. 2)

The nation's strategy in this area must emphasize health maintenance as well as treatment for illness. This will involve sound programs of preventive maintenance, health education and environmental management. The high-quality services must be available to all regardless of ability to pay.

1. The comprehensive personal health services should include all those components that will promote physical, social, emotional and intellectual health. This should include long-term care acceptable to the individual and his family. These can be efficiently and capably provided by pooling varied specialized talents with group or individual medical practices.

2. The health-care services should encourage the development of a variety of reimbursement methods for the agencies providing the services. The methods should encourage continuation and expansion of the team approach to diagnosis and management. Inpatient and outpatient services should be paid for on a per-capita basis. Legal barriers to prepayment for group practice should be eliminated.

3. A universal financial system for health service payments should be established with both public and private sector participation. The system can be used to restructure the health-care delivery system to the concept of total health care by using the power of the purse to promote rational organization and provide incentives for efficiency in service delivery. This is in keeping with America's competitive and pluralistic traditions.



4. Health education for all consistent with the concept of total health care must be vigorously promoted. Instruction at all educational levels, including adult education, should insure knowledge about life-style, nutrition, family planning, genetic counselling, immunization, sex information and hazards such as alcohol, drugs, smoking and pollution. Peer-group counselling should be encouraged, where appropriate.

5. Wider and more immediate application of research findings are essential for improving the nation's general health. Funding cuts in biomedical research programs must be restored and additional support should go to research in the behavioral and social sciences relating to health care and its delivery.

6. The disabling effect of poverty or the long-range effects of inferior housing, nutrition, education and recreation cannot be overcome by health-care services alone. Special attention should be given to the following areas:

a. Prompt elimination of malnutrition which is associated with many irreversible handicapping conditions. A massive attack must be mounted, which will include expanding and improving all types of food-assistive programs, upgrading the nutritive value of food products and developing sound nutrition education programs. Mechanisms must be developed for successfully delivering food assistance to the poor, infants and young children and to pregnant and nursing mothers. UCPA has adopted a position statement on infant undernutrition as related to developmental disabilities, which is available on request.

b. High-quality day-care and early childhood programs should be developed for infants and young children, who are the most vulnerable to poverty's environment.

c. The present system of health-care services programs for the poor and near-poor must be expanded until the comprehensive health-care financing system discussed in this section is developed.

C. Child Development and Educational Services (Right No. 3)

1. UCPA favors the accelerated expansion of services for both children and adults that provide a variety of developmental programs for the individual and supportive services for the individual and his family.

2. UCPA believes the federal government should be responsible for developmental programs.

3. UCPA supports inclusion of cerebral palsied children and adults in developmental programs with their peers of comparable interests and abilities if appropriate standards are developed for these facilities and for the staff qualifications. The cerebral palsied should have separate programs only when they are so severely and multiply handicapped that inclusions is impractical or impossible.



4. UCPA supports the Bureau of Education for the Handicapped in its total commitment throughout the United States of 100% enrollment in appropriate classes of all children who need special services, on the premise that every child has a right to a free public education.

D. Vocational Training and Income Security (Rights Nos. 4-6)

1. Welfare reforms are vitally important since a disproportionate number of handicapped persons are found in families of low socio-economic levels. These should include:

a. Establishment of national living standards for individuals and families, including minimum basic benefits. The minimum benefits should provide a nutritionally adequate diet and decent living standards, with special consideration for handicapped persons and their families.

b. The federal government should make such payments directly to individuals and families.

2. Training and an opportunity to work should be provided for all individuals able to work. They are entitled to a living wage in keeping with national minimum-wage standards. The aged, infirm and mothers of small children, however, are entitled to dignity and self-respect even though they cannot work.

E. Long-Term Care and Services (Right No. 7)

These services must include suitable choices of places to live, appropriate maintenance services, meaningful daily activities, adequate income maintenance and a monitoring protective advocacy system which includes protection and civil and human rights.

1. A protective advocacy system should be rapidly developed for those handicapped who are unable to manage themselves or their affairs without help. This system should be separate from the service-giving agencies, be statutory and should have a follow-along lifetime partnership with the individual and his family to ensure the availability, acceptability and appropriateness of services.

2. An orderly movement from institutional to community services should be begun. Appropriate alternatives include small regional centers, small group homes, adaptive apartments, hotels, foster homes, nursing homes, half-way houses, modified hotels and motels and care in the individual's own home. Those needing some form of residential care should have a variety of alternatives from which to choose and should be free to choose among them within his abilities to cope.



3. The principle of accreditation standards for residential and community services for the handicapped is strongly supported, as is rapid compliance with them. The kinds of standards developed by the JCAH Accreditation Council for Facilities for the Mentally Retarded are vigorously endorsed.

4. A strong commitment should be made to the philosophy of individualized programs and out-of-bed care for all except those for whom it would be a threat to life.

5. Greater emphasis should be placed on integrating physically handicapped and physically normal residents having compatible interests and intellectual activities.

F. Mobility and Life Pursuits (Rights Nos. 8-10)

A new concept of mobility for the handicapped must be developed in our nation. This will include:

1. Eliminating architectural and transportation barriers which keep the handicapped from functioning independently or from accepting employment. Legislation and regulations may be necessary to accomplish this.

2. Finding a viable alternative for those individuals who cannot hold a job. A valid life pursuit and life enrichment must be part of this alternative, with outlets for creative expression which include integrating handicapped and non-handicapped people.

3. Opening air travel and mass transportation to the handicapped.

4. Encouraging formation of CYCP consumer groups to bring life enrichment to severely handicapped persons.

5. Promptly adapting scientific and technological developments to the needs of the handicapped.

III. LEGISLATIVE APPROACH AND COMMITTEE APPROACH
AT NATIONAL AND STATE LEVELS

UCPA's legislative approach will be maximally effective only if the national, state and local Governmental Activities Committees work carefully together and along the same lines. The assumption that the desired changes can be accomplished at only the federal level is untenable and strong, active participation at least at the state level is vitally needed. The following statements apply, in addition to the foregoing Policy Approach statements:



1. The realistic needs of the groups mentioned in particular legislation should be reflected in the authorization levels for funding that legislation.

2. Persons concerned with the welfare of the handicapped should be appointed to advisory boards or committees helping the various federal and state agencies. Consumer groups, voluntary agencies and the disabled themselves should be substantially represented, along with the service-providers. These boards should be responsible for reviewing the operating regulations for federal and state supported services.

3. An effective Developmental Disabilities Advisory Council with strong consumer representation is a must for each state. It should plan, develop, coordinate and monitor a comprehensive service system for the developmentally disabled. It should also be an advocate ensuring right-of- access to appropriate generic services. UCPA is committed to an open rather than a categorical approach to services for the handicapped and strongly supports the Developmental Disabilities approach.

4. UCPA supports the principle of earmarking funds for specific programs such as day-care, education and rehabilitation until adequate services for the severely handicapped are established. Earmarking funds for specific immunization programs as measles is also recommended.

5. Coalitions amongst voluntary agencies are strongly favored to enhance services, educate the public and cooperate with all concerned local, state and federal governmental agencies.



UCPA LEGISLATIVE PRIORITIES

94th Congress, 1975-1976

The primary priority area of the UCPA Governmental Activities Office for the 94th Congress is accessing comprehensive services for adults severely disabled by cerebral palsy and other developmental disabilities, especially those who are unemployed, residing in inappropriate situations, and who have exited from the school system. The secondary priority area addresses the needs of those developmentally disabled individuals in the early childhood period. Among individuals with disabilities, young children and adults seem to be the most neglected and underserved.

These priority areas are consistent with the UCPA IHF Plan (The Individual With Cerebral Palsy and His Family), the UCPA Bill of Rights for the Handicapped, and the UCPA Legislative Policy Statement on National Health, Education, and Welfare Issues.

Legislative priorities for action, 1975-1976 are:

- 1) Developmental Disabilities. To encourage the strengthening of the Office of Developmental Disabilities within HEW's Office of Human Development. This includes extension of the Developmental Disabilities Act for 3 years, increased planning and coordination authority of the Federal and State DD Councils, and full staffing of the Office of Developmental Disabilities to adequately implement the act.
- 2) Housing. To implement the Housing and Community Development Act of 1974 to insure optimal initiation of suitable alternative living arrangements for the severely disabled at the community level.
- 3) Transportation. To encourage the Department of Transportation (DOT) to implement existing legislative mandates to provide equal mobility toward the goal of an integrated, available, and accessible mass transportation system; DOT encouragement of the utilization of specialized transportation programs for the disabled until such time as a comprehensive and accessible system can be developed; and support of any congressional initiatives to increase transportation services for the disabled.
- 4) Education. To develop a comprehensive continuum of educational services for severely disabled individuals beginning at birth and continuing through adulthood with particular emphasis on preschool and adult services. This includes monitoring services to the disabled in the Headstart program; encouraging expanded preschool programming; and extension of the Vocational Education Act, the Higher Education Amendments, and the Adult Education program with specific legislative recognition to the needs of the disabled who are traditionally excluded from entrance into these programs.



5) Staff-Volunteer Development and Training. To encourage the earmarking of training funds in all human service legislation in order to insure quality services to the severely disabled. This includes cooperative efforts with the UCPA Professional Services Program Department and UCPA Advocacy Project, monitoring of existing HEW programs to insure adequate training support, and examination of the Comprehensive Employment and Training Act to determine its role in this endeavor.

6) Rehabilitation-Employment. To ensure appropriate services to the severely disabled under the Rehabilitation Act of 1973 within the scope of limitations established by P.L. 93-112 and P.L. 94-516. This includes assisting in the preparation of an affirmative Comprehensive Needs Study as mandated by P.L. 93-112, HEW emphasis on work activity programs as an integral component of the rehabilitation process, and encouragement of on-the-job training of rehabilitation counsellors to better serve the individual and comprehensive needs of the severely disabled.

7) Supplemental Security Income. To improve through legislation and program delivery the responsiveness of the Supplemental Security Income program to the needs of the severely disabled. This includes (a) immediate and appropriate referral to State and local agencies administering Social Services, Medicaid, Vocational Rehabilitation, and Housing Assistance Payment, (b) special considerations of the needs of disabled children, (c) re-examination of SSI relationship to various living arrangements, (d) clarification of student status, and (e) development of policy statement affirming that Section 8 rent subsidy payments are not to be considered countable income for SSI eligibility purposes.

8) Utilization of Existing Legislative Resources. To survey and impact on existing federal legislative resources for the disabled currently untapped by UCPA. Examples include monitoring the program study of the Office for Handicapped Individuals, exploring Department of Labor programs, and examining the impact of federal feeding and nutrition programs on UCPA affiliates.

Implementation Activities. A number of existing federal programs require monitoring and influencing by UCPA but are not legislative priorities at this immediate point in time. Each of these activities are also primary interests, concerns, and priorities of other UCPA departments. Likewise, the UCPA Governmental Activities Committee recognizes the political climate which generally opposes any new federal spending programs. However, should momentum be created for passage of such legislation, UCPA will actively be involved. Identified implementation activities, 1975-1976 are:

- 1) Social Services. To maximize Social Service programs for the disabled under Title XX of the Social Security Act. This is directly related to priority number five, staff-volunteer development and training



and priority number eight, utilization of existing legislative resources. It is expected that the UCPA Consumer Caucus and the UCPA Advocacy Project will be actively involved in the legal and civil advocacy and protective services areas. The UCPA Program Department will be actively involved with social services in encouraging new program initiatives and affiliate involvement in the development of state plans.

- 2) Accountability. To encourage increased accountability and quality assurance of all programs receiving federal financial assistance. The Program and Medical Departments are acutely involved in this process as demonstrated by UCPA's membership on the Joint Commission of Accreditation of Hospitals.
- 3) Compliance Boards. To assure the inclusion of governmental and non-governmental representatives on all relevant compliance boards. This is a shared responsibility with the Medical, Program, and Legal Departments.
- 4) Right to Education. To support the Brademas-Williams excess costs for special education bills which includes the principle of the right to education for every child. This will be a shared concern of the Program and Legal Departments as well as Concerned Youth for Cerebral Palsy (CYCP).
- 5) Child and Family Services. To support the Child and Family Services Act authorizing grants for educational, health, nutritional, and social services for preschool children and their families with priorities established for handicapped children. Activity will be shared with the Program Department.
- 6) Architectural Barriers. To work with the Program and Public Relations-Public Information Departments and the Consumer Caucus and CYCP to ensure that federal, state, and local regulations are adhered to by all public agencies in the removal of architectural barriers.
- 7) National Health Insurance. To develop principles which will provide adequate guarantees of coverage for severely disabled individuals particularly from birth on. The UCPA Washington office will rely on the Medical and Program Departments for advice and guidance.



UCPA LEGISLATIVE PRIORITIES FOR ACTION:
A STATUS REPORT ON THE 94th CONGRESS,
1ST SESSION, 1975

The primary priority area of the UCPA Governmental Activities Office for the 94th Congress is accessing comprehensive services for adults severely disabled by cerebral palsy and other developmental disabilities, especially those who are unemployed, residing in inappropriate situations, and who have exited from the school system. The secondary priority area addresses the needs of those developmentally disabled individuals in the early childhood period. Among individuals with disabilities, young children and adults seem to be the most neglected and underserved.

These priority areas are consistent with the UCPA IHF Plan (The Individual with Cerebral Palsy and His Family), the UCPA Bill of Rights for the Handicapped, and the UCPA Legislative Policy Statement on National Health, Education, and Welfare issues.

Legislative Priorities for action 1975-1976 are:

1) Developmental Disabilities. To encourage the strengthening of the Office of Developmental Disabilities within HEW's Office of Human Development. This includes extension of the Developmental Disabilities Act for three years, increased planning and coordination authority of the Federal and State DD Councils, and full staffing of the Office of Developmental Disabilities to adequately implement the Act.

A) Status: The "Developmental Disabilities Assistance and Bill of Rights Act" was enacted into law as P.L. 94-103 on October 4, 1975. In addition, the Developmental Disabilities Office has been elevated into a separate office under the HEW Assistant Secretary for Human Development with a significant staff increase.

B) Activities: Most activity by UCPA in this area has been undertaken as a member of the Consortium Concerned with Developmental Disabilities (CCDD) Task Force on Developmental Disabilities. This CCDD Task Force drafted the compromise language for the Bill of Rights, continually monitored and pushed for ~~passage~~ passage of the act, and jointly testified before Congress on fiscal year 1976 appropriations to implement the Act.

Outside the CCDD, UCPA submitted written congressional statements of support for passage of the act, circulated a strong letter supporting the establishment of a viable and strong administrative structure, and worked closely with the Developmental Disabilities Technical Assistance System (DD/TAS) and the National Conference on Developmental Disabilities (NCDD) in implementing the Act.

The Developmental Disabilities extension legislation was reported in January, March, April, May, June, July, August, and October 1975 issues of Word From Washington and implementation areas



were discussed in the March, May, July, and October 1975 issues of WW. UCPA Washington office staff participated in the presentations on the DD Act at numerous conferences including the National Rehabilitation Training Institute.

2) Housing. To implement the Housing and Community Development Act of 1974 to insure optimal initiation of suitable alternative living arrangements for the severely disabled at the community level.

A) Status: Substantial progress has been made in implementing the HCD of 1974. Communication channels have been opened with the Department of Housing and Urban Development, the Housing Assistance Council, the National Association of Housing and Redevelopment Officials, the International Center for Social Gerontology, the National Science Academy, the Developmental Disabilities Office, The President's Committee on Mental Retardation, and the Architectural and Transportation Barriers Compliance Board. There have been isolated examples of UCPA affiliates success with the HCD Act. The major obstacle remains the unwillingness of HUD to respond in any substantive manner.

B) Activities: Almost all activity at the Washington level has been conducted under the auspices of the CCDD Task Force on Housing, which is chaired by the UCPA Governmental Activities Office. UCPA has also been represented on the steering committee of the National Coalition on Housing and the Handicapped, an organization whose effectiveness has yet to be demonstrated. UCPA presented testimony before the public hearing on housing of the Architectural and Transportation Barriers Compliance Board on behalf of the CCDD Task Force. UCPA also serves on the seven member expert advisory panel of the National Association of Housing and Redevelopment Officials DHEW grant to develop a manual on how to use HUD supported programs in initiating housing programs at the local level for individuals with disabilities.

The UCPA Governmental Activities office developed a Local Action Manual on the Housing and Community Development Act and between October 1974 and October 1974, presented it to over 1200 individuals. The CCDD Task Force on Housing conducted a series of briefing sessions for the HUD Task Force on Housing for the Handicapped in an attempt to articulate a working concept of the specific residential needs of the disabled population, to demonstrate several existing residential models, and to outline obstacles encountered by member chapters in implementing the HCD Act. The HUD Task Force of the Assistant to the Secretary, Programs for the Elderly and Handicapped, is composed of one member from each of the major HUD operating divisions.



The CCDD Task Force on Housing was instrumental in seeking a congressional amendment to H.R. 8912 to eliminate Section 8 rent subsidy payments from affecting SSI payment levels and eligibility. The CCDD committee has also acted as an initial screening group for Developmental Disabilities office housing grant proposals, has recommended needed areas requiring HUD publications, and has surveyed their local chapters to determine the scope of activity and success of efforts in initiating housing related programs through the HCD mechanism.

UCPA Washington office initiated contacts with a number of private housing organizations and has provided needed staff support to UCPA Professional Services Program Department housing efforts. Every 1975 issue of Word From Washington except February, March, and November has discussed components of the HCD Act.

3) Transportation. To encourage the Department of Transportation (DOT) to implement existing legislative mandates to provide equal mobility toward the goal of an integrated, available and accessible mass transportation system; DOT encouragement of the utilization of specialized transportation programs for the disabled until such time as a comprehensive and accessible system can be developed; and support of any congressional initiatives to increase transportation services for the disabled.

A) Status: Federal agencies have issued proposed regulations to implement most existing legislative mandates, have organized public hearings for their discussions, but have yet to issue final regulations on most of these programs. The Senate has passed S.662, the "National Mass Transportation Assistance Act Amendments of 1975" to help meet the needs of the disabled in urban areas.

B) Activities: UCPA has presented testimony on codification of requirements for elderly and handicapped transportation services under the Urban Mass Transportation Administration (UMTA), has been appointed to the advisory panel on transportation for the disabled of the American Public Transit Authority (APTA), has monitored and influenced Section 16(b) UMTA capital assistance grants to thirty UCPA affiliates, has submitted a written statement to the Senate in support of S.662, and has completed a compilation of existing federal transportation laws impacting on the disabled. All 1975 issues of Word From Washington except August and December discussed transportation developments.

4) Education. To develop a comprehensive continuum of educational services for severely disabled individuals beginning at birth and continuing through adulthood with particular emphasis on preschool and adult services. This includes monitoring services to the disabled in the Headstart program; encouraging expanded preschool programming; and extension of the Vocational Education Act, the Higher Education Amendments and the Adult Education program with specific legislative recognition of the needs of the disabled who are traditionally excluded from entrance into these programs.



A) Status: Refer to Implementation Issue #4 Right to Education. This priority does not entail a single passage of a bill or a related measure of success. An examination of UCPA activities in this regard reflect isolated attention but not concentrated focus.

B) Activities: The UCPA Governmental Activities Office has developed an analysis paper on 104 potential federal funding sources for children's program, has developed an article for Beelines on the federal involvement with infant programs, has prepared an article for Word From Washington on the Right to Read program, and has testified before Congress on extension of the Vocational Education Amendments.

5) Staff-Volunteer Development and Training. To encourage the earmarking of training funds in all human service legislation in order to insure quality services to the severely disabled. This includes cooperative efforts with the UCPA Professional Services Program Department and UCPA Advocacy Project, monitoring of existing HEW programs to insure adequate training support, and examination of the Comprehensive Employment and Training Act to determine its role in this endeavor.

A) Status: This priority has received a great amount of staff attention and time during 1975.

B) Activities: During the first 10 months of 1975, 12 UCPA affiliates executive staff and volunteers participated in the UCPA Governmental Activities Intern Program. The intern program involves a week's appointment with federal officials and congressional staff who have expertise in program areas in which the intern has expressed an interest.

In its first concrete effort to launch "Operation Revenue," the UCPA Washington Office developed a Local Action Manual (IAM) on the "Housing and Community Development Act of 1974." The manual was presented to over 1200 individuals between October 1974 and October 1975.

Out of Washington seminars, workshops and orientation sessions were significant activities of the UCPA Governmental Activities staff during 1975.

- (1) UCPA Midwest District Workshop, January, Chicago, Benson and Ross
- (2) UCPA Governmental Activities Executive Group Meeting, February, Washington, Benson, Ross, Fuller and Boulware
- (3) Orientation for New UCPA Affiliate Staff, March, New York, Benson and Ross
- (4) Regional Developmental Disabilities Conference, March, Atlanta, Benson



- (5) UCPA of Illinois Conference on Vocational Rehabilitation, April, Springfield, Ross
- (6) HEW Region V Seminar for State Developmental Disabilities Council Members and Agency Directors, April, Ross
- (7) Alabama Workshop on Social Services, April, Birmingham, Benson
- (8) Georgia Workshop on Children's Programs, April, Athens, Benson
- (9) Regional Developmental Disabilities Conference, May, Chicago, Benson and Ross
- (10) Regional Developmental Disabilities Conference, May, Portland, Benson
- (11) UCP of Ohio Social Services Workshop, May, Columbus, Ross
- (12) UCP of California Workshop, May, Burlingame, Benson
- (13) UCP of Wisconsin Workshop, July, Madison, Ross
- (14) Wisconsin Developmental Disabilities Conference, July, Madison, Ross
- (15) National Rehabilitation Training Institute, July, Hollywood, Fla. Benson
- (16) UCP of North Carolina Conference, October, Raleigh, Benson
- (17) North Carolina NASW Conference, October, Raleigh, Benson
- (18) UCP of Indiana State Director Orientation, October, Indianapolis, Ross
- (19) Indiana Governor's Conference on the Handicapped, October, Indianapolis, Ross
- (20) UCP of Western New York Legislative Conference, October, Buffalo, Ross
- (21) UCP of Western New York Housing Seminar, October, Buffalo, Ross
- (22) National Rehabilitation Training Institute, October, Hollywood, Fla. Benson
- (23) Cystic Fibrosis Foundation Legislative Planning Session, November, Atlanta, Benson
- (24) UCPA Governmental Activities Committee Executive Group Meeting, November, Washington, Benson, Ross, Fuller and Boulware
- (25) UCP of Florida State Director-UCPA Southeast District Leaders Orientation Session, December, Atlanta, Benson

Out of Washington Seminars:

UCPA Related	13
Other Settings (many including UCPA)	12

By Geographic Area

Northeast District	2
Mideast District	4
Southeast District	6
Southwest District	0
Midwest District	6
Western District	2
National in Scope	5



6) Rehabilitation-Employment. To insure appropriate services to the severely disabled under the Rehabilitation Act of 1973 within the scope of limitation established by P.L. 93-112 and P.L. 93-516. This includes assisting in the preparation of an affirmative Comprehensive Needs Study as mandated by P.L. 93-112, HEW emphasis on work activity programs as an integral component of the rehabilitation process and encouragement of on-the-job training of rehabilitation counsellors to better serve the individual and comprehensive needs of the severely disabled.

A) Status: Problems have been identified in several states related to serving the severely disabled and hearings have been held on extending the Rehabilitation Act of 1973.

B) Activities: UCPA has attempted to work with several of her sister agencies to revitalize the old National Rehabilitation Association Rehab Coalition. In recognition of the dominance of providers and professionals in the rehab coalition, the CCDD has organized a task force on rehabilitation with UCPA a member. UCPA testified before the joint committees of Congress requesting a two year extension of the Rehabilitation Act with increased authorization levels and a set-aside for projects to serve the severely disabled.

In our testimony, UCPA advocated for extensive congressional oversight hearings to examine services for the severely disabled, state agency administration, and civil rights-non-discrimination affirmative action.

UCPA Washington staff acted as faculty in two National Rehabilitation Training Institute conferences and as a presentator at a conference sponsored by UCP of Illinois for State rehabilitation counsellors.

In conjunction with the UCPA Professional Services Program Department, the UCPA Washington office initiated a survey of selected affiliates and prepared a report for the Urban Institute, the HEW contractors conducting the Comprehensive Needs Study of the severely disabled.

7) Supplemental Security Income. To improve through legislation and program delivery the responsiveness of the Supplemental Security Income program to the needs of the severely disabled. This includes (a) immediate and appropriate referral to state and local agencies administering Social Services, Medicaid, Vocational Rehabilitation and Housing Assistance Payments, (b) Special consideration of the needs of disabled children, (c) re-examination of SSI relationship to various living arrangements, (d) clarification of student status and (e) development of a policy statement affirming that Section 8 rent subsidy payments are not to be considered countable income for SSI eligibility purposes.



A) Status: Two SSI reform bills, H.R. 8911 and H.R. 8912, reported by the Subcommittee on Public Assistance are stalled in the House Ways and Means Committee. All of the above listed concerns are addressed by these two bills.

B) Activities: UCPA activity has been directed by its membership on the CCDD Task Force on SSI-Social Services-Medicaid. This has included submission of written statements for the record to the House Ways and Means Committee as well as continuing personal contact with committee professional staff. CCDD Task Force members periodically meet with Bureau of Supplemental Security Income (BSSI) executive staff for briefings around mutually accepted subjects. In addition, the UCPA Washington office represented the national UCPA executive director in a meeting with the Commissioner of the Social Security Administration (SSA) regarding increasing the responsiveness of local SSA offices to consumers and applicants.

8) Utilization of Existing Resources. To survey and impact on existing federal legislative resources for the disabled currently untapped by UCPA. Examples include monitoring the program study of the Office for Handicapped Individuals, exploring the Department of Labor programs and examining the impact of federal feeding and nutrition programs on UCPA affiliates.

A) Status: This has been the primary responsibility of the UCPA Legislative Analyst.

B) Activities: Special Analysis papers have been developed on potential federal funding sources for both adult and children service programs, on the Department of Agriculture, the Department of Labor, and on the Childrens and Mental Health Interstate Compacts. In addition, special papers and Word From Washington articles have been prepared to help affiliates utilize existing federal resources.

Implementation Activities. A number of existing federal programs require monitoring and guidance by UCPA but are not legislative priorities at this immediate point in time. Each of these activities are also primary interests, concerns and priorities of other UCPA departments. Likewise, the UCPA Governmental Activities Committee recognizes the political climate which generally opposes any new federal spending programs. However, should momentum be created for passage of such legislation, UCPA will actively be involved. Identified implementation activities for 1975-1976 are:

1) Social Services. To maximize Social Service programs for the disabled under Title XX of the Social Security Act. This is directly related to priority number five, staff-volunteer development and training and priority number eight, utilization of existing legislative resources. It is expected that the UCPA Consumer Caucus and the UCPA Advocacy Project will be actively involved in the legal and civil advocacy and protective services areas. The UCPA Program Department will be actively involved with social services in encouraging new program initiatives and affiliate involvement in the development of state plans.



A) Status: Final regulations have been issued on the Title XX program. Congressional and administration initiatives have been undertaken to modify, alter, and expand the Title XX program.

B) Activities. All UCPA activity in this area has been undertaken under the auspices of the CCDD Task Force on SSI-Social Services-Medicaid and the Social Services Coalition. A number of speaking engagements and seminars on the Social Services program have been conducted by UCPA Washington office staff. Numerous affiliates have become involved in the Title XX program and have received support from Washington. And the January, May, July, August, September, October, and November 1975 issues of Word From Washington have reviewed the Title XX program.

2) Accountability. To encourage increased accountability and quality assurance of all programs receiving federal financial assistance. The Program and Medical Departments are acutely involved in this process as demonstrated by UCPA's membership on the Joint Commission on Accreditation of Hospitals.

A) Status: In all seminars, workshops, speaking engagements, etc., UCPA Governmental Activities office staff have emphasized the need for accountability.

B) Activities: The UCPA Governmental Activities Office has supported the UCPA Professional Services Program Department efforts in developing a nationwide movement toward JCAH-ACF/MR accreditation. In addition, staff took part in a workshop on "Legality, Accountability, and Quality Control" at the National Rehabilitation Institute Conference.

3) Compliance Boards. To assure the inclusion of governmental and non-governmental representatives on all relevant compliance boards. This is a shared responsibility with the Medical, Program and Legal Departments.

A) Status: Limited efforts have been made in this area.

B) Activities: Three individuals associated with UCPA have been named to the National Advisory Council on Developmental Disabilities and two such volunteers have been named to the National Advisory Council to the White House Conference on Handicapped Individuals. UCPA Washington office staff contacts have been made with the National Advisory Committee on the Handicapped and the Architectural and Transportation Barriers Compliance Board.

4) Right to Education. To support the Brademas-Williams excess costs for special education bills which include the principle of the right to education for every child. This will be a shared concern of the Program and Legal Departments as well as Concerned Youth for Cerebral Palsy (CYCP).



A) Status: The "Education for All Handicapped Children Act" has been signed into law as P.L. 94-142.

B) Activity: This subject was removed from the priority list to an implementation activity because the expectation of substantial congressional movement towards passage in 1975 seemed remote. It has become, however, a significant priority of UCPA during the last six months of 1975. A substantial amount of staff time has been devoted to this issue.

UCPA activity has followed the leadership of the Council for Exceptional Children and has been undertaken as part of the CCDD Task Force on Education efforts. UCPA testified before both House and Senate on these education bills, testified before Congress on needed appropriations to further implement the Act, and UCPA staff periodically met with the Deputy Commissioner of the Bureau for the Education of the Handicapped (BEH). Written information, such as the Word From Washington (all 1975 issues except January, March, and April), discussed this issue in-depth.

5) Child and Family Services. To support the Child and Family Services Act authorizing grants for educational, health, nutritional and social services for preschool children and their families with priorities established for handicapped children. Activity will be shared with the Program Department.

A) Status: Bill has been introduced and joint hearings have been held.

B) Activities: UCPA has testified before Congress supporting enactment of this legislation.

6) Architectural Barriers. To work with the Program and Public Relations-Public Information Departments and the Consumer Caucus and CYCP to ensure that federal, state, and local regulations are adhered to by all public agencies in the removal of architectural barriers.

A) Status: Little activity has been undertaken in this area. The Architectural and Transportation Barriers Compliance Board (A&TBCB) has submitted its annual report to Congress.

B) Activity: Staff support has been made to the A&TBCB and support of UCP of Indiana efforts related to newly constructed swimming pools have been made.



7) National Health Insurance. To develop principles which will provide adequate guarantees of coverage for severely disabled individuals particularly from birth on. The UCPA Washington office will rely on the Medical and Program Departments for advice and guidance.

A) Status: Many bills have been introduced, congressional hearings have been held, and plans for congressional hearings around the nation are being made.

B) Activities: UCPA has submitted a written statement to the House Ways and Means Committee and has participated with both the National Easter Seal Society Ad Hoc Task Force on National Health Insurance and the CCDD Task Force on Health.

Other Issues

(1) Civil Rights-Non-discrimination - Affirmative Action: No regulations have been promulgated to implement Section 504 of the Rehabilitation Act and Section 503 regulations contain several waiver authorities objected to by many persons with disabilities. In addition, the HEW Office for Civil Rights (OCR) has proposed eliminating the current requirement that HEW investigate and resolve all citizen complaints it receives. UCPA has joined three coalition efforts organized by the National Easter Seal Society, the Children's Defense Fund, and the Leadership Conference on Civil Rights in attempting to influence OCR efforts.

(2) Lobbying Registration: Several bills have been introduced to regulate the lobbying activities of organizations, including Internal Revenue Service 501(c)(3) tax-exempt agencies. UCPA Governmental Activities Office staff have appeared before Congressional committees as a member of a panel representing the National Health Council.

(3) Contribution Solicitation: Several bills have been introduced to regulate the manner in which charitable organizations solicit funds. UCPA has attended regular briefing sessions on the subject conducted by the National Health Council and have reported these legislative proposals in the Word From Washington.

(4) Child Nutrition: UCPA has worked under the leadership of the Children's Defense Fund in seeking passage of P.L. 94-105, the "National School Lunch Act and Child Nutrition Act of 1966 Amendments of 1975."

(5) EPSDT: The CCDD Task Force on Health, of which UCPA is a member, has taken an active role in working with HEW to implement the Medicaid Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) Program. Task Force emphasis has been to seek the establishment of an adequate developmental assessment tool under EPSDT.



(6) Forward Health Plan/Comprehensive Health Planning: Under the leadership of the National Health Council, UCPA has become actively involved with the development of HEW's five year Forward Plan for Health. The UCPA Washington office arranged appointments with high level HEW officials with the UCPA National Executive Vice-President and followed these meetings up with additional staff contacts. UCPA has remained briefed on the Comprehensive Health Planning program and has occasionally reviewed both CHP and Forward Health Plan in the Word From Washington.



ROLE OF UCPA GOVERNMENTAL ACTIVITIES COMMITTEE

The UCPA Governmental Activities Committee is appointed for a two year term by the president of the organization who also appoints the chairman and vice chairman of the committee. The committee is presently composed of 12 members, six district representatives appointed by the district vice president and six at large members appointed by the president.

The Committee is responsible for seeing that Governmental Activities Staff Office analyses and records all current and proposed legislation, rules and regulations, legislative processes and funding implementation on all subjects concerning the disabled with emphasis on the problems of the Cerebral Palsied. It is responsible for the dissemination of information and recommendations in connection with this analysis. It is responsible for developing and establishing legislative priorities on the Federal level.

The Committee is also responsible for the encouragement of the development of Governmental Activities Committee on the state and local level. It also develops, reviews and updates a Legislative Policy Statement on Health, Education and Welfare issues.

The full committee meets at least once a year and the Executive group, appointed by the chairman, meets as often as necessary.



UNITED CEREBRAL PALSY ASSOCIATIONS, INC.
GOVERNMENTAL ACTIVITIES COMMITTEE (1975-1977)

CHAIRMAN

- * The Hon. Richard C. Loux
Kans. Corp. Commission
State Office Bldg., 4th Floor
Topeka, Kansas 66612

VICE CHAIRMAN

- * Elsie D. Helsel, Ph.D.
188 Longview Heights
Athens, Ohio 45701

MEMBERS

Northeast District

Mrs. Helen Ross
48 Pilgard Lane
Galstonbury, Connecticut 06033

Midwest District

William E. Laughlin
605 16th Street
Lincoln, Illinois 62656

Mideast District

- * Mrs. Ralph L. Lee, Jr.
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Southeast District

Mrs. Grace B. Futch
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Western District

Gerald E. Varty, Esq.
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MEMBERS -AT -LARGE

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D. D./TAS
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- * James Stearns
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Washington, D. C. 20003

Mrs. Georgine E. Willis
3000 San Jacinto Street
Dallas, Texas 75204

Jack O. Hoxsie
9635 Cecilia Street
Downey, California 90241

- * Executive Group Member



ROLE OF THE GOVERNMENTAL ACTIVITIES OFFICE

The Washington office was established in 1968 by UCPA, Inc., to respond to the organizations need to know more about and have more input into legislation.

Our initial objectives for the Washington office were:

- (1) To help our affiliates better utilize federal resources -- at the time UCP went to Washington, "resources" meant "grants";
- (2) To make contact with the informational outlets in Washington and to disseminate this information to our affiliates;
- (3) To get involved in the federal legislative process;
- (4) To establish a presence for UCPA in Washington.

UCPA has established its self in Washington as an effective, efficient, cooperative voluntary organization that not only aggressively advocates for its clients -- individuals with cerebral palsy and their families -- but also is available to staffers on the Hill and in the agencies as a helpful resource. The phones are busy with calls from the Hill and from federal agencies serving the handicapped asking for information, asking UCPA to send a representative to a briefing session or a meeting, asking for help with the preparation of a statement for the Floor, or even asking UCPA to draft language for a bill or an amendment. The staff has learned without batting an eye to produce an instructed witness from Kansas in 24 hours, to submit a statement and 75 copies delivered before the close of business in one day, to write a script for two Senators to engage in a colloquy on the Floor, and to match up the schedule of a Governor of a state and Senator Kennedy for testimony on DDA.

Our Washington office staff consists of Clarke Ross, Assistant Director, Julie Fuller, Legislative Analyst (Part Time) "Patrick" Boulware, Administrative Secretary, and Hal Benson, as Director. It is a close knit staff which must work as a team in order to accomplish its objectives.

Now, although we have done well in establishing a presence in offices concerned with legislation or implementation of programs for the handicapped, up until recently we have not been so well known in offices such as the Department of Housing and Urban Development, the Department of Labor, the Department of Agriculture and Transportation. These programs too have rich resources which we are in the process of learning about. A major task is the monitoring of these federal agencies as they implement legislation passed by Congress.



Concerning our initial objective of getting control of the informational outlets in Washington, not only do we feel we have accomplished this objective, we have done so well that we have become an informational outlet ourselves. Our newsletter Word From Washington goes into almost every state capital in the nation. Our present circulation is about 2500 and rising at the rate of approximately 25 per month.

The staff also produces an in-depth Analysis of pertinent bills, laws, and regulations for programs affecting the handicapped. These Analyses are mailed to a VIP list of executive directors and individuals who give evidence of being interested in legislation. The evidence at this point consists of mailing us copies of letters of interventions with the Congress. Each month the Word From Washington lists the Analyses that are available to any affiliate that wishes to request them. We also send out information memoranda on various subjects, along with copies of special reports and special documents such as laws, regulations and information from other organizations.

Another information service to our affiliates is, of course, our Action Alerts. These cover such action items as availability of grants, need for changes in proposed regulations, and the need for Congressional contact on bills before Congress. We try to keep such Alerts to a minimum, asking affiliates for intervention only when we feel it is extremely important.

In order to help our affiliates learn about the options, the new programs, and how to access them on behalf of our clients, we have a number of directions in which we as a staff move. The essential thing is to respond, as quickly as possible, to requests for information from either Congress, the Administration or our affiliates.

This year, the staff conducted six District Workshops plus participated in sixteen other district, state or local meetings across the country. We have developed a Local Action Manual for the Housing Act to assist people in learning about the key concepts of the legislation, the particular areas of interest to the developmentally disabled and suggestions on what to do on the local level to access the funds and bring about program implementation. This manual has been well received and we hope to develop others as significant legislation is passed which warrants it.

We have an affiliate intern program whereby an affiliate can send someone, at its expense, to spend a week in Washington at our office, learning about the Federal process and significant legislation and its implementation. A program is designed to fit the needs of the individual intern.

The staff is available for individual affiliate consultation as our time and budget allows. Of course, we are always available to respond to your requests by telephone or mail.



The primary priority area of the UCPA Governmental Activities office, the 94th Congress, is accessing comprehensive services for adults severely disabled by cerebral palsy and other developmental disabilities, especially those who are unemployed, residing in inappropriate situations, and who have existed from the school system. The secondary priority area addresses the needs of those developmentally disabled individuals in the early childhood period. Among individuals with disabilities, young children and adults seem to be the most neglected and unserved.

These priority areas are consistent with the UCPA IHF Plan (The Individual with Cerebral Palsy and His Family), the UCPA Bill of Rights for the Handicapped, and the UCPA Legislative Policy Statement on National Health, Education, and Welfare issues.

The staff is confident that it can continue to help affiliates utilize governmental resources at federal, state, and local levels in order to obtain maximal benefits for clients -- individuals with cerebral palsy and their families.



UCPA GOVERNMENTAL ACTIVITIES INTERN PROGRAM

The UCPA Governmental Activities Intern Program has been a successful experience with eighteen interns participating over a twenty month period during 1974-1975.

The basis of the program is to provide the intern with appointments with federal officials and congressional staff who have expertise in program areas in which the intern has an interest. The Washington office requires from each intern a clear statement of the intern's goals and objectives for coming to Washington. These are to be developed from the intern's personal and professional perspective as well as from the local affiliate's perspective. These goals are to be as specific as possible to guarantee appropriate appointment arrangements.

Any individual inquiring into the intern program is forwarded several evaluations and schedules from previous interns. These documents provide the nature and approach of the program. Every intern is expected to develop a well thought-out evaluation with recommendations for improvements.

All costs are to be borne by the affiliate or the intern. Housing is arranged at the Capitol Hill Quality Inn, 415 New Jersey Avenue, N.W., Washington, D. C. 20001. Though somewhat expensive, UCPA has a special rate. The hotel is a ten minute walk from HEW, a ten to fifteen minute walk from the UCPA office, and two to three minutes from congressional offices. It is generally accessible to wheelchair users although problems will be encountered by the more severely disabled. The Washington office arranges reservations at the request of the intern.

Most interns to date - and this we recommend - have arrived Sunday evening and departed Friday late afternoon or evening. Though we structure a full and busy week, we leave free time for congressional appointments, leisure time for museums and the like, and time for business appointments the intern wishes to make on his own.

Every attempt is made to structure the program around the intern's interests and needs. Because of popularity of the program and the time pressures and commitments of both the UCPA intern training coordinator and the federal officials with whom appointments are made, recent arrangements have attempted to have two or three interns share a week. We believe that this small number of individuals still permits individualized attention and we believe that the interns learn a great deal by sharing experiences, background, etc.



It is hoped that interns will bring a dozen or so packets of material with them to distribute at appointments. These packets can be a valuable tool in outlining the local affiliate's programs and future plans.

It should be emphasized that the intern program is not a program to come to Washington and be awarded federal grants, although this has happened. The trend in federal programming today - as exemplified by the General Revenue Sharing, the Comprehensive Employment and Training Act, the Community Development Program, the Housing Assistance Program and the Social Services Program - is that local communities and states are the crucial decision makers, the allocators of federal funds. The intern program permits the local or state affiliate to examine public policy and regulations of a given program from the national level and to understand the role of local and state governments. But with the exception of special project activities, funding allocations are made at local levels, not in Washington.

One last point should be stressed. Some program areas identified by the interns are not adequately recognized nor staffed by federal agencies. Frequently, the best resource for a given area will be a private agency with headquarters or governmental activities offices in Washington. Occasionally, no resource person can be identified for a given area.



GOVERNMENTAL ACTIVITIES INTERN PROGRAM

UNITED CEREBRAL PALSY ASSOCIATIONS, INC.

FACT SHEET

- 1) Time Frame Twenty Months
March 1974 - October 1975

- 2) UCPA One Week Interns 16

Affiliate Executive Directors	4
Affiliate Administrative Staff	3
Affiliate Program Staff	4
Volunteers (not consumers)	4
Consumers	1

- 3) UCPA One Week Interns 16

Northeast District	6
Mideast District	3
Southeast District	1
Midwest District	1
Southwest District	1
Western District	4

- 4) Other Interns 2

State Officer (one week)	1
Student (one month)	1

- 5) Intern Evaluations Available
Upon Request

- 6) Further Information:

E. Clarke Ross
Assistant Director
Governmental Activities Office
UCPA
Chester Arthur Building
Suite 141
425 I Street, N. W.
Washington, D. C. 20001



CONGRESSIONAL ORGANIZATION AND JURISDICTION

All Federal programs are established by an act of Congress. Federal statute has its origin in Congress in the form of a bill. Bills are introduced by either Senators or Representatives and may originate in various ways. They may be introduced by legislators on their own initiative, they may be recommended by the President and his agencies, they may be framed by congressional committees, or they may be the result of proposals from citizens, lobbyists, and special interest groups. Public opinion is extremely important to a bill's consideration. Important to individual legislators is that they receive proper credit for initial sponsorship of a bill. The search for partners or co-sponsorship is the political side of a bill's introduction and one of the lubricants of the legislative process.

All bills are referred to committee for consideration. The standing committees, 22 in the House and 18 in the Senate, are organized along subject matter lines to examine specific categories of legislation. This is known as the committee's area of jurisdiction. Committee members are from all political parties represented in the Congress with the chairman selected from the majority party using the seniority technique. The minority party member with longest tenure on the committee serves as the "ranking minority member." Most substantial legislative functions on a bill (conducting hearing, drafting and considering legislation, etc.) are conducted by subcommittees of the full committee.

Primary Congressional Committees with Jurisdiction Over Legislation of Importance to Persons with Disabilities

- 1) House Committee on Education and Labor has jurisdiction over all education programs, including special education, vocational rehabilitation, programs for children and Headstart.
- 2) House Committee on Interstate and Foreign Committee, Subcommittee on Health and the Environment has jurisdiction over all health legislation and the Developmental Disabilities Program.
- 3) House Ways and Means Committee has jurisdiction over most titles contained in the Social Security Act.
- 4) Senate Labor and Public Welfare Committee holds jurisdiction over federal programs in education, health, poverty, labor, employment, children and youth, and special programs for the handicapped. The Subcommittee on the Handicapped is one of the committee's twelve subcommittees.
- 5) Senate Finance Committee maintains jurisdiction over all programs authorized under the Social Security Act.
- 6) Appropriations Committees, House and Senate. Each chamber of Congress maintains an appropriations committee which annually allocates funds for all federal programs.



Bills reported from committee (once cleared by the Rules Committee in the House) are voted on the floor of the chamber, referred to a Conference Committee composed of members from each chamber if bills on the same subject are passed containing differences, referred back to the floor of each chamber for approval of the Conference Committee agreement, and forwarded to the President. The President has ten days to act on a bill passed by Congress. He may sign the bill into law. He may take no action and if Congress is in session the bill automatically becomes law in ten days. He may take no action and if Congress is in adjournment the bill is "pocket vetoed" and must be reintroduced and repassed. Or the President may veto the bill which requires a two-third vote in each chamber in order to override the veto and make the bill law.

Congress maintains three other functions which are important to fulfilling its responsibilities. Congressional Resolutions are frequently passed as expressions of Congressional intent and purpose. They have no authority as law but are political expressions of opinion. With the assistance of the General Accounting Office (GAO) Congressional Oversight is conducted whereby federal programs are investigated and evaluated. Increasingly, members of Congress have become the ombudsmen of American government, answering mail and attempting to solve problems of individual constituents.

Any organization and individual attempting to influence public policy regarding problems faced by disabled persons must understand this legislative process to be effective.

It is important that five key legislative terms be understood:

Bill: Legislative proposals before Congress are in the form of bills and are designated as HR (House) and S (Senate) according to the Chamber in which they originate and by a number assigned in the order in which they were introduced, from the beginning of each two year Congressional term.

Act: The term for legislation which has passed both houses of Congress and has been signed by the President or passed over his veto, thus becoming law.

Authorization Bill: Authorizes a program, specifies its general aim and conduct and puts a ceiling on monies that can be used to finance it. The monies indicated are the estimate required to meet the need addressed.



Appropriation Bill:

Grants the actual monies approved by the authorization bills, but not necessarily to the total permissible under the authorization bill. Factors such as total revenue, presidential priorities, appropriation history of the program, and congressional priorities greatly influence the actual appropriation level. Appropriation bills originate in the House.

Expenditure:

The actual spending of money as distinguished from the appropriation of it. Expenditures are made by the Administration, Appropriation by the Congress.

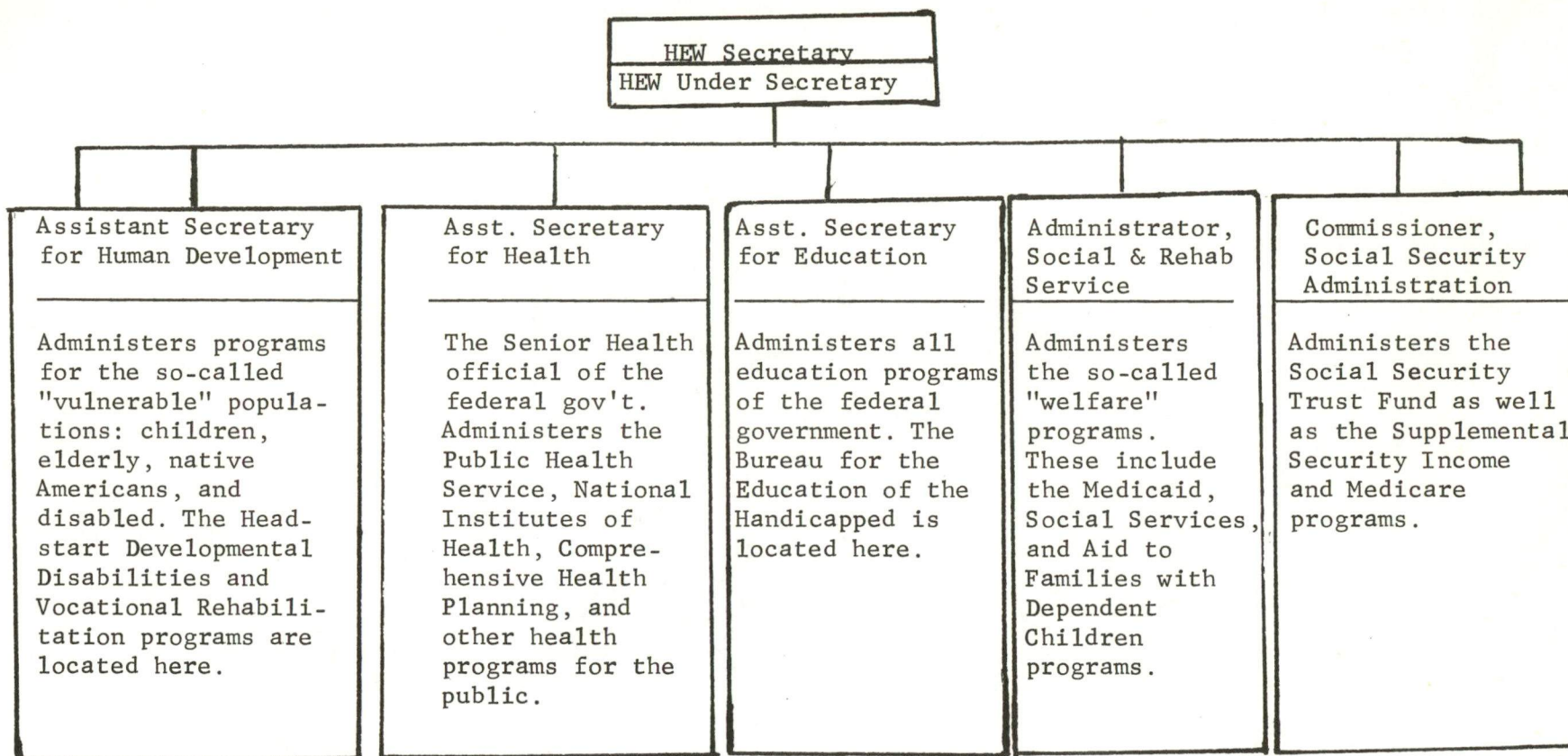


HEW: DESCRIPTION AND ORGANIZATION CHART

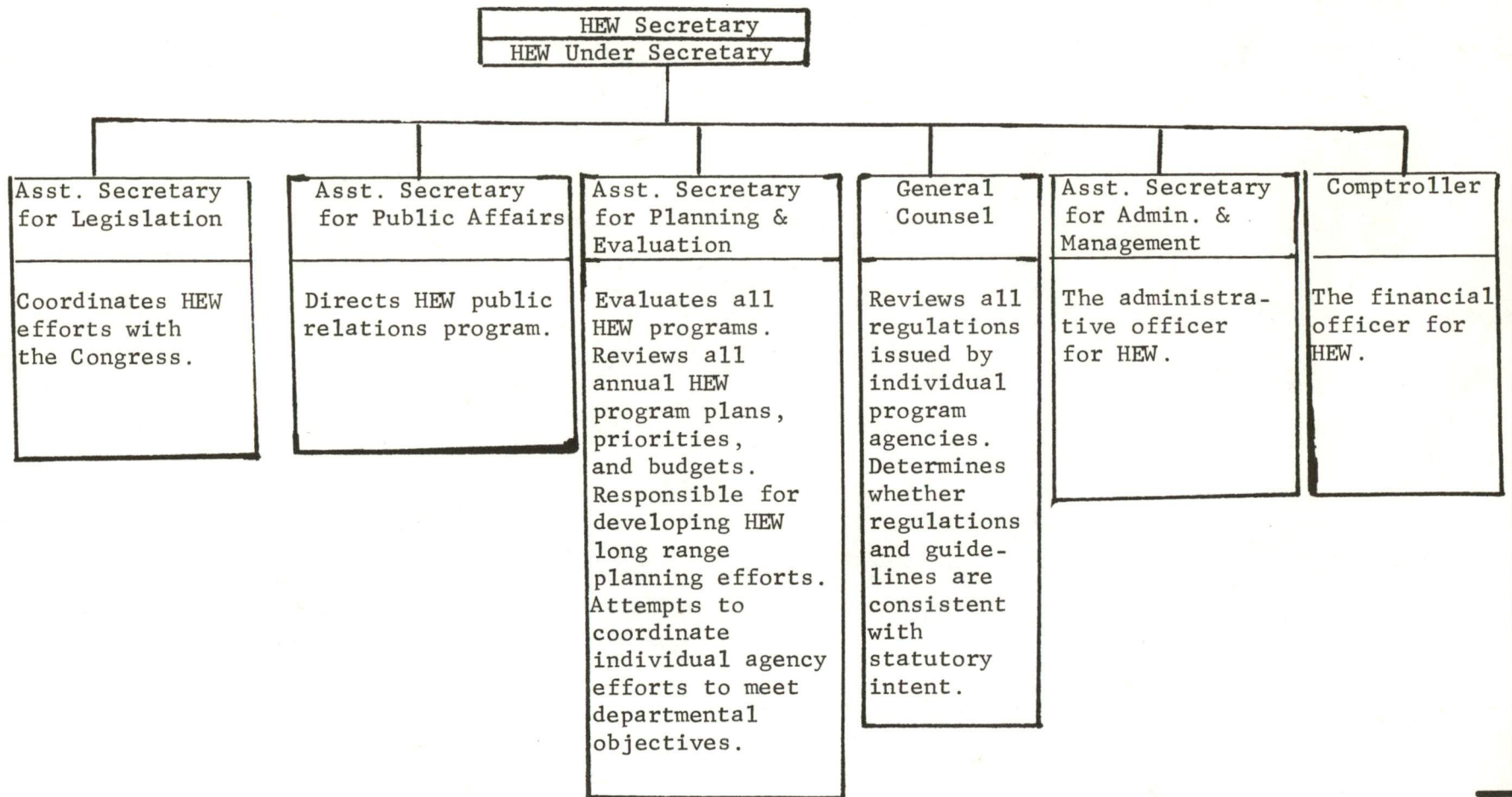
Most of the federal programs reviewed by this Orientation Notebook are administered by the Department of Health, Education, and Welfare (HEW). The largest domestically oriented federal department, HEW administers over 300 programs from its central office in Washington, D. C. and its 10 regional offices. HEW employs roughly 126,000 individuals with an annual budget in excess of \$110 billion. The Secretary of HEW is a member of the President's Cabinet.

On an organizational chart of HEW, two lines of authority immediately become apparent. These lines relate to program directors, the actual administrators of service programs; and administrative directors, the support personnel who attempt to provide uniformity, coordination, and continuity to total HEW efforts.

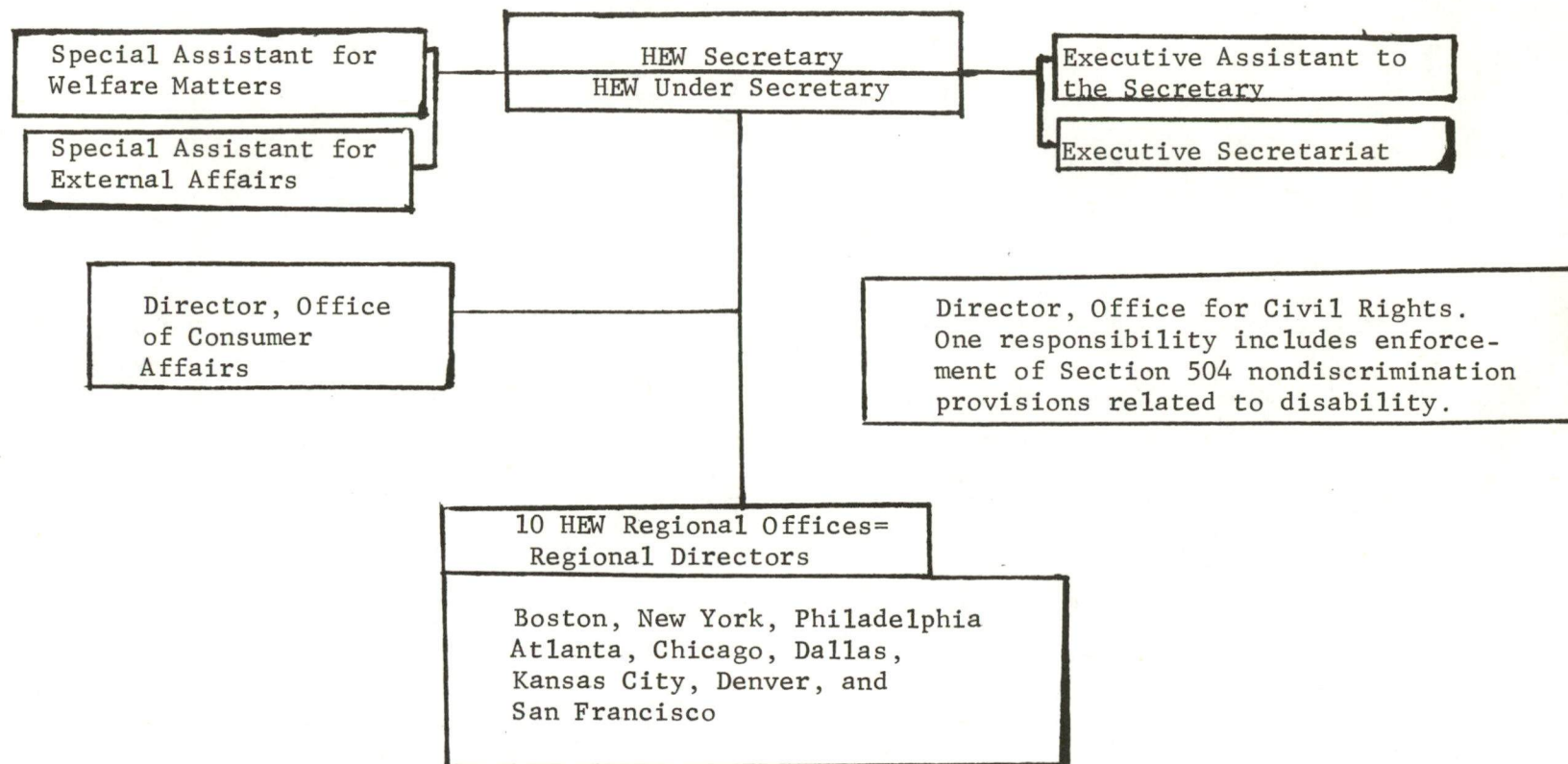
1) Program Directors



2) Administrative Directors



- 3) Other HEW Offices. A number of other offices within HEW are important to the Department's overall activities. Their directors do not carry the seniority or authority of either program directors or administrative directors but they are vital functioning components of HEW.





THE FEDERAL ADVOCATES: DDO, OHI, PCMR, PCEH, ATBCB

There are five separate federal offices which are targeted on the needs of the disabled and have among their responsibilities a mandate of advocacy for the disabled.

- (1) Developmental Disabilities Office (DDO). This office is located under the HEW Assistant Secretary for Human Development. DDO is the federal advocate for individuals with developmental disabilities. The office is responsible for program policy development, preparation of regulations, review of the project grant and University Affiliated Facility grant applications, and overall program management functions to implement the "Developmentally Disabled Assistance and Bill of Rights Act of 1975." DDO also performs the staff functions for the National Advisory Council on Developmental Disabilities.

Address: Developmental Disabilities Office
Room 3070, HEW South Building
330 C Street, S. W.
Washington, D. C. 20201

- (2) Office for Handicapped Individuals (OHI). OHI is also located under the HEW Assistant Secretary for Human Development. OHI's purpose is to focus HEW's planning and resources more effectively for the handicapped. Specifically, the office will prepare a long range projection for the provision of comprehensive services to the handicapped, analyze and evaluate on a continuous basis the operation of programs for the handicapped, encourage coordination and cooperative planning among programs serving the handicapped, develop ways to promote the utilization of research related to the handicapped, and provide for a central clearinghouse for information and resources available to handicapped people.

Address: Office for Handicapped Individuals
Room 3517, HEW South Building
330 C Street, S. W.
Washington, D. C. 20201



- (3) President's Committee on Mental Retardation (PCMR). This office is also under the HEW Assistant Secretary for Human Development. PCMR attempts to focus attention and efforts of government and private citizens on the problems associated with mental retardation. The committee is a group of prominent Americans working in the area of research and manpower development, prevention, service, and information.

Address: President's Committee on Mental Retardation
Room 2614, ROB #3
7th and D Street, S. W.
Washington, D. C. 20201

- (4) President's Committee on Employment of the Handicapped (PCEH). Administratively under the Department of Labor, PCEH fosters communications within and outside government to encourage the employment of handicapped persons. This communication process takes the form of publications, an annual meeting, and working with the Governor's Committees on Employment of the Handicapped. PCEH has organized numerous committees to issue policy statements and recommendations related to barriers and obstacles preventing employment of the handicapped.

Address: President's Committee on Employment of the Handicapped
Room 660
1111 20th Street, N. W.
Washington, D. C. 20210

- (5) Architectural and Transportation Barriers Compliance Board (ATBCB). An interagency committee composed of all federal agencies which impact on architectural and transportation barriers. ATBCB is responsible for eliminating such barriers in federally supported programs as well as investigating and examining alternative approaches to the architectural, transportation, and attitudinal barriers confronting disabled persons.

Address: Architectural and Transportation Barriers Compliance Board
Room 1004, HEW South Building
330 C Street, N. W.
Washington, D. C. 20201



TRENDS IN FEDERAL PROGRAMMING FOR THE SEVERELY DISABLED:
IMPACT ON LOCAL AND STATE SERVICE AGENCIES

If local service programs are to remain viable and operate on a somewhat stable basis, program administrators will have to anticipate trends in public programs at their inception. Every aspect of programming the continuum of services needed by severely disabled individuals during their life span is influenced by state and federal government. This influence can be direct, as in the regulation and monitoring of a grant or contract utilizing federal funds, or it can be very indirect, such as the upgrading of services through the promulgation of standards which may not directly improve services of a single agency but have the effect of improving services in the field at large. Quality of service, financing of service, and management of service are interdependent and all are influenced by public policy developments. This paper outlines the following trends in federal programming for the severely disabled which impacts on local and state service agencies, including affiliates of United Cerebral Palsy Associations.

- Accountability
 - 1) Certification of Need
 - 2) Maintenance of Effort
 - 3) Accreditation/Standards
- Program Services Delivery
 - 1) Individualized Plans
 - 2) Due Process
 - 3) Affirmative Action/Non-discrimination
 - 4) Service Provider - Advocate Relationship
 - 5) Deinstitutionalization
- Financing/Administration
 - 1) Decentralized Decision Making
 - 2) Categorization of Targeted Populations
 - 3) Cost Determinations
 - 4) National Health/Policy/National Health Insurance



Federal programming trends are extremely important but are not the end-all to serving the disabled. As Samuel Johnson once said, "The law is the last result of human experience for the benefit of the public."

● ACCOUNTABILITY

1) CERTIFICATION OF NEED

Federal requirements are increasingly asking the difficult question of the appropriateness of service need in all human services programs. The effort is to prevent duplication, prevent disorganization, prevent the marked unevenness in the accessibility to and level of services. Some examples of this:

- a) Developmental Disabilities. Section 127 of P.L. 91-517 requires that applications for grants be supported by reasonable assurances that grants will not result in any decrease in the level of state, local, and other non-federal funds for services for persons with developmental disabilities.
- b) Social Security. Section 1117 of the Social Security Act requires each state to expend at least an equal amount of state funds that were expended during the previous fiscal year under the Supplemental Security Income, Aid to Families With Dependent Children, and Medicaid programs before federal funds are permitted to be released.

A common federal approach to measuring maintenance of effort is requiring that the aggregate level of non-federal funds available to and spent by recipients of federal funds is no lower for any fiscal year that it was for the year average immediately proceeding the fiscal year in which federal funds were allotted.

3) ACCREDITATION/STANDARDS

As more and more public monies flow into agencies and facilities, the need for increased accountability, quality assurances, and cost saving assurances, increase. Organizations representing the disability field have long advocated the voluntary accreditation process utilizing standards of excellence. These accreditation procedures may be viewed as both an educational and evaluative process. Voluntary standards include those of the Accreditation Council for Facilities for the Mentally Retarded (ACF/MR) of the Joint Commission on Accreditation of Hospitals (JCAH), the American Speech and Hearing Association (ASHA), and the Commission on Accreditation of Rehabilitation Facilities (CARF).



Mandatory, nationwide federal standards were first established when the federal government attempted to implement the Medicare and Medicaid programs. In the past ten years, we have witnessed a marked progression in the objective and scope of national standards. During the late 1960's, the emphasis of federal standards was placed on the physical plant in which services were provided. Questions of safety and sanitation dominated. With the emergence of the 1970's, the scope of standards evolved into program assessment. The quality of services provided by all professional disciplines, the staff-client ratio, outcome measures were the types of activities examined by standards. In 1975, we see the emphasis on standards moving into the area of personal rights. Such items as privacy, confidentiality, individualized treatment plans, the right of the involved to influence the service provided him, have become the foremost areas of discussion and debate.

The federal government is increasingly requiring compliance with certain program standards prior to the receipt of federal funds. Federal programs currently mandating standards of interest to agencies serving the disabled include:

- a) Intermediate Care Facility Program under the Medicaid Program.
- b) Developmental Disabilities. Title II of P.L. 94-103, the Establishment and Protection of the Rights of Persons with Developmental Disabilities.
- c) Medicare standards for such services as home health, physical therapy, and speech pathology.

● PROGRAM SERVICE DELIVERY

1) INDIVIDUALIZED PLANS

Federal services programs are increasingly requiring the development of comprehensive written individualized service plans. These plans are to be reviewed and modified at frequent intervals and to involve the consumer of service in the plan's preparation. Examples are:

- a) Vocational Rehabilitation. Section 102 of P.L. 93-112 requires that a written rehabilitation program be developed for each client. Such a program is to be developed jointly by the VR counselor and the disabled person.
- b) Developmental Disabilities. Title II of P.L. 94-103 requires any agency serving the developmentally disabled and in receipt of federal DD funds must insure that an individualized written habilitation plan is developed and modified at frequent intervals.
- c) Medicare regulations require that outpatient physical therapy and speech pathology services be provided under an individualized written plan to be reviewed periodically by a physician.



- d) Federal Education statute (P.L. 93-389) requires that special education be provided under the guidance of a written individualized plan developed on an interdisciplinary approach and with the objective of improving the capacity of the child to learn and function.

2) DUE PROCESS

Due process of law was once a term only understood by lawyers but now it is becoming part of our everyday vocabulary. It has a special meaning to parents of disabled children and to persons with disabilities. It is a legal way of saying that there are certain principles and practices that must be respected to be sure that every person is treated fairly and is not denied his rights as a citizen. Examples include:

- a) Education. Title VI, the Education for the Handicapped Act, requires states and local school districts to provide procedures for insuring that handicapped children and their parents or guardians are guaranteed procedural safeguards in decisions regarding identification, evaluation, and educational placement of handicapped children.
- b) Social Security. The Supplemental Security Income Program establishes detailed criteria permitting the applicant and recipient to question and challenge decisions regarding his eligibility, payment levels, etc.

3) AFFIRMATIVE ACTION - NON-DISCRIMINATION

Increasingly, the federal government is requiring all recipients of federal funds, and particularly those agencies claiming to serve the disabled, to recruit and place disabled persons in crucial decision making positions. Three examples will demonstrate.

- a) Developmental Disabilities Section 106 of P.L. 94-103 requires each recipient of federal assistance under the DD program shall take affirmative action to employ and advance in employment qualified disabled individuals.
- b) Section 503 of the Rehabilitation Act requires any agency in receipt of a federal contract in excess of \$2,500 shall operate an affirmative action program for persons with disabilities.
- c) Section 504 of the Rehabilitation Act prohibits any otherwise qualified disabled individual from being denied benefits or subjected to discrimination under any program or activity receiving federal financial assistance.



4) SERVICE PROVIDER - ADVOCATE RELATIONSHIPS

Section 141(a) of P.L. 94-103 requires State DD Planning Councils to serve as advocates for persons with developmental disabilities. Many UCPA associated individuals who currently serve on State DD councils are there as advocates. But who is an advocate? Several influential congressional staff members are asking the serious question - can a single agency serve as both an advocate for the disabled and a direct provider of services for the disabled? In the Senate Labor and Public Welfare Committee report on the "Developmentally Disabled Assistance and Bill of Rights act of 1974," the statement is made:

Protective and Personal Advocacy

"The Committee further recognizes that there is an inherent conflict in the role a state must play in delivering services and administering programs for persons with developmental disabilities and in protecting the human and legal rights of such persons. The Committee also believes that it is most important to distinguish between these two roles in light of the nature and the problems confronting such persons who are not able to adequately protect their own rights. It is for this reason that the Committee requires the establishment of a protective and personal advocacy function by the state. The protective and personal advocacy agency or agencies required by this provision shall be independent of any state agency administering or delivering services to developmentally disabled persons.

This newly established agency shall have the authority to review all complaints regarding infringement of human rights, denial of benefits, and any other complaint on the part of an individual. Decisions of this independent agency shall be subject to appropriate judicial review. This protective and personal advocacy is needed to provide the mechanism by which a developmentally disabled individual within the delivery system has a means to reach outside the established delivery system in a case where it is felt that his rights as an individual citizen are being violated."

5) DEINSTITUTIONALIZATION

Section 111 of P.L. 94-103 mandates each state in receipt of federal Developmental Disabilities funds to develop a plan designed to eliminate inappropriate placement in institutions of persons with developmental disabilities and to improve the quality of care and the state of surroundings of persons for whom institutional care is appropriate. The act also requires states to support the establishment of community programs as alternatives to institutionalization. Section 110 of P.L. 94-103 mandates not less than 10% of a state's DD allotment in fiscal year 1976 to be expended for the purpose of developing plans designed to eliminate inappropriate placement in institutions. For each succeeding fiscal year, not less than 30% of the state's allotment must be expended for this purpose.



The President's Committee on Mental Retardation (PCMR) is currently drafting a deinstitutionalization strategy to coordinate Department of Health, Education, and Welfare (HEW) resources in assisting states to meet this objective. Basic to the PCMR effort are activities designed to (a) reduce institutional intake by offering alternative types of placement, (b) increase capabilities and independence of residents through highly skilled care and training, (c) increase community facilities and home like living arrangements, and (d) promote public acceptance of the disabled as neighbors and employees.

o FINANCING/ADMINISTRATION

1) Decentralized Decision Making

New Federalism stresses the importance of states and local communities as the crucial decision making arenas and remains politically attractive today. Examples of such approaches include:

- a) General Revenue Sharing where revenue generated by Federal income tax mechanisms are returned to states, cities, and counties with few strings attached.
- b) Comprehensive Employment and Training Act (CETA) designed to make bloc grants to about 500 local and state prime sponsors who will plan and operate manpower programs to meet local needs.
- c) Community Development (CD) Program providing bloc grants to metropolitan areas to develop viable urban communities.
- d) Housing Assistance Program to provide housing assistance, specifically rent subsidy payments, to low income persons and families.
- e) The Social Services Program which places responsibility on the states to develop comprehensive supportive and social services programs.

Though revenue sharing approaches will continue and primary decision making will rest at the state and local level, the Congress will attempt to target federal priorities for expenditures of funds. These priorities will generally be very broad in nature. For example:

- a) In the General Revenue Sharing program local governments are restricted in their use of funds to the following categories: public safety, environmental protection, public transportation, health, recreation, libraries, social services for the poor and aged, and financial administration.



- b) Emphasis in the CETA program is upon programs of outreach, counselling, training, and supportive services needed to enable individuals to secure and retain employment at their maximum.
- c) Permitted activities under CD program include acquisition of property under certain narrow categories, development of public works, code enforcement, improvement of certain building, removal of architectural barriers, relocation activities, and provision of public services not otherwise available in designated areas.
- d) The Housing Assistance Program permits almost any necessary activity primarily designed to provide decent, safe, and sanitary dwellings to persons and families with low incomes.
- e) Almost any Social Service is permitted provided it is directed at least to one of the 5 following goals: 1) achieving or maintaining economic self-support to prevent, reduce, or eliminate dependency, (2) achieving or maintaining self-sufficiency, including reduction or prevention of dependency, (3) preventing or remedying neglect, abuse, or exploitation of children and adults unable to protect their own interests or preserving, rehabilitating, or reuniting families, (4) preventing or reducing inappropriate institutional care by providing for community-based care, home-based care, or other forms of less intensive care, or (5) securing referral or admission for institutional care when other forms of care are not appropriate or providing services to individuals in institutions.

2) CATEGORIZATION OF TARGETED POPULATIONS

A politically appealing approach to serving individuals in need is to place them in specific categories and establish special programs for each category. The current management trend is one of non-categorization of target populations. This trend is exemplified by the proposed Allied Services legislation (S. 2489) and by the creation within the Department of Health, Education, and Welfare of the Office of Human Development (OHD). S. 2489 would provide grants to states to encourage integrated planning, management, and delivery of human services. OHD represents the so-called "vulnerable" population groups - children, elderly, minorities and the disabled.



Unfortunately, categorization remains today. We are faced with a serious problem of inequity, of marked unevenness in the accessibility to and the level of services. Eligibility rules vary markedly across the country. Preschool children, young adults, and persons residing in rural areas are particularly short changed. Great disparities are found between disabilities. The conclusion of the Rand Study is most accurate:

"Whether a child receives special education assistance and the amount of that assistance depend unmistakably and strongly on where his parents live."

The 1974 Vanderbilt University study on the Future of Children: Categories, Labels, and Their Consequences concludes:

"There are more than a dozen classical categories commonly used to identify the disabilities of exceptional children; among them are mental retardation, emotional disturbance, antisocial behavior and delinquency, economic disadvantage, visual impairments, hearing impairments, speech and language disorders, orthopedic handicaps, neurological impairments, learning disabilities, and developmental disabilities. And there are dozens of other terms more or less synonymous with these. The vocabulary of exceptionality varies from state to state, from profession to profession, from institution to institution, and from time to time.

For a multitude of reasons, these conventional categories and labels and the procedures for arriving at them are inadequate. They are imprecise: they say too little, and they say too much. They suggest only vaguely the kind of help a child may need and they tend to describe conditions in negative terms. Generally, negative labels affect a child's self-concept in a negative way, and probably do more harm than good. We recognize of course, that negative labels refer to real conditions that are inherently undesirable, and we have already noted that it is impossible to get away from labels entirely. What is needed, then is a deepened acceptance and appreciation of the handicapped or delinquent as complex human beings different from yet similar to all others, and for whom any single label will be insufficient. Needed as well are ways of describing individuals that are more precise than the conventional labels.

The reliability of diagnostic procedures leading to the classification of exceptional children is always less than perfect."

A few examples will demonstrate this categorization:

- a) Developmental Disabilities. P.L. 94-103 emphasizes onset of disability before the age of 18, the indefinite continuation of the disability, and the substantial handicap to the person's ability to function normally in society. However, certain



generic categories of disability - mental retardation, cerebral palsy, epilepsy, autism, and dyslexia - are specifically listed in the law for special focus and attention.

- b) Vocational Rehabilitation. Generally, to be eligible for VR services, a disabled person has to be over the age of 13 or 14 years of age and be determined by a rehabilitation counsellor to have some rather immediate potential for employment, preferably competitive employment.
- c) Social Services. A disabled person must either be a recipient of Supplemental Security Income (which itself is strictly means tested), be a member of an AFDC family or fall within the State's median income category before services are offered.

At some point in time, if we are to serve the best interests of the disabled, we must put aside labels, and use single definitions of disability, to permit access to all existing categorical programs. To succeed in accessing services, we must give up our petty jealousies with its accompanying visibility and competitiveness and join together in coalition efforts.

In an effort to reduce fragmentation, provide increased flexibility to the states, and take the first steps, UCPA is advocating standardization of eligibility for SSI (Title XVI), Medicaid (Title XIX), and Social Services (Title XX).

3) COST DETERMINATIONS

Social professionalism, the financial management of human services programs, is emerging in state legislatures as a priority activity. This means that the increased cost of providing human services and the concept of measurement as it relates to cost is becoming the most important business of State legislatures. The concept of measurement as it relates to cost is becoming a realistic means of influencing legislative decisions. Thus, agencies serving the developmentally disabled must compete with other pressing needs. Good program management must have verifiable cost reporting procedures.

Cost accounting serves four major purposes. (a) To explain program operations and the purposes for which funds are used. (b) To improve internal program efficiency by enabling careful examination of each cost item to see if services could be performed or obtained at less expense through a change in operating procedures. (c) To provide a basis for evaluating the effects of a program to ascertain if it warrants expansion or contraction. (d) To assist in comparing alternative ways of providing services to ascertain which alternative achieves the states purpose at the least cost.



4) NATIONAL HEALTH POLICY/NATIONAL HEALTH INSURANCE

There are many persons in the country who feel that the enactment of a national health insurance program will provide solutions to many of the problems faced by providers and consumers alike. As of today, this is not so. The current expectation is that national health insurance (NHI) will be an incremental approach. The first step will be the amendment of the Medicare program (Title (XVIII) of the Social Security Act to simplify reimbursement, improve management, and slowly increase benefits. We must remember, NHI is primarily a financing mechanism, not an overall reform program.

Examining the current national health insurance discussions, the "National Health Planning and Resources Development Act of 1974," and HEW "Forward Plan for Health, FY 1977-1981," we easily see four primary areas of focus:

- a) An emphasis on acute care - symptoms and conditions having a rapid onset, which are pronounced, and which are of relatively short duration.
- b) An emphasis on catastrophic coverage - currently viewed in terms of financial catastrophies related to health and not covering conditions.
- c) An emphasis on preventive care - the focus being on the underlying conditions or antecedent causes of preventable diseases rather than on the diseases themselves. This relates more to environmental and attitudinal causes than to such activities as screening and diagnosis.
- d) An emphasis on restorative care - this means providing concentrated and comprehensive services to the individual disabled on the job in order to get that person back into the economy as quickly as possible. Maintenance care and habilitation services are clearly excluded from this focus.

● CONCLUSION

A quotation by Senator Abraham Ribicoff seems an appropriate closing:

"We seem unwilling to admit the truth about legislation, that it is only speculation: a theory, a hope, a guess, a leap of faith. All we are saying in any bill is that we think this proposal is worth a try. This is the program that represents the best of our collective thinking, or what we hope is our best, about the step the nation needs to take at this point in time."



CURRENT ISSUES OF FEDERAL LEGISLATION AND PROGRAM IMPLEMENTATION:
FROM THE PERSPECTIVE OF WASHINGTON BASED COALITION EFFORTS
ON BEHALF OF THE DISABLED

INTRODUCTION

Developmental Disabilities Act as Stimulant

Essentials for Interagency Collaboration and Coalition Development

Washington Based Coalitions

- (1) Consortium Concerned With Developmental Disabilities
 - a) Task Force on Developmental Disabilities
 - b) Task Force on Education
 - c) Task Force on SSI-Social Services-Medicaid
 - d) Task Force on Health
 - e) Task Force on Housing
- (2) National Health Council
- (3) CEC Interagency Group
- (4) Easter Seal Ad Hoc Committee
- (5) National Coalition on Housing and the Handicapped
- (6) Social Services Coalition
- (7) National Center for Voluntary Action
- (8) Children's Defense Fund
- (9) Rehabilitation Planning Group

CONCLUSION

Appendix: Consortium Concerned With Developmental Disabilities



It is generally agreed upon today that interagency collaboration and the utilization of coalitions is desirable and necessary. It is agreed that collaboration and coalitions reduce fragmentation, reduce inefficiency, eliminate duplication, and increases political influence on public policy decisions. But the difficult questions are how do we specifically collaborate and how do we specifically converge our lines of responsibility.

When one refers to collaboration and coalitions, we believe that many of the national organizations serving the disabled with Washington based offices, particularly those serving the developmentally disabled, have gained insight and experience over the last several years. This paper will discuss those experiences and insights while reviewing current issues of federal legislation and program implementation which the coalitions to which UCPA belong are presently addressing.

Developmental Disabilities Act as Stimulant

The stimulus behind most UCPA Washington collaborative efforts was the enactment of the Developmental Disabilities (DD) Act. The DD Act layed the groundwork for a truly coordinated attack on the problems of substantially handicapped individuals whose disabilities originated early in childhood. The approach and concept of writing federal legislation based on a functional approach to meeting needs was an abrupt about face from previous categorical approaches. Even today, there are many who are reluctant to accept a non-categorical, functional approach to accessing services for the disabled.

The DD act established a mechanism at the federal and state level which potentially develops a comprehensive service network across departmental lines to maximize the potential of the target group, protect their civil and human rights, permit them maximum opportunity for making their own decisions and choices to the degree that they are able, and to live their lives with dignity in the community with their peers. The focal point of this mechanism is the State DD Planning Council which is mandated to have as their membership representatives of the principle State Service agencies, representatives of local agencies and non-governmental organizations serving the developmentally disabled, professional representatives, and at least one-third of the membership to be consumers or their parents or guardians.

An extension bill is currently sitting on President Ford's desk for signature or veto. This bill would greatly expand the role of the State DD Planning Council, and further broaden the definition of developmental disability to reemphasize the functional approach to serving the disabled.

Essentials for Interagency Collaboration and Coalition Development

There are several essential elements which must be addressed if coalitions are to develop and be effective.

- (1) Agency Identification. Before agencies can collaborate, they must have a clear identity and understanding of their



own purpose and of their sister agencies. A determined effort must be made to delineate the similarities, differences, and overlapping functions with clarification of areas of function, competency, and effectiveness taking place in the process. Are agency priorities similar?

(2) Staffing Patterns. Does each agency have sufficient staff or a knowledgeable volunteer to devote to collaborate efforts? Are there sufficient and feasible ways for staff functions and roles to become more interlocking? Are agencies willing to share information and expertise?

(3) Respect. Basic to interagency collaboration, no matter what the nature of the agencies, is the need to develop and foster goodwill, understanding, and respect for each other. This respect must encompass the dignity of agencies and the persons who staff the agencies.

WASHINGTON BASED COALITIONS

The remainder of this paper will review nine existing coalitions composed of Washington based legislative offices; will briefly discuss the origin, organization, and success of the coalition; will review its areas of concentration; and will discuss the pending legislative issues considered by each coalition.

(1) Consortium Concerned With Developmental Disabilities (CCDD)

In the spring of 1973, the five national organizations primarily involved with the implementation of the Developmental Disabilities Act - the National Association for Retarded Citizens, the Epilepsy Foundation of America, United Cerebral Palsy Associations, the National Association of State Mental Health Program Directors, and the National Association of Coordinators of State Programs for the Mentally Retarded - expanded their ad hoc planning committee and invited some 50 national organizations to come together and organize the CCDD. Today, 21 national organizations (list attached) representing 8 consumer, parent voluntary health agencies; 5 professional associations; 4 state agency representatives; 3 provider groups; and 1 private foundation, comprise the CCDD. In addition, the past and current chairman of the National Advisory Council on Services and Facilities for the Developmentally Disabled serve CCDD as honorary advisors.

CCDD attempts to coordinate and complement governmental activities of member organizations on national policy issues related to federal legislation and program implementation. In its first year and a half, the CCDD met every six to eight weeks. It soon became obvious that a core of six to ten organizations were undertaking all substantial activity and the six week meetings were merely briefing sessions for the other organizations. Needless to say, the "workers" were becoming very frustrated and felt the six week meetings were wasting valuable time.



In December 1974, CCDD reorganized itself into five small working groups- Task Forces. Task Force chairmen were selected on the basis of the involvement and priority of the organization with the task force activity. The full CCDD meets formally twice a year for briefing by task force chairmen, for adoption and discussion of policy positions recommended by the task forces, and occasionally meets around crisis issues when called together by the CCDD chairman with the advice of the Task Force chairmen.

(a) CCDD Task Force on Developmental Disabilities

Chaired by the National Association for Retarded Citizens (NARC), the task force is charged with monitoring the Developmental Disabilities Act. The task force's priority is enactment of an extension bill for at least three years. Specific issues may be discussed during the question and answer period.

(b) CCDD Task Force on Education

Chaired by the Council for Exceptional Children (CEC), the task force is currently engaged with passage of the Education for All Handicapped Children's Act and monitoring implementation of the Education Amendments of 1974. The task force meets with the Associate Commissioner of Education for the Bureau of Education for the Handicapped every six months regarding program implementation.

The Education for all Handicapped Children's Act has passed both the House and Senate and has been referred to Conference Committee. These bills are historic milestones in the affirmation of the basic constitutional rights of disabled children and their parents and in the assurance of a firm federal commitment to assist the states and localities in providing the necessary financial resource for the education needs of such children. Some of the unresolved issues include:

(1) Target Date to insure that all disabled children have an appropriate education available to them. Missing in the House bill (H.R. 7217) and not later than 1978 in the Senate bill (S.6).

(2) Distribution Formula. The House bill would pass all money through the state to the local school districts. The Senate bill would allow the State Education agency to retain 60% of the federal funds with 40% being passed through to the local areas.

The house bill would allocate federal funds based on $\frac{1}{2}$ of the national average expenditures (\$600) per pupil school childxthe number of handicapped children being served in each state. The Senate bill would allocate funds based on formula multiplying \$300x the number of handicapped children being served in each state.



(c) CCDD Task Force on SSI - Social Services-Medicaid

Chaired by the National Association of Coordinators of State Programs for the Mentally Retarded (NACSPMR), the task force is currently engaged with implementation issues related to Titles XVI, XIX, and XX of the Social Security Act.

(1) SSI. The House Ways and Means Committee is currently marking up H.R. 8911 and H.R. 8912, a package of amendments to the Supplemental Security Income program. The amendments of foremost interest to CCDD include:

(a) A provision to permit the full SSI payment to continue for the first four months after a person is institutionalized. Under current law the payment automatically drops to \$25 a month, thus making it difficult for persons receiving short term institutional care to maintain their living arrangements in the community.

(b) A provision to limit the definition of child to age 18 in all cases. Under current law, parental liability applies to students ages 18-21.

(c) A provision to mandate the referral of disabled SSI children to the Maternal and Child Health/Crippled Childrens Services program. Current laws requires no referral for young children and referral of older children (over 13 or 14) to the Vocational Rehabilitation Agency.

(d) A provision to change the current one-third reduction in SSI payments which occurs when a recipient lives in the household of another to one-fifth reduction.

(e) A provision to disregard all housing support payments through HUD programs, especially the Section 8 housing assistance payments program, in calculating SSI eligibility and payment levels. Rental subsidies are currently considered unearned income for SSI purposes.

(f) A provision to permit non-profit charitable organizations to subsidize a person living outside an institution without considering the subsidy as income available to the person. The subsidy must be targeted to a documentable need of the SSI recipient.



(2) Medicaid. The task force is engaged in implementation difficulties with HEW. These include:

- a) The issuance of rights of residents in intermediate care facilities (ICF's). Such rights would be personal management of one's own financial affairs, confidentiality of records, association and communication with persons of one's own choosing, privacy during visits, right to have unannounced visitors during specified hours, and retention of personal clothing and possessions.
- b) Opposition to the challenge of Oklahoma and other states to submitting an acceptable state plan for meeting ICF/MR standards by 1977.
- c) Expansion and improvement in the delivery of home health care benefits.

(3) Social Services. Implementation issues again dominate.

- a) To access staff training funds for CCDD member chapters.
- b) To oppose an effort to eliminate the means test just for the elderly. The CCDD believes such an attempt would discriminate between different groups within the Title XX population. Such an issue should be approached in an equally applicable basis and a spend-down provision should be incorporated.
- c) To attempt to modify regulations governing eligibility documentation which are excessive, costly, and threaten confidentiality.
- d) To support S. 2425 to increase the present \$2.5 billion appropriations ceiling to permit an additional \$500 million for day care services.

(d) CCDD Task Force on Health

Chaired by the National Society for Autistic Children (NSAC), the task force is engaged in monitoring national health insurance congressional proposals and working with HEW in implementing the Medicaid Early Periodic Screening, Diagnosis, and Treatment Program (EPSDT). The CCDD Task Force is represented on HEW's interagency task force with emphasis on the development of an appropriate developmental screening tool.

(e) CCDD Task Force on Housing

Chaired by United Cerebral Palsy Associations (UCPA), the task force has launched efforts with Congress, with HUD, and with



the private housing industry sector.

(1) The task force is the author and initiator behind the SSI amendment to disregard housing payments in determining SSI eligibility and payment levels.

(2) The task force has testified before the Architectural and Transportation Barriers Compliance Board at their June national hearing and before various HUD meetings outlining barriers and obstacles preventing successful implementation of the Housing and Community Development Act in meeting the housing needs of the disabled. These efforts include encouraging HUD to initiate a training program for local housing authority officials related to P.L. 93-383 and the disabled, the naming of HUD Regional Office Coordinators of Programs for the Elderly and Handicapped, the linking up of HEW-HUD-DOT programs to provide the necessary program support of housing for the disabled, the updating of housing design standards to ensure accessibility by the physically disabled, the launching of the Section 202 housing construction program with proper coordination with State DD Councils, the publication of a HUD brochure on how community agencies serving the disabled should involve themselves with HUD, and the development of internal HUD reporting mechanisms to evaluate HUD success in serving the disabled.

(3) CCDD task force appointment to two special federal project advisory committees: The National Association of Housing and Redevelopment Offices (NAHRO) project to publicize housing benefits for the disabled under P.L. 93-383 and the National Academy of Sciences (NAS) project to work with the National Association of Home Builders (NAHB) to encourage barrier free housing design.

UCPA is deeply committed to the CCDD as demonstrated by its membership on all five task forces.

(2) National Health Council (NHC)

The National Health Council (NHC) is composed of 74 national organizations which act to advance the nation's health. Formed in 1921, NHC represents almost all the major national voluntary health organizations, **as well as**, professional, civic, insurance, and government groups with a strong health orientation. The ultimate purpose is to facilitate cooperation and mutual understanding among members. The Council's primary activities include health education, clearinghouse for health information, and annual assessments of associations implying accreditation and high standards.



In 1974, NHC established a Washington Office to keep members informed of legislative and judicial activities which impact on all members. One of the foremost objectives of the NHC Washington office is to avoid duplicating any single member's efforts

Washington based members meet every three months to share information and develop joint strategy. Where possible, NHC represents all member agencies. NHC efforts to date have been involved with legislation to regulate the lobbying efforts of voluntary, tax-exempt organizations; to regulate charitable contribution solicitation; to amend the Internal Revenue Code relating to tax exemptions for certain types of charitable giving; and to work with HEW in its development of Forward Health Plan, F.Y. 1977-1981. UCPA's Governmental Activities Director serves on the NHC Government Relations Committee.

In addition, the NHC Washington Office sponsors the Health Organization Seminar where members may informally discuss public health policy over dinner with prominent federal officials and congressional members.

(3) CEC Interagency Group

Once a year, the Council for Exceptional Children (CEC) calls together all interested parties for an extended day long discussion of special education public policy developments. This group includes almost everyone whose involved with special education on the Washington scene.

(4) Easter Seal Ad Hoc Committee

A top priority of the National Easter Seal Society for Crippled Children and Adults is the enactment of a national health insurance program which will include comprehensive rehabilitation benefits. The Easter Seal Society periodically calls together all rehabilitation interests to discuss and plan joint activity in this area.

National health insurance will be developed in incremental steps, not in one comprehensive program. In 1973, with enactment of P.L. 92-603, disabled recipients of Social Security (Title II) were announced eligible for the Medicare Program (Title XVIII). A primary focus of the Easter Seal Ad Hoc Committee has been to seek congressional amendment of Medicare to insure fuller utilization of rehabilitation benefits. Specifically:

- (a) To reduce the 24 month waiting period before disabled persons are eligible for Medicare.
- (b) To clarify that outpatient rehabilitation facilities are acceptable providers for Medicare purposes.
- (c) To raise the unacceptably low rate of reimbursement for physical therapy, occupational therapy, and speech therapy. Medicare regulations establish a single schedule of reimbursement rates which do not recognize the variations in overhead costs of providers of various size.



(d) To increase benefits under Medicare to include a comprehensive rehabilitation program.

(5) National Coalition on Housing and the Handicapped

In the fall of 1974, supported by a federal grant, a coalition of organizations led by Goodwill Industries and including UCPA, sponsored the first national conference on housing and the handicapped. One outgrowth of that conference was the formation of a National Coalition on Housing and the Handicapped. The Coalition has been a failure though it continues to exist. It has been a failure for several reasons:

(a) Only the Coalition members who belong to the Consortium Concerned with Developmental Disabilities have chapters seeking the creation of housing programs at the local level.

(b) Few national organizations are willing to permit intensive staff involvement in coalition activities. Limited funding and other priorities have taken their toll.

(c) A large scale coalition representing the nation is a dream of a few hard working and conscientious individuals but not of many national organizations at this point in time.

(6) Social Services Coalition

This is a coalition of over 40 national organizations involved with the social services programs. Its members include the National Governors Conference, the American Public Welfare Association, the AFL-CIO, the Child Welfare League, and its leader, the National Association of Social Workers. Only four disability organizations belong: NARC, UCPA, NACSPMR, and NASMPHD.

P. L. 93-647, which established the new Title XX Social Services program is the culmination of over two years of coalition efforts with HEW and the Congress. The coalition continues to meet whenever new legislative developments and implementation problems arise. It is the single best example of the potentiality of coalition efforts for it represents the full continuum of the human services field and achieved an acceptable social services program when it was one of the most controversial federal programs ever enacted.

(7) National Center for Voluntary Action (NCVA)

The NCVA calls together voluntary organizations when issues arise which affect the entire field. The issues considered by the National Health Council are all priorities of NCVA as well as recent congressional efforts to provide tax deductions to volunteers working for various types of tax exempt organizations.



(8) Children's Defense Fund

UCPA regularly joins the Leadership Conference on Civil Rights by invitation of the Children's Defense Fund when issues arise concerning civil rights and the disabled. The Leadership Conference represents 140 organizations representing minority groups, women, and disabled persons. In addition to the general issues of civil rights, two federal statutory provisions specifically relate to the disabled.

(a) Section 503 of the Rehabilitation Act requires any agency in receipt of a federal contract in excess of \$2,500 shall operate an affirmative action program for persons with disabilities.

(b) Section 504 of the Rehabilitation Act prohibits any otherwise qualified disabled individual from being denied benefits or subjected to discrimination under any program or activity receiving Federal financial assistance.

(9) Rehabilitation Planning Group

Coalitions are frequently the work of one dominant personality. This is true with the coalition efforts in Washington involved with the Vocational Rehabilitation program. For 40 years E. B. Whitten was executive director of the National Rehabilitation Association (NRA). A powerful and influential rehabilitation coalition operated for years under E. B.'s guidance. It included every major component of the rehab field - providers, professionals, consumers, public officials, and interested parties.

In 1974, E. B. Whitten retired. And with him went the Rehabilitation Coalition. With the Rehabilitation Act of 1973 approaching the extension period again, the International Association of Rehabilitation Facilities (IARF), a provider organization whose priority lies with rehab agencies, has called together a rehabilitation planning group. But the old togetherness is missing and the rehab field is missing an effective coalition. The focus of IARF is too narrow to encompass the entire rehab field.

CONCLUSION

Coalition efforts can be successful and can provide the margin between achievement and failure. To work, individual coalition members must be honest with themselves and with each other. A commitment to the overall effort must be made. Interagency collaboration is a thrust of future endeavors.

In looking at the future, Robert F. Kennedy said: "We must consider how we propose to get there and what obstacles lie in our path. For such a vision is never self-fulfilling. We cannot stand idly by and expect our dreams to come true under their own power. The future is not a gift: it is an achievement. This is the essential challenge of the present."



APPENDIX ONE: THE CONSORTIUM CONCERNED WITH DEVELOPMENTAL DISABILITIES

The Consortium Concerned with Developmental Disabilities (CCDD) is a coalition of 22 national organizations primarily concerned with legislation and federal governmental programs impacting on those citizens with developmental disabilities. Formed in the spring of 1973, CCDD attempts to coordinate and complement governmental activities of member organizations on national policy issues. To facilitate this coordination, CCDD established five small working groups - Task Forces - in December 1974. Of the five groups organized, one was a Task Force on Housing. The list of full CCDD members and the Task Force on Housing follows:

Consortium Concerned With Developmental Disabilities

- *National Association for Retarded Citizens
- *United Cerebral Palsy Associations
 - Epilepsy Foundation of America
 - American Association on Mental Deficiency
- *National Easter Seal Society for Crippled Children and Adults
 - American Speech and Hearing Association
 - Council for Exceptional Children
 - Association of University Affiliated Facilities
 - National Council of Community Mental Health Centers
 - National Association for Mental Health, Inc.
 - Spina Bifida Association
- National Association of State Mental Health Program Directors
- *National Association of Coordinators of State Programs for the Mentally Retarded
 - Association for Children with Learning Disabilities
 - National Society for Autistic Children
- *National Association of Private Residential Facilities for the Mentally Retarded
 - National Association of Superintendents of State Residential Facilities
 - Council of State Administrators of Vocational Rehabilitation
 - Joseph P. Kennedy Foundation
 - American Occupational Therapy Association
 - National Association of School Psychologists
 - National Conference on Developmental Disabilities
 - Chairman, National Advisory Council on Services and Facilities for the Developmentally Disabled (Honorary Advisor)
 - Elizabeth M. Boggs, Ph.D., former chairman
 - Jewel B. Hamilton, current chairman

*Task Force on Housing Members



ADVOCACY

"The Committee further recognizes that there is an inherent conflict in the role a state must play in delivering services and administering programs for persons with developmental disabilities and in protecting the human and legal rights of such persons. The Committee also believes that it is most important to distinguish between these two roles in light of the nature and the problems confronting such persons who are not able to adequately protect their own rights. It is for this reason that the Committee requires the establishment of a protective and personal advocacy function by the state. The protective and personal advocacy agency or agencies required by this provision shall be independent of any state agency administering or delivering services to developmentally disabled persons.

This newly established agency shall have the authority to review all complaints regarding infringement of human rights, denial of benefits, and any other complaint on the part of an individual. Decisions of this independent agency shall be subject to appropriate judicial review. This protective and personal advocacy is needed to provide the mechanism by which a developmentally disabled individual within the delivery system has a means to reach outside the established delivery system in a case where it is felt that his rights as an individual citizen are being violated."

(From the Senate Labor
and Public Welfare
Committee Report on
Extension of the
Developmental Disabilities
Act)

The "Developmentally Disabled Assistance and Bill of Rights Act" (P.L. 94-103) establishes a new statutory mechanism to create and protect the rights of persons with developmental disabilities. Emphasis on the program is placed on personal, protective, and group advocacy.



(1) P.L. 94-103, Congressional Findings, Rights of Persons With Developmental Disabilities

"Sec. 111. Congress makes the following findings respecting the rights of persons with developmental disabilities:

"(1) Persons with developmental disabilities have a right to appropriate treatment, services, and habilitation for such disabilities.

"(2) The treatment, services, and habilitation for a person with developmental disabilities should be designed to maximize the developmental potential of the person and should be provided in the setting that is least restrictive of the person's personal liberty.

"(3) The Federal Government and the States both have an obligation to assure that public funds are not provided to any institutional or other residential program for persons with developmental disabilities that--

"(A) does not provide treatment, services and habilitation which is appropriate to the needs of such persons; or

"(B) does not meet the following minimum standards:

"(i) Provision of a nourishing, well-balanced daily diet to the persons with developmental disabilities being served by the program.

"(ii) Provision to such persons of appropriate and sufficient medical and dental services.

"(iii) Prohibition of the use of physical restraint on such persons unless absolutely necessary and prohibition of the use of such restraint as a punishment or as a substitute for a habilitation program.

"(iv) Prohibition on the excessive use of chemical restraints on such persons and the use of such restraints as punishment or as a substitute for a habilitation program or in quantities that interfere with services, treatment, or habilitation for such persons.

"(v) Permission for close relatives of such persons to visit them at reasonable hours without prior notice.

"(vi) Compliance with adequate fire and safety standards as may be promulgated by the Secretary.



"(4) All programs for persons with developmental disabilities should meet standards which are designed to assure the most favorable possible outcome for those served, and--

"(A) in the case of residential programs serving persons in need of comprehensive health-related, habilitative, or rehabilitative services, which are ~~at~~ **least equivalent** to those standards applicable to intermediate care facilities for the mentally retarded promulgated in regulations of the Secretary on January 17, 1974 (39 Fed. Reg. pt.II), as appropriate when taking into account the size of the institutions and the service delivery arrangements of the facilities of the programs;

"(B) in the case of other residential programs for persons with developmental disabilities, which assure that care is appropriate to the needs of the persons being served by such programs, assure that the persons admitted to facilities of such programs are persons whose needs can be met through services provided by such facilities, and assure that the facilities under such programs provide for the humane care of the residents of the facilities, are sanitary, and protect their rights; and

"(C) in the case of non-residential programs, which assure the care provided by such programs is appropriate to the persons served by the programs."

(2) Federally Supported State Advocacy Offices

Under P.L. 94-103, by October 1, 1977, every state, as a condition to receiving any funds authorized under the Developmental Disabilities Act, must have in effect a system to protect and advocate the rights of persons with developmental disabilities. Such a system will have the authority to pursue legal, administrative, and other appropriate remedies to insure the protection of the rights of persons receiving treatment, services, or habilitation because of their developmental disabilities. This system must be independent of any state agency which provides treatment, services, or habilitation.

(3) Role of State DD Councils

The Developmental Disabilities Technical Assistance System (Chapel Hill, North Carolina) maintains that State Developmental Disabilities Councils have enormous potential as a unique structure in state government for advocating an improvement of a total system of service delivery for persons who are developmentally disabled. That potential can be developed if the Council is able to: (1) generate, specify, and organize for



effective action its own convictions and beliefs, relative to the problems of serving the developmentally disabled; (2) develop a leadership and operational style that has workable diplomacy in that state's organizational/bureaucratic ecology, and (3) acquire the technical competencies necessary in order to efficiently and effectively implement its intentions and to interact successfully with other organizations. The advocacy of the Council is evidenced in two ways: (1) the value system or beliefs it adopts and (2) its own actions which give witness to those values.

The State Council's role is vital. Confronting the system is most effective when the system as a whole is understood. The various laws and regulations responding to the needs of the developmentally disabled are often complex and detailed. Specialists at the state level are needed to constantly examine written material and provide relevant considerations for local advocates.



CIVIL RIGHTS, NONDISCRIMINATION, AND
AFFIRMATIVE ACTION

Title VI of the Civil Rights Act of 1964 forbids discrimination on the basis of race, color, or national origin in any federally assisted program. Title IX of the Education Amendments of 1972 prohibits discrimination on the basis of sex in federally aided education programs. Only recently, have attempts been made to eliminate discrimination against persons with disabilities.

(1) Nondiscrimination, Section 504

Section 504 of the Rehabilitation Act of 1973 (P.L. 93-112) is the primary non-discrimination clause in federal statute relating to the disabled. Section 504 reads: "No otherwise qualified handicapped individual in the United States -- shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance."

The parameters and scope of this provision remain undefined for no regulations have been issued on the subject. The Office of Civil Rights, Room 3256, HEW North Building, 330 Independence Avenue, S. W., Washington, D. C. 20201, has administrative responsibility for implementing Section 504.

(2) Affirmative Action, Section 503

Section 503 of the Rehabilitation Act of 1973 (P.L. 93-112) requires government contractors and subcontractors to take affirmative action to employ and advance in employment qualified handicapped individuals. The purpose of Section 503 is to open up more employment opportunities for qualified handicapped persons and eliminate job discrimination based on handicaps. The program is administered by the Office of Contracts Compliance, Employment Standards Administration, Department of Labor, Room N-3318, 200 Constitution Avenue, N. W., Washington, D. C. 20210.

Proposed regulations were issued on August 29, 1975. The affirmative action program applies only to contractors and subcontractors holding a contract of \$50,000 or more and having 50 or more employees. Each contractor must maintain an affirmative action program at each establishment, which shall be kept separate and distinct from any affirmative action program required under any other law. A summary of the affirmative action program must be disseminated to all incumbent and newly hired employees. The clout rests with the provision that contractors must make reasonable accommodation to the physical and mental limitation of an employee or applicant "unless the contractor can demonstrate that such an accommodation would impose an undue hardship on the conduct of the contractor's business." The factors included in undue hardship determination are business necessity, financial cost and expenses, and resulting personnel problems.



EVOLUTION OF THE DD CONCEPT

The first Federal Developmental Disabilities law P.L. 91-517 enacted in 1970 set forth this legal definition of developmental disability: In Section 102(1) 7.

(1) The term "developmental disability" means a disability attributable to mental retardation, cerebral palsy, epilepsy, or another neurological condition of an individual found by the Secretary to be closely related to mental retardation or to require treatment similar to that required for mentally retarded individuals, which disability originates before such individual attains age eighteen, which as continued or can be expected to continue indefinitely, and which constitutes a substantial handicap to such individuals.

In September, 1972, Federal Regulations clarified this definition by specifying that an individual with any of the three conditions -- mental retardation, cerebral palsy, epilepsy -- would qualify automatically as developmentally disabled provided there was a "substantial handicap."

"Substantial handicap: was defined in the Regs:

(t) "Substantial Handicap" means that a physical or mental disability is of such severity that, alone or in connection with social, legal or economic constraints, it requires the provision of specialized services over an extended period of time directed toward the individual's social, personal, physical or economic habilitation or rehabilitation.

The Secretary of HEW never defined any "other neurological conditions." However, new legislation instructs HEW to submit a report to Congress within six months from enactment, specifying the conditions that should be amended under the definition of developmental disabilities. Also, HEW is to contract outside of HEW for an objective study to determine the basis of the definition of developmental disabilities.

To date, the definition of developmental disability, as set forth by Congress in legislation and as interpreted by the Executive Branch in Regulations, has relied heavily on the medical, diagnostic categories. Definition by diagnostic category is useful in part as a widespread short-hand system to denote a variety of conditions.

The definition of developmental disabilities in the 1970 DD Act clustered three categorical disorders, mental retardation, cerebral palsy and epilepsy. It is important to understand the thinking of those who developed the definition. In 1970, empirical data was available on two points (1) all three of the conditions are major causes of substantial handicap to adults disabled in childhood, and (2) all three of the disorders imply multiple handicaps requiring special services throughout childhood and adult life. Let's review the data.



(1) In 1970, Social Security Administration figures showed mental retardation, cerebral palsy and epilepsy as the leading causes of disability in adults whose handicap originated in childhood. These three disorders account for 80% of all adults disabled in childhood receiving Social Security benefits. Thus of all handicapping conditions that affect children, mental retardation, cerebral palsy, and epilepsy command attention as long term, chronic, and severe impairments.

(2) There is ample evidence of multiple handicaps and of the overlapping of the three conditions clinically. Of the 750,000 individuals with cerebral palsy, two-thirds are also mentally retarded. An estimated 20-30% of epileptic individuals are mentally retarded (Conley). Of institutionalized mentally retarded persons, one half have seizure disorders.

The facts further show that a primary diagnosis of any one of the three -- MR, CP, epilepsy -- is likely to be accompanied by a wide spectrum of other disabilities. Of all individuals with cerebral palsy 70% have speech and communication disorders; one-third have visual problems; one-fifth have learning disabilities. Slightly over 30% of retarded children suffer additional physical handicaps and perhaps 40% suffer psychiatric problems (Conley). Thus there were empirical indicators of some commonality among the three disorders.

The concept of developmental disability recognizes the commonality of service needs among people with long term, substantial (often multiple) handicaps that occur early in life. It reflects the growing awareness of parents and professionals in 1970 of the inadequacies of traditional categorical programs enacted during the sixties. Somehow the individual with multiple handicaps didn't fit into the categorical programs. Somehow the categorical programs were designed for people with moderate disabilities and not tailored to the individual needs of the severely disabled. The multiply handicapped and the severely handicapped just didn't get served. There was a growing awareness of the inadequacies of using diagnostic tags to deliver services.

At about the same time advocates for the handicapped were becoming increasingly sensitive to the inherent dangers of "labeling." For a complete discussion of the labeling phenomena consult: The Future of Children: Categories, Labels, and Their Consequences (Nicholas Hobbs).

The data, the disenchantment with categories, and the new sensitivity of labeling converged in a call for functional definition of handicap.

The DD legislation is in a sense schizophrenic, combining a functional definition and now four categorical groups, with autism added this past year. However, its underlying philosophy and its clear intent is a functional, non-categorical approach to severe disability originating in childhood. Hobbs states that "conceptually the Developmental Disabilities Legislation is quite advanced in identifying a special group on the basis of service needs rather than symptoms or status."



DESCRIPTION OF THE DD PROGRAM

The Developmental Disabilities Extension Act (P.L. 94-103) of 1975 insures the continued targeting of funds and resources to developmentally disabled individuals through a combination of national, state and local efforts. To this end, the legislation is designed to assist states in developing a comprehensive plan which will bring together all available resources so that such persons may be served in the most effective, efficient way.

To this end, the DD service concept is marked by an emphasis on comprehensive, coordinated, life long, supportive services for the DD individual and his family. This emphasis is unique among all other federal human service legislation which define services for a particular phase of life or age limits (i.e. special education: 3-21; or VR: the employment years); or provide for limited kinds of services (i.e. Title XX Social Services, but not medical or educational).

Title I of the Act authorizes grants for the purposes of:

- (1) Developing and implementing a comprehensive and continuing plan for a system of services;
- (2) Providing direct services to developmentally disabled persons;
- (3) Training specialized personnel for services and research;
- (4) Developing or demonstrating new or improved techniques of services;
- (5) Demonstration and training grants
- (6) Renovating and modernizing University Affiliated Facilities for the interdisciplinary training of professional personnel.

The services supported by federal funds are designed to fill gaps in the existing service structure in the state and for expanding services to groups of developmentally disabled persons not now receiving services. The program is not designed to relieve states of support for existing services.

"Services for persons with developmental disabilities" means specialized services or special adaptation of generic services directed toward the alleviation of a developmental disability or toward the social, personal, physical, or economic habilitation or rehabilitation of a disabled person. In most instances, clusters or combinations of services are provided rather than individual discrete services.



Examples of services supported under the Developmentally Disabled Assistance Act are:

Diagnosis	Domiciliary Care	Counseling
Evaluation	Special Living Arrangements	Protective and
Treatment	Training	Other Social
Personal Care	Education	Services
Day Care	Sheltered Employment	Information and
	Recreation	Referral
		Follow-a-Long
		Transportation

The intent of Title II is to develop a mechanism to establish and protect the rights of persons with developmental disabilities and to assure that they obtain quality services needed for maximum development, physically, psychologically and socially. It also mandates that states receiving federal support must assure the HEW Secretary that every program has a habilitation plan for each developmentally disabled person receiving services under the Act and that they provide for the annual review of each plan.



THE POPULATION

The following four categories make up the major portion of the Developmental Disabilities population.

CEREBRAL PALSY

Cerebral palsy is the general term applied to a group of permanently disabling symptoms resulting from damage to the developing brain that may occur before, during or after birth and that results in loss of impairment of control over voluntary muscles (UCPA).

Cerebral palsy is characterized by awkward or involuntary movements, poor balance, irregular gait, poorly articulated tightness of muscles -- caused by disturbance of the brains motor control.

The six major types of cerebral palsy are:

- a. Spasticity: muscle spasms the most frequently occurring motor symptoms of cerebral palsy.
- b. Athetosis: marked by constantly recurring, slow involuntary writhing movements of the arms and legs; this occurs in about 25 percent of cases.
- c. Ataxia: walking like a drunken person; occurs in about 7 percent of cases.
- d. Tremor: similar to the fine tremulousness seen in adults who have Parkinsonism; 1-5 percent of cases.
- e. Rigidity: muscles contract slowly and stiffly, leading to clumsiness; 7 percent of cases.
- f. Mixed: two or more of the above.

The motor difficulty may involve all four extremities or it may be limited to just one; or an arm or leg on one side of the body may be disabled (the most common type).

In some persons with cerebral palsy, the symptoms are so slight that except for some clumsiness they may be unnoticed. Others may be extensively handicapped, in a wheelchair and require assistance with the most basic activities of daily living, such as feeding and toileting.

The causes of cerebral palsy like the causes of mental retardation and epilepsy are closely tied to pre-natal and perinatal problems including:



- *Prematurity
- *Anoxia - lack of oxygen to the newborn
- *Complications of labor or delivery
- *Jaundice of newborn due to RH incompatibility

Other causes similar to mental retardation and epilepsy are infections, head trauma and toxicity. In more than one-third of the cases of cerebral palsy, the cause is unknown.

The prevalence of cerebral palsy is estimated to be .1 percent to .2 percent. UCPA indicates that 750,000 persons have cerebral palsy. About 15,000 babies are born with cerebral palsy each year, or one newborn in every 200 births.

Cerebral Palsy: Resources

United Cerebral Palsy Associations, Inc.
66 East 34th Street
New York, New York 10016
(212) 889-6655

MENTAL RETARDATION

Stedman defines mental retardation as "subnormal intellectual function from birth or early age accompanied by impairment in learning, social and/or adaptive functions."

Mental Retardation Description:

Technically, intellectual function is measured by an IQ test and is said to be subnormal when the score is below one standard deviation from the mean. Generally, this is a cut-off point at 84 or below.

Impaired learning, social and/or adaptive behavior is more difficult to measure objectively. The American Association on Mental Deficiency has developed an adaptive categorical system to assist in evaluating this component.

Probably half of all mental retardation can be traced to the pre-natal or perinatal period. The most significant factors associated with mental retardation are prematurity (less than 37 weeks) and low birth weight (less than 2500 grams). Other factors indicating mothers are at high risk for bearing mentally retarded children are:

- Maternal Age
- Maternal Diet
- Poor or No Pre-Natal Care
- Low Socio-Economic Status

The AAMD has classified eight major causes of mental retardation as infection, (i.e., rubella) intoxication (i.e., lead), trauma, metabolic (PKU), growth, nutritional problems, new growth, unknown pre-natal causes, psychogenic cause and cultural-familial mental retardation.



According to the National Association for Retarded Citizens, mental retardation affects three percent of the population -- an estimated 6.1 million Americans. This figure has been used by advocates and planners as a crude rule of thumb for estimating the number of mentally retarded individuals in a community. However, precise measurements of mental retardation prevalence vary due to:

Changes in Definition of MR
Different Means of Identifying MR Individuals
Confusion Over Socio-Cultural Retardation

Systematic epidemiologic surveys of the prevalence of "severe" retardation in this country have confirmed a general rate of .3 percent.

Resources: Mental Retardation

National Association for Retarded Citizens
2709 Avenue E, East
P. O. Box 6190
Arlington, Texas 76011

American Association on Mental Deficiency
5201 Connecticut Avenue, N. W.
Washington, D. C. 20015

EPILEPSY

Epilepsy refers to a group of neurological conditions called convulsive disorders. Epilepsy is characterized by an abnormal chemical - electrical discharge of damaged nerve cells in the brain. The discharge is manifest in various forms of physical activity called seizures. The type of seizure activity will vary according to the location and spread of the discharge in the brain. Epilepsy, then, is a symptom of neurological impairment.

"Generalized" seizures arise deep in the brain and include the grand mal convulsion and petit mal laps of consciousness.

"Focal seizures" are located in an identifiable area of the brain called the focus and involve only part of the body. Jacksonian seizures are focal and involve upper or lower limbs only.

From one quarter to one half of all epilepsy is labeled idiopathic, of unknown origin.

Epilepsy Causes

A major cause of epilepsy is traumatic head injury including damage to the head during birth. Other causes include anoxia at birth, genetically transmitted disorders, fever, toxic states, allergy, infections, brain tumor and vascular insufficiency.

Anticonvulsant medication is the most common treatment for epilepsy. Between 80 and 85 percent of epileptics can achieve enough seizure



control to lead essentially normal lives (Rodin, 1972).

Estimates of the prevalence of epilepsy in the United States population range from less than 1 percent to 5 percent. The Epilepsy Foundation of America states that the prevalence rate is at least 2 percent or 4 million Americans. Epidemiologic studies of epilepsy are confronted by:

- *definitional problems

- *patient reluctance to being identified due to stigma of epilepsy

Epilepsy Resources

Epilepsy Foundation of America
Suite 406
1828 L Street, N. W.
Washington, D. C. 20036

Autism

Autism is a term for a severe disturbance of mental and emotional development that appears in young children. These children come to medical attention around age 2 with developmental retardation. By age 4 or 5, the autistic child presents a well defined syndrome of absent or very limited speech, stereotypic behavior, social isolation, demand for maintenance of sameness in the environment, episodes of severe disorganization and panic, impoverished social relations and involvement with inanimate objects rather than people.

Autism is a profoundly handicapping disturbance in neurological organization that appears early in life and continues throughout life. Its etiology is obscure but there are many indications of central nervous system impairment.

Prevalence estimates for autism range from 2 to 4.5 cases per 10,000 population. This variation is due to lack of standardized definition or diagnostic criteria.

Autism: Resources

National Society for Autistic Children
Information and Referral Service
306 31st Street
Huntington, West Virginia 25702

NIMH Clearinghouse
5600 Fishers Lane
Rockville, Maryland 28052



DD COUNCILS

The heart of the developmental disabilities concept is the DD Council, a broadly conceived partnership which reaches out across state government departments and beyond to embrace private professionals providing for services to the developmentally disabled and consumers of services or their representatives.

NATIONAL ADVISORY COUNCIL

The Developmentally Disabled Assistance Act provides for the establishment of a National Advisory Council on Services and Facilities for the Developmentally Disabled. The purpose of the Council is to advise the HEW Secretary on regulations and to study and evaluate the effectiveness of programs provided under the Act to help persons with developmental disabilities. An annual report is required by Congress on the efficiency of the administration of the Act. The Council may receive technical assistance, and the Secretary is required to make available the assistance and data the Council needs in carrying out its functions.

The Advisory Council has 25 members, 9 representing Federal agencies, 16 from the field, including State and local governments, institutions of higher education, and organizations representing consumers of services, and at least five must be developmentally disabled or the parents or guardians of disabled persons.

Previous representatives of the Cerebral Palsy on the Council were Mrs. Clark O. Murray, Jr. and Mr. Dale Engstrom. Present members representing the Cerebral Palsy are Mr. James Stearns and Mr. Thomas Johnson.

STATE DD PLANNING COUNCILS

The DD Act required each state and territory to designate or form a State Planning and Advisory Council in order to participate in the DD program. Either a newly formed body or the designation of an existing State Council or agency was permitted by the regulations so long as the other requirements were met.

The Council sets the direction and the pace of growth of the program through its work in planning and evaluation. It must evaluate the State plan at least once a year and submit revisions to the HEW Secretary. Council membership includes representatives of each of the principal State agencies and of local agencies and non-governmental organizations which provide DD services; at least one-third of the Council must be made up of developmentally disabled persons or their representatives.



The DD Act and federal regulations which support it are primarily concerned with setting minimum levels of compliances. They detail the least which state and DD Council must do in order to participate in the formula grant program -- this is, to receive their share of the appropriated federal funds. Beyond these levels of minimum compliance, the DD Act and regulations by their lack of specificity encourage flexibility and creative initiative on the part of each state and DD Council to work out patterns of organization and activity which are effective in their unique situation.

Local and State UCPA affiliates should be sure that the interests of the Cerebral Palsy are represented on these State Councils.



STATE PLAN AND ACTIVITIES

Each State is required to submit a State plan for DD to be approved by the HEW Secretary. In simple terms, State Plan is a "contract" between the State and the Federal Government. The Federal Government offers the State an amount of money provided it meets specified requirements. In the State Plan the State spells out how it will comply with those requirements. There are many Federal programs which offer Federal funds to States and require a State Plan.

In addition to the requirements concerning the State Planning Council and the designation of State agencies to administer the plan, the State Plan must:

(1) Describe how other existing State-Federal programs provide for the developmentally disabled and how new programs will complement and augment, but not duplicate, these programs. At least nine specific programs are to be taken into account:

- vocational rehabilitation
- public assistance
- social services
- crippled children's services
- education for the handicapped
- medical assistance
- maternal and child health
- comprehensive health planning
- mental health

(2) Contain a plan to eliminate inappropriate placements in institutions and to improve the quality of care and the state of surroundings for persons who are in institutions. Support the establishment of community programs designed for the care and habilitation of persons with developmental disabilities. Provide for fair and equitable arrangements for employees of institutions which are affected by the removal of large numbers of persons with developmental disabilities.

(3) Determine priorities for services. Provide for maintaining standards with respect to the scope, quality, and administration of facilities and services under the State plan. Show how services and facilities will be provided. Provide for a design for implementing the State plan and for periodic evaluation. Provide that the administering State agencies will make reports and keep records.



(4) Contain assurance for the protection of human rights of all persons with developmental disabilities receiving services under the Act.

(5) Set forth policies and procedures to insure effective expenditures of funds. Contain assurances that funds will be used to strengthen services, part of the funds will be made available to local groups or agencies (Federal funds will be used to supplement, rather than supplant, non-Federal funds that would otherwise be available), and the State itself bears a reasonable share of the non-Federal cost of implementing the plan.

(6) Provide financial and technical assistance to urban and rural poverty areas in securing services and facilities.

(7) Provide for early screening, diagnosis, and evaluation of developmentally disabled infants and preschool children.

(8) Provide for counseling, program coordination, follow-along services, protection services, and personal advocacy on behalf of developmentally disabled adults.

(9) Provide for an evaluation system and describe the methods to be used to assess the effectiveness of State programs under the plan.

(10) Provide for the maximum utilization of available community resources, including volunteers serving under the Domestic Volunteer Services Act of 1973.

All of this may sound exceptionally complex, however, it need not be. In many states it is a relatively routine procedure of surveying programs and needs, highlighting some outstanding needs, and accounting for the federal money spent. The DD act and regulations requires that the DD Council review, evaluate, and modify its State Plan at least annually to receive each year's grant of federal dollars.

A DD Council may meet all of its required federal obligations and still not be a particularly effective organization or it may use its creativity to take advantage of the DD Act's flexibility. Beyond the annual submission of the State Plan the regulations make the DD council "responsible for planning activities for all developmentally disabled persons in the State." The DD council has an open-ended challenge to develop its State Plan beyond the legal requirement into a comprehensive plan and evaluation. This requires sophisticated data gathering and program monitoring. It means use of the DD Councils' limited budget to initiate, strengthen, or broaden key programs and then help state agencies incorporate them into their service systems. It means helping to find new administrative and legislative initiatives which maximize the available human and economic resources. All of this requires strong Council leadership, dedicated members, supportive staff, and a cooperative administering agency. That is the challenge of the DD concept.



SUPPLEMENTAL SECURITY INCOME

Title XVI of the Social Security Act established the Supplemental Security Income (SSI) program. Basic program features of the SSI program include nationally uniform eligibility requirements, a basic Federal income floor, a federally administered income maintenance program with basic payments federally financed from general revenues, a state supplemental payment program with federal government administering the state supplements at federal expense at the state's option, and elimination of parental and relative responsibility and liability for aged, blind, and disabled adults. Title XVI replaced the old federal-state income programs for the aged, blind, and disabled as previously authorized under Titles I, X, and XIV. The SSI program became effective January 1, 1974.

I) Social Security and SSI

Both Social Security and SSI are income maintenance devices but they differ in principle and purpose. The basic idea underlying Social Security is that the protection which people have grows out of their work and the contributions they and their employers pay. Social Security is approached in the context of insurance. Because savings and income other than earnings have no part in determining eligibility or benefit amounts, the worker can build on Social Security in providing for his retirement years.

SSI is considered to be a public assistance program. Eligibility for assistance payments is based on current financial need. SSI is paid for through Federal general revenues and State or local taxes. SSI provides only minimum maintenance standards because income and resources are considered in determining both eligibility and payment amounts. SSI attempts to provide a minimum income base for persons who are unable to support themselves because of age, disability, or blindness and who have limited resources and little or no income from Social Security or other sources.

II) Eligibility

An individual or couple must be aged (65 years or older), blind, or disabled and in financial need to be eligible for SSI. The definition of disabled is the same as that used in Social Security -- physical or mental impairment that prevents one from doing any substantial gainful work. An individual must have countable income no greater than the current SSI payment level. An individual must also have \$1,500 or less in countable income.



III) SSI Income Limits

An individual must have countable income no greater than the current SSI payment level. A very complex formula is used in determining countable income. Specifically excluded from determining countable income are regular cash payments made by state or local governments which are based on financial need (such as state SSI supplemental payments), \$20 a month of any income received such as Social Security benefits, \$65 a month of earned income, one-half of remaining earned income over the \$65 a month level up to the SSI payment level with all other income, and such items as home produce and special income necessary for self-support plans.

A differentiation is made between earned and unearned income although both are considered in determining SSI eligibility and payment levels. Earned income includes wages and net earnings from self-employment. Unearned income is all income which is not earned income and includes such items as Social Security payments, life insurance proceeds, gifts, rents, interests, pensions, etc.

IV) Supplemental State Payments

In order to qualify for federal matching funds for Medicaid, states must agree to maintain the payment levels of all recipients on state Titles I, X, and XIV (aged, blind, and disabled programs) rolls in December 1973 at the December 1973 income level. Every state may elect to have the federal government administer the state payments and absorb the administrative expenses.

The state has the option of making additional payments to recipients who are eligible for SSI but who did not previously receive assistance under the former state programs, can elect to have federal administration of state supplemental payments at federal expense, and can establish additional income disregards for eligibility to its payments.

V) Special Living Arrangements

An individual's place of residence frequently determines his eligibility for and income levels of SSI. This is a highly complex subject. Information on this subject is available by writing the UCPA Governmental Activities Office and requesting Analysis, Vol. 3, No. 7, November 1974, "Supplemental Security Income Payments to Residents of Institutions and Group Homes - Both Publicly and Privately Operated," and Word from Washington, Vol. 6, No. 12, December 1975 "Proposed SSI Regulations on Unearned Income."



VI) Application Process

Individuals are to apply for SSI at their local Social Security office by furnishing their social security number, proof of age, medical information if blind or disabled, and information regarding pensions and sources of income.

VII) Federal Administration

Bureau of Supplemental Security Income
Social Security Administration
Room 1112, West High Rise
6401 Security Boulevard
Baltimore, Maryland 21235



SOCIAL SECURITY

Title II of the Social Security Act is the basic Social Security Program of the United States authorizing federal old-age, survivors, and disability insurance benefits. There are two types of coverage for which children disabled from birth may be eligible - childhood disability benefits and disabled worker benefits.

I) Childhood Disability Benefits

A child disabled before the age of twenty-two can begin receiving monthly social security payments if a parent who is insured under social security retires, becomes disabled, or dies. The child needs no work credit of his own and payments will continue throughout the child's adult lifetime as long as the disability continues and there is no change in the parent's entitlement.

II) Disabled Worker Benefits

Any individual, including one who is disabled, who works and pays social security taxes on his earnings can qualify for disabled worker's benefits when his disability becomes so severe as to prevent further substantial work.

For individuals under the age of 24, one must earn credit for one and one-half years of work (six quarters in which he earned at least \$50 per quarter) out of a three year period ending when the disability status was established. If the individual is 24-30 he needs credit for having worked under social security for at least half the period from the time he reached 21 until disability was established. If over age 30, the individual has to have earned at least 20 quarters during the immediate past 40 quarter period.

The level of payment is dependent on previous average earnings with at least two years of earnings used to figure average earnings for disability benefits. After an individual has qualified for benefits the law provides a five month waiting period before payments can be made.

III) Disability Definition

An individual is considered disabled if he has a physical or mental impairment that prevents him from doing any substantial gainful work. If such a person has a medical condition that prevents him from doing usual work, then his age, education, training, and vocational experience may also be considered in deciding whether or not he could be expected to engage in any other type of work.



IV) Rehabilitation Services

Everyone applying for benefits **under** Social Security -- whether the application is allowed or denied - is considered by the State Vocational Rehabilitation Agency for such services as counselling, training in new employment skills, training in the use of prosthesis, and job placement. The Social Security Administration maintains a separate trust fund which finances rehabilitation services for Title II recipients. These funds are allocated to the State Vocational Rehabilitation Agency. The maximum amount allocated nationally equals 1½% of disability benefits paid the previous year.

V) Federal Administration/Further Information

Bureau of Disability Insurance
Social Security Administration
Room 760, Social Security Building
6401 Security Boulevard
Baltimore, Maryland 21235

Social Security and Cerebral Palsy, SSA 75-10126, should be available from your local Social Security Office.



SOCIAL SERVICES

P.L. 93-647, the "Social Services Amendments of 1974," established a new legislative framework for the Social Services program by creating a new Title XX of the Social Security Act. The new act permits increased flexibility on the part of the States in the choice of services and relaxes past eligibility requirements.

I) Historical Background

The social services program was originally authorized under Titles I, VI, X, XIV, and XVI of the Social Security Act. Eligibility for social services required a "means test." Individuals were eligible for services if they had incomes at or below an economic standard established by the State. Means test criteria varied from State to State.

Generally, all recipients of financial assistance under Aid to the Aged (Title I), Aid to families with Dependent Children (AFDC, Title IVA), Aid to the Blind (Title X), Aid to the Permanently and Totally Disabled (APTD, Title XIV), and Aid to Aged, Blind and Disabled (Title XVI) were automatically eligible for social services. In addition, potential recipients of financial assistance under the above titles were social services eligible. Potential recipients were those individuals likely to apply for financial assistance within the next 5 years. Many States determined that individuals with substantial physical or mental handicaps were likely to be eligible for financial assistance at some point in the future.

The Social Security Act authorized the federal government to reimburse States at the rate of 75% of their expenditures for eligible social services costs. Originally, the program was "open ended." The federal government matched 3-to-1 the costs of services provided by the state under the State plan. The program was not contained or restricted by an annual appropriations.

Under the program, any services approved in the State plan could be purchased from other service providers who could meet all agency standards and regulations. By contracting for purchase of services, many UCPA affiliates received financial assistance from the State for services. The most frequent use of social services funds by UCPA affiliates at this time was for day care. In addition, donated private funds could be transferred to the States for their use in State/local share requirements for federal reimbursement.

At that point in time, federal regulations required an individual service plan designed to meet specific service needs of each social service recipient. States could choose from a wide range of social services including:



- A) Family Planning
- B) Child Care
- C) Health Services (not including medical care)
- D) Education Services, Training and Employment Services
- E) Consumer Education and Money Management
- F) Housing Services
- G) Homemaker and Home Management
- H) Legal Services
- I) Placement Services
- J) Comprehensive Foster Care
- K) Comprehensive Protective Services
- L) Comprehensive Child Development Services
- M) Community Planning and Resource Development
- N) Information and Referral

In 1972, the General Revenue Sharing Act was enacted as P.L. 92-512 with a Title III "Limitation on Grants for Social Services Under Public Assistance Programs." P.L. 92-512 established a \$2.5 billion limitation on federal matching funds for social services, allocated funds to the states on a population basis, and placed severe limitations on the use of social services funds with emphasis on recipients of financial assistance under Titles I, X, XIV, XVI, and IVA.

When Congress established the Supplemental Income (SSI) program in 1972 by P.L. 92-603, it also established a new Title IV of the Social Security Act repealing the social services authorized under Titles I, X, and XIV and consolidating social services in Title IVA and VI. 1973 and 1974 witnessed substantial controversy over HEW attempts to further restrict utilization and access to social services funds through the promulgation of regulations. After lengthy negotiations between all interested parties, P.L. 93-647 was enacted as a compromise approach.

II) Goals and Objectives of Title XX

Every Social Service supported with federal funds must be directed at one of the following goals:

- A) Achieving or maintaining economic self-support to prevent, reduce, or eliminate dependency.
- B) Achieving or maintaining self-sufficiency, including reduction or prevention of dependency.
- C) Preventing or remedying neglect, abuse or exploitation.
- D) Preventing or reducing inappropriate institutional care by providing for community based care, home based care, or other forms of less intensive care.
- E) Securing referral or admission for institutional care where appropriate.



The objectives of the social services program must be directed toward at least one of the five above stated goals, shall be stated in measurable terms, and will be evaluated on the extent that they were achieved.

III) Services Authorized Under Title XX

At least one service directed at each of the five program goals must be provided by a state in order to receive federal funds. In addition, at least three services must be provided to SSI recipients who require such services.

A state may receive federal matching for any social service provided (A) it is described as a separately identifiable service (B) it is described as to method of delivery, (C) it is described as to its relationship to the overall program goals and objectives, (D) it is identified with respect to the category of eligible persons to be served, and (E) it is identified according to geographic area.

Certain types of services are prohibited from being supported with federal funds or are required to meet certain restrictions and limitations. Such services include:

A) Educational services, where generally available to State residents without cost and without regard to income, is prohibited from receiving federal funds.

B) Medical or remedial care may be supported with federal funds if not available under Medicaid, if it does not exceed 25% of the total service cost, and if it is an integral but subordinate part of a service.

An example of a permissible medical service would be a child development center which provides infant stimulation and has on staff a nurse who functions as an integral part of the center's program. The nurse's salary could be a Title XX cost.

C) Emergency shelter may be supported with federal funds only as part of a protective service for a child in clear and present danger of abuse, neglect, or exploitation and only for 30 days in any 12 month period.

D) Services by foster care facilities may be supported with federal funds only if the service is in addition to basic foster care, if the caregivers are capable of providing the service, and if the identified service is necessary because of a physical, mental, emotional, or behavioral condition.



E) Room and board is only permitted to be supported with federal funds when it is an integral but subordinate part of a service and can only be provided for a period of six consecutive months. Room and board must be explicitly identified as part of the social service and must not exceed 30% of the total cost for providing the service.

F) In-reach services, federal social services funds used for an individual residing in a public or private institution including a skilled nursing home or intermediate care facility, are permitted under certain narrow situations. In-reach services are designed to prepare a resident for return to the community. Such services must be separately identifiable in the services plan, must be provided to individuals currently residing in the community, and must only be provided by an agency outside the institution, such as a UCPA affiliate.

IV) Eligibility for Title XX

Determinations of eligibility are to be made by the designated State agency or by the provider of service if the State so specifies. Special priority is placed upon recipients of AFDC (Title IV-A) (Aid to Families With Dependent Children) and recipients of SSI (Title XVI) (Supplemental Security Income).

Fifty percent of a State's federal social services funds are required to be used for services to AFDC, SSI, or Medicaid (Title XIX, Medical Assistance) recipients.

Federal matching for free social services is available for persons with income up to 80% of the median family income in a State adjusted for family size and services on a fee schedule up to 115% of the median income of a State. The 80% figure may be substituted by the full national median income which is currently \$12,041 for a family of four.

V) State Needs Assessment Under Title XX

Each State social services plan shall describe how the needs of all residents of the state were taken into account developing the services plan. The description of the needs assessment must include:

- 1) Data sources used or to be used.
- 2) Public and private organizations consulted or to be consulted.
- 3) The manner in which the results of the needs assessment were utilized in development of the services plan.



VI) Available Title XX Funds

Federal matching is available on a 3 to 1 basis, 75% matching, for all approved social services. In addition, 90% federal matching is available for family planning services.

Title III of the General Revenue Sharing Act, P.L. 92-512, established a \$2.5 billion ceiling on federal matching funds for social services. Social Services funds are to be divided among the states on a population basis.

VII. Further Information

This outline is a simplified and condensed review of the Social Services Program. Further information is available by writing the UCPA Governmental Activities office and requesting:

- A) Analysis, Volume Three, Number Six, October 1974, "The Social Services Program: Historical Background, Current Situation, Pending Legislation - Impact on UCPA Affiliates."
- B) May 7, 1975 paper entitled "The Title XX Social Services Program: Impact on Services for the Severely Disabled From the Perspective of the HEW Proposed Regulations."

The January 1975, Volume 5, Number 1, Word From Washington provides a brief review of the enactment of P.L. 93-647.

Available from HEW is an excellent brochure, "A Citizens Handbook - Social Services '75: Program Options and Public Participation Under Title 20 of the Social Security Act." Every UCPA affiliate was mailed a copy of this brochure on June 16, 1975.

VIII) Federal Administration

Community Services Administration
Department of Health, Education
and Welfare
Room 5129, HEW South Building
330 C Street, S. W.
Washington, D. C. 20201



MEDICAID

I) General Introduction

Title XIX of the Social Security Act - Grants to States for Medical Assistance Programs or Medicaid - is a program authorizing federal grants to the states to provide medical services to families with dependent children and the aged, blind, and disabled individuals whose income and resources are insufficient to meet the cost of necessary medical services. Federal Medicaid funds are also available for rehabilitation and related services to help such families and individuals to attain or retain capability for independence or self-care. An annual State Medical Assistance Plan is required to be submitted to HEW outlining methods of administration, eligibility criteria, and types and scope of medical benefits to be provided under the plan. Federal matching shall in no case be less than 50% nor more than 83%.

In order to receive federal matching, states must provide inpatient hospital services, outpatient hospital services, laboratory and X-ray services, skilled nursing home services for individuals age 21 or older, physicians' services, home health care services for individuals entitled to skilled nursing home services, transportation to and from medical care and services, and child health screening.

Two Medicaid services are of particular importance to individuals with developmental disabilities - EPSDT services and ICF/MR services.

II) EPSDT - Early and Periodic Screening, Diagnosis, and Treatment Services

EPSDT - Early and Periodic Screening, Diagnosis, and Treatment services - is a program of prevention, early detection, and treatment aimed at providing health services which might correct and eliminate the health related sources of disability, dependency and poverty.

EPSDT was established by the 1967 amendments to the Medicaid program whereby Congress directed attention to the importance of preventive health services and early detection and treatment of disease in children eligible for Medicaid. In 1972, by P.L. 92-603, Congress required every state receiving Medicaid matching funds to implement an EPSDT program initially for all Medicaid eligible children under the age of six and eventually under the age of twenty-one.



A) Screening

Screening is viewed as the first step in identifying, through relatively simple and inexpensive tests and observations, high risk children. Each state is mandated to provide for an initial screening to determine an assessment of an individual's physical and mental health.

The State is to determine the specific evaluation procedure and mechanisms needed to carry out the screening program and each program should be designed for the specific community in which it will be used.

At a minimum, an EPSDT screening program must include (1) medical history, (2) physical examination, (3) immunization status assessment, (4) dental, hearing, and vision screening, (5) developmental assessment, and (6) screening for anemia, lead absorption, tuberculosis, bacteriuria, and sickle cell disease and trait.

B) Additional Requirements

Each state must have an outreach program to inform AFDC families about the screening program. Every state must also seek out and develop agreements with facilities and practitioners throughout the state that can provide screening and diagnostic services for early case finding purposes.

Each state must provide for diagnostic services for individuals, found through the screening process, to be in need of further diagnostic study. States must also provide any treatment within the amount, duration, and scope of its state plan, needed by an individual who has received screening and diagnostic services. A state may provide EPSDT services for individuals under 21 years of age without providing similar services for those over 21.

C) Status Report, January 1976

HEW estimates that 25 million poor or near poor children would benefit from EPSDT services and of those, roughly 13 million are Medicaid eligible. To date, only 1.5 million Medicaid eligible children have been screened.

P.L. 92-603, requires that the Federal share of the Aid to Families with Dependent Children (AFDC) matching funds be reduced by 1% beginning July 1, 1974 if a state fails to launch an EPSDT program. In July 1975, HEW announced that Hawaii, Indiana, Minnesota, Montana, New Mexico, North Dakota, and Pennsylvania would lose 1% of AFDC funds for failure to implement EPSDT.

HEW has not yet issued guidelines regarding EPSDT developmental assessment tools. HEW has contracted with the American Orthopsychiatric Association to develop this tool. UCPA, as a member of the Consortium Concerned with Developmental Disabilities (CCDD) Task Force on Health, is monitoring and seeking to influence the EPSDT guidelines regarding developmental assessment.



D) Further Information

The EPSDT program is under the authority of M. Keith Weikel, M.D., Commissioner, Medical Services Administration, DHEW, Room 4094, HEW South Building, 330 C Street, S. W., Washington, D. C. 20201.

Valuable written information available from MSA includes:

- | | |
|--|--------------|
| (1) Why EPSDT? | SRS 75-02049 |
| (2) EPSDT Guidelines | SRS 73-24921 |
| (3) EPSDT Needs Physicians and Dentists | SRS 75-24104 |
| (4) A Guide to Screening Under EPSDT | SRS 75-24516 |
| (5) A Guide to Dental Care Under EPSDT | SRS 75-24515 |
| (6) A Report on Professional Health Provider Participation under EPSDT | SRS 75-24517 |

III) ICF/MR - Intermediate Care Facility Program for the Mentally Retarded

Intermediate care is an optional service which the state may receive federal matching to provide. No state is mandated to provide intermediate care.

Under original enactment, intermediate care services were federally funded for financial recipients of Titles, I, IVA, X, and XIV of the Social Security Act (aged, families with dependent children, blind, and disabled) under Title XI of the Social Security Act (general provisions). Public Law 92-223, Section 4(a)(I) transferred authority for funding ICF's from Title XI to Title XIX. The intent of Congress was to create closer integration between skilled nursing home services and intermediate care. The act, signed into law on December 28, 1971, extended ICF benefits to medically indigent persons as well as categorically eligible persons and extended ICF benefits to children.

Section 4(a)2(d) of P.L. 92-223 permitted residential institutions for the mentally retarded to qualify as ICF's provided four criteria were met: (1) the primary purpose of the institution (or a distinct part thereof) is the provision of health or rehabilitative services to mentally retarded individuals, (2) services provided meet HEW standards, (3) all retarded residents had to receive "active treatment," and (4) there is no reduction in the level of state support for the program. The ICF/MR program is designed for persons with mental retardation and related conditions, defined as "those individuals who have epilepsy, cerebral palsy, or other developmental disabilities." An ICF/MR is defined as "an institution (or distinct part thereof) primarily for the diagnosis, with related conditions, which provides in a protected residential setting, individualized ongoing evaluation, planning, 24 hour supervision, coordination, and integration of health or rehabilitative services to help each individual reach his maximum of functioning capabilities."



When a state elects to provide intermediate care services, it must cover general intermediate care but it does not have to cover ICF/MR care if it so decides.

Active treatment is defined as including (1) regular participation in professionally developed and supervised activities, experiences, and therapies; (2) an individual plan of care; (3) an interdisciplinary professional evaluation; (4) re-evaluation medically, socially, and psychologically at least annually; and (5) an individual post-institutionalization plan. The ICF/MR program has adopted "a modified version" of the Joint Commission on Accreditation of Hospitals-Accreditation Council for Facilities for the Mentally Retarded (JCAH-ACF/MR) standards to be totally effective not later than March 18, 1977. The ICF/MR and ACF/MR program standards differ in the areas of seclusion, activity schedules, design and equipment, life safety code, staffing patterns, barred enclosures, review of behavior modification program, and number of residents per room. The "Life Safety Code" is required in both sets of standards except the ICF program uses the 1967 edition while ACF/MR uses the 1970 edition.

A) Status Report, January 1976

As the March 18, 1977 compliance date approaches, providers of service and state officials increase their attempts to modify the regulations and postpone the March deadline. Oklahoma has been the first state to appeal to HEW to postpone the date. HEW regulations specify that by June 30, 1975 all states must submit an acceptable plan detailing the steps to be taken to meet the March 1977 standards. Oklahoma failed to submit the plan on time but received a delay in termination of funds from HEW. Meanwhile Senator Henry Bellmon (Okla.) introduced S. 1938 which would place a twelve month moratorium on enforcement of the ICF/MR standards.

IV) Federal Administration

M. Keith Weikel, M.D.
Commissioner
Medical Services Administration
DHEW, Room 4094
330 C Street, S. W.
Washington, D. C. 20201



MEDICARE

Title XVIII of the Social Security Act established the Medicare Program, a health insurance program for persons 65 and older and for recipients of Social Security who are disabled. It is a federal government program administered by the Social Security Administration. Medicare contains two programs - Hospital Insurance (Part A) and Medical Insurance (Part B).

I) Part A - Hospital Insurance

Medicare's hospital insurance helps pay for three kinds of care - inpatient hospital care, inpatient care in a skilled nursing facility, and home health care. Medicare will pay for most but not all services provided in these settings with co-insurance and deductible payments required by the individual. There are also strict limitations on how many days of care can be provided. Everyone receiving Social Security is automatically covered by Part A without paying monthly premiums.

Medicare service limitations are made by benefit periods. A benefit period is a way of measuring services under the hospital insurance program. There is no limit to the number of benefit periods any individual may have but each benefit period is restricted to the time frames and limits the days of service per benefit period. The concept of benefit period is not compatible to individuals whose needs are long term and continuing.

II) Part B - Medical Insurance

Medicare's Medical Insurance Program can help pay for doctor's services, outpatient hospital care, outpatient physical therapy and speech pathology services, home health care, and related medical services. Persons eligible for Medicare elect to be covered by Part B Medical Insurance and pay a monthly premium for its coverage. Deductibles are also required as well as limitations on the scope and kinds of services. Nearly all people who become entitled to Hospital Insurance are automatically enrolled for Medical Insurance. Advance information is forwarded to Medicare eligible individuals who may decline Part B coverage.

III) Restricted Services

Medicare does not cover care that is not "reasonable and necessary" for the treatment illness or injury. To assist Medicare in deciding whether inpatient care is reasonable and necessary, each hospital and skilled nursing facility must have a Utilization Review Committee composed of at least two doctors. A Professional Standards Review Organization (PSRO) may take the place of a Utilization Review Committee.



Medicare also does not cover care that is "custodial." Care is considered custodial when it is primarily for the purpose of meeting personal needs and could be provided by persons without professional skills or training. Self help skill training is clearly prohibited.

IV) Medicare Providers

An individual should always make sure that the persons or organizations providing services are approved for Medicare payments. Providers must meet licensing and standards requirements.

Outpatient physical therapy and speech pathology services may be furnished under supervision of participating hospitals, skilled nursing facilities, home health agencies or approved clinics, rehabilitation agencies, or public health agencies under a plan established and periodically reviewed by a doctor.

V) Insurance Claims

Insurance payments can be made in one of two ways: to the doctor or supplier, a method known as assignment or directly to the insured individual. A "Request for Medicare Payment" form, also called Form 1490, must be filled out and submitted in order to pay for services of doctors and suppliers. All Social Security offices and most doctor's offices have copies of the form.

The federal government selects private organizations, called carriers, to process all Medicare claims. In most cases, one carrier handles claims for an entire state. A listing of these carriers is available from the UCPA Governmental Activities Office.

VI) Federal Administration

Bureau of Health Insurance
Social Security Administration
Room 700, East High Rise
6401 Security Boulevard
Baltimore, Maryland 21235



MATERNAL AND CHILD HEALTH/CRIPPLED
CHILDREN'S SERVICES

Title V of the Social Security authorizes the federal government to promote the health of mothers and children through two programs: Maternal and Child Health Services and Crippled Children's Services. Title V earmarks grants to states to extend and improve services, provides a variety of training opportunities, and supports research to find better ways to improve the health of mothers and children.

(1) State Maternal and Child Health Services

Title V state formula grants support such activities for mothers as maternity clinics, nursing services, hospital in-patient care, family planning services, dental care for expectant mothers, and classes for expectant parents. The MCH state grant program also supports well-child clinics for health supervision of babies and children, nursing services for children, pediatric clinics, hospital in-patient care mostly of premature infants, school health examinations and screening tests, immunizations, and special clinics for the mentally retarded.

(2) State Crippled Children's Services

State Crippled Children's (CC) programs attempt to locate and provide diagnostic, medical and other health related, hospitalization, and followup services to children with crippling conditions. Free diagnostic services are available to every child brought to a CC program clinic. The CC agencies help parents with financial planning for treatment and care and may assume part or all of the cost of services, depending on the child's condition, the family's resources, and availability of funds. States are granted wide flexibility in defining "crippling conditions" which CC agencies will serve. All states currently include children under age 21 with disabilities requiring orthopedic or plastic treatment, such as cleft palate, club feet, and chronic conditions affecting muscles, bone, and joints.

(3) Administering Agency

Office for Maternal and Child Health
Bureau of Community Health Services
Room 12-05, Parklawn Building
5600 Fishers Lane
Rockville, Maryland 20852



VOCATIONAL REHABILITATION

A primary priority of UCPA - both the Professional Services Program Department in initiating new program services and the Washington office in influencing federal legislation - is accessing services to adults severely disabled by cerebral palsy and other developmental disabilities. We are concerned with the adult who has exited from the school system, who is inappropriately housed, and who is either unemployed or underemployed. We are attempting to increase opportunities at the local level to improve the quality of life for those with severe and multiple disabilities.

The following information related to rehabilitation legislation will cover these areas:

- (1) Congressional intent and statutory base
- (2) Federal regulatory interpretation and emphasis
- (3) State implementation problems and issues
- (4) Comprehensive needs study of persons with severe disabilities
- (5) Concluding remarks

CONGRESSIONAL INTENT AND STATUTORY BASE

Congressional concern and interest in serving those with severe disabilities was expressed in the "Rehabilitation Act of 1973" (P.L. 93-112) and the "Rehabilitation Act Amendments of 1974" (P.L. 93-516). The final federal regulations implementing P.L. 93-112 clearly summarize the statutory requirements related to serving the severely disabled:

"Although the Act mandates priority in the provision of vocational rehabilitation services to severely handicapped individuals, it does not eliminate the requirements for the establishment of vocational objectives and the achievement of vocational goals for the handicapped persons being served under the public rehabilitation program."



Before reviewing the exact federal requirements in present statutes let us look back to 1972 and 1973 when Congress was debating enactment of the Rehabilitation program through extension legislation. This legislation was overwhelmingly passed by the Congress on two occasions, but vetoed both times by President Nixon. Central to each veto was the question of serving the severely disabled irregardless of immediate vocational potential. The Congress placed particular emphasis on developing a method of providing services which would be responsive to individual needs and would ensure that no individual would be excluded from the program merely because his handicap appeared to be too severe. Services were to be expanded to enable individuals for whom a vocational goal was not presently possible, to prepare to live more independently. In vetoing the legislation, President Nixon stated he was opposed to goals that were "medical in nature" and he did not want to impair the vocational ethic nor "dilute the resources of that program or distort its objective by turning it toward welfare or medical goals."

When examining the present statutory language, let us keep fully in mind the congressional intent behind the act. Let us also remember that new legislation will be considered in 1976. The Senate Labor and Public Welfare Committee declared:

"The Committee also found that there was a large segment of the handicapped population that could not be served under the present program parameters due to the fact that no vocational goal could be achieved or might not seem achievable at the time the individual attempts to enter the program. The Committee feels a strong responsibility to see that these individuals do receive the services that they need, particularly that maximum efforts are made to develop a vocational goal for them."

P.L. 93-112 includes three specific requirements and provisions in serving the severely disabled:

(1) Section 2(1) declares the purpose of the Act to develop and implement comprehensive and continuing state plans and programs for the disabled, "serving first those with the most severe handicaps, so that they may prepare for and engage in gainful employment."

(2) and (3) Section 101(a)(5)(A) and (B) specify state planning requirements related to serving the severely disabled. Each state plan must include a description of the methods to be used to expand and improve services to handicapped individuals with the most severe handicaps. The state must also study and consider a broad variety of means for providing services to individuals with the most severe handicaps.



P.L. 93-516 amended the state plan section (section 101) and the individualized written rehabilitation program provisions in Section 102 of the act to require each state to keep sufficient and detailed records to enable HEW to analyze and evaluate annually the reasons for persons determined ineligible for VR services. The state is required also to analyze these records and to review the criteria used with respect to such ineligibility determinations.

Thus, the statutory language of the Rehabilitation Act remains primarily concerned only for those persons with severe disabilities who have a clear potential for competitive employment. But states must nevertheless increase their responsiveness, attention, and activity to those with **severe** disabilities.

HEW REGULATIONS

Final regulations implementing P.L. 93-112 (issued December 5, 1974) are consistent with the statutory requirements of the Act. The regulations clarify confusion over terms and concepts outlined in the act. I will emphasize just a few of these terms and concepts as they relate to the severely disabled.

(1) "Severely handicapped individual" means a handicapped individual, (1) who has a severe physical or mental disability which seriously limits his functional capacities (mobility, communication, self-care, self-direction, work tolerance, or work skills) in terms of employability; and (2) whose vocational rehabilitation can be expected to require multiple vocational rehabilitation services over an extended period of time, and (3) who has one or more physical or mental disabilities resulting from amputation, arthritis, blindness, cancer, cerebral palsy, cystic fibrosis, deafness, heart disease, hemiplegia, hemophillia, respiratory or pulmonary dysfunction, mental retardation, mental illness, multiple sclerosis, muscular dystrophy, musculoskeletal disorders, neurological disorders, neurological disorders (including stroke and epilepsy), paraplegia, quadriplegia, and other spinal cord conditions, sickle cell anemia, and end-stage renal disease, or another disability or combination of disabilities determined on the basis of an evaluation or rehabilitation potential to cause comparable substantial functional limitation.

(2) "Employability" refers to a determination that the provision of vocational rehabilitation services is likely to enable an individual to enter or retain employment consistent with his capabilities and abilities in the competitive labor market; the practice of a profession; self-employment; homemaking; farm or family work (including work for which payment is in kind rather than in cash); sheltered employment; homebound employment; or other gainful work.



(3) "Substantial handicap to employment" means that a physical or mental disability (in light of attendant medical, psychological, vocational, educational, and other related factors) impedes an individuals occupational performance, by preventing his obtaining, retaining, or preparing for employment consistent with his capacities and abilities.

An important new provision of the act relates to individualized written rehabilitation programs. Each state is required to initiate and continuously develop for each disabled individual an individualized written plan. All VR services will be provided in accordance with the plan. The written plan is to be the major element of the individual's case record, is to be developed jointly by the appropriate counsellors and the disabled individuals, and a copy of the plan must be provided to the disabled individual. The written program must place primary emphasis on the determination and achievement of a vocational goal. The plan must be reviewed at least annually and in the case of termination of services, the rationale for termination must be recorded as an amendment to the plan demonstrating "beyond any reasonable doubt that such individual is not capable of achieving a vocational goal."

STATE AGENCY ADMINISTRATION

The new act places a great deal of responsibility on the non-profit voluntary agencies to monitor state administration of the program and to serve as advocates on behalf of the disabled. Several issues and questions are critical to this point.

(1) Communication. Regular, clear cut lines of communication between the voluntary and state agency sectors must be developed. Regularly scheduled meetings to seek solutions would be part of this approach. Systematic feedback and planning are also important components.

(2) Continuum of Services. Has the voluntary sector worked out a logical continuum of services with the state agency which eliminates duplication and ensures progression? Does a continuum exist where an individual potentially can move from developmental day programming to work activities to sheltered workshop to sheltered employment to competitive employment?

(3) Catch 22 Certification. Does the state VR agency still play the old catch 22 certification game? This involves a certification of employability by OVR only after a job has been offered to a client but also involves a private employer only making a job offer after OVR certified the individual is employable.



(4) Successful Closures. Does the state VR agency and the state legislature still judge the success of the program by the percentage of successful closures made in relation to clients served? Are there still other disincentives for serving the severely disabled?

(5) State Agency Coordination. The State Vocational Education agency and the State Employment Service must work closely together with the State Vocational Rehabilitation Agency. Is there a comprehensive plan between these two agencies and vocational rehabilitation? Has a continuum between these agencies developed where the individual is referred in a logical progression from one of these state agencies to the other?

(6) Outreach. Has the state VR agency developed an effective outreach mechanism with the public schools, the private schools and agencies, and with the state institutions?

(7) Continuing Education. Has the state undertaken a training program to fully acquaint rehabilitation counselors to adequately serve the severely disabled? Has the voluntary agencies constructively offered their assistance in such training endeavors?

(8) Follow-up. Who follows the individual along after he leaves OVR? Is this OVR's responsibility or social services or the voluntary sector's?

COMPREHENSIVE NEEDS STUDY

P.L. 93-112 mandates HEW to undertake a study of the comprehensive needs of individuals with the most severe handicap to determine the feasibility of serving such individuals through the rehabilitation program. HEW has contracted with the Urban Institute to conduct the study. The Urban Institute requested UCPA to participate in the study.

To facilitate better documentation, the Urban Institute questionnaire was mailed to seventeen UCPA affiliates known to be operating ongoing adult programs. The affiliates responses were condensed into a single study.

Special needs of the severely disabled adult identified by the UCPA survey included:

- continuing education in basic academics and the broad educational areas
- residential planning and services for a variety of alternatives in living arrangements
- training in independent living
- transportation alternatives
- health care and maintenance (medical, dental, therapies, adaptive equipment and prosthetic devices)



- training in activities of daily living
- training in socialization skills
- vocational rehabilitation sponsorship
- vocational counseling and planning
- prevocational skills training
- income maintenance
- outlets for social and recreational activities including day time activity programs
- assistance in self-care when physical limitations preclude attaining independence
- expansion of opportunities for development of personal awareness and self-esteem including the establishment of a meaningful scheme to daily living
- means of understanding one's community and access to it
- adaptive clothing
- full time permanent employment

From the reports, only 16% of the disabled population (1729 persons) included in this survey had received services from state vocational rehabilitation programs. The following are some specific comments from UCPA affiliates responding to the survey related to experience with state OVR:

- Fifty per cent of the severely disabled would probably not apply because of the state vocational rehabilitation services' known standard of closing cases of providing long term management.
- State vocational rehabilitation programs are set up to serve only clients with vocational potential; therefore, it has been able to intercede effectively with relatively few clients.
- In general the only term which can be used in regard to vocational rehabilitation services is bad.
- Vocational rehabilitation referred those clients seen to an activity center since training for employment was considered non-feasible.
- Some clients were placed in sheltered workshops and subsequently terminated because of lack of production.
- Clients served are considered unemployable and therefore little contact was ~~made~~ by the state vocational rehabilitation program.
- Ninty per cent are considered ineligible for state vocational rehabilitation services.
- Clients are rejected because they are considered physically and/or mentally too involved to be rehabilitated.
- In some cases, services are only offered at the State's Vocational School whether it is practical for the individual's circumstances or not.
- VR counselors have become disattached from the severely involved client.
- Most vocational rehabilitation counselors are insensitive to the severely involved client's need.



Two affiliates reported excellent cooperation from state vocational rehabilitation programs. The key positive factors appear to be an openness and willingness on the part of these vocational rehabilitation programs to serve the severely handicapped and cooperate with the private agencies serving them. The communication established between vocational rehabilitation and these two private agencies has been excellent.

The CNS of UCPA concluded that expansion of the VR program to serve all the disabled, irregardless of severity of disability, would be highly beneficial.

Identifiable measurable benefits include at least the following:

- increase functioning in all areas
- movement toward independence
- progress from supervised living to independent living
- changes in personal appearance
- changes in behavior and socialization
- increased self-confidence
- enhanced decision making abilities
- increased productivity in leisure time
- decreased deterioration in physical, intellectual and emotional status
- decreased cost for basic care as independence increases
- increased compensatory educational experiences

Among those benefits considered non-measurable would be included:

- elevated feelings of self-worth
- increased maturation and personal growth
- feelings of being more like other people
- benefits of respite for family members

CONCLUSION

Federal rehabilitation statutes still restrict accessibility to service to those disabled individuals for whom a counselor determines has potential for employment, preferably competitive employment.

The legislation over the past two years mandated a number of gains for the severely disabled. These gains do not reflect the full programming needs of the severely disabled adult but they are a beginning. The trend in Washington is to address an individual's comprehensive needs to meet his functional limitations head-on. Unfortunately, in many areas of the country, we have in rehabilitation what sociologists call system maintenance, the almost automatic resistance of a prevailing power structure and social organism towards change.



We in the rehabilitation field, and this includes UCPA, have not developed the vision or originality to develop meaningful job opportunities for all persons with disabilities. We have not utilized existing technology. In this regard, it is important to emphasize the provision of physical assistance for those who cannot manage self-help but who could otherwise be employed at professional and technical levels if such assistance were available. We are hopeful that future rehabilitation legislation will provide the tools we need to serve the disabled, regardless of diagnostic labels, regardless of competitive employment potential.

Administering Agency

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FEDERALLY SUPPORTED EDUCATION FOR THE HANDICAPPED PROGRAMS

● Evolving Federal Role

For many years the only federal activities in special education for the handicapped were Gallaudet College for deaf pupils, which first received federal support in 1864, and the American Printing House for the Blind, which was established in 1879.

In 1958, P.L. 85-905 created the captioned films program for the deaf. Aimed primarily at recreation and cultural enrichment for deaf persons, amendments in 1962 and 1965 by public laws 87-715 and 89-258 broadened the program into a comprehensive instructional program. P.L. 89-276 enacted in 1961 authorized training programs for teachers of the deaf.

The first federal education effort on behalf of the developmentally disabled was in the area of mental retardation. In 1958, P.L. 85-926 encouraged teaching of mentally retarded children through grants to institutions of higher learning and State education agencies. This MR effort was strengthened with the passage in 1963 of the Mental Retardation Facilities and Community Mental Health Centers Construction Act (P.L. 88-164) Title II of 88-164 combined the existing legislation of programs for training personnel in the areas of mental retardation and deafness to include training of all handicapped children. Research and demonstration projects were authorized for the first time in the area of education for the handicapped.

1965 witnessed the first significant federal support of educational services. P.L. 89-10 established the Elementary and Secondary Education Act (ESEA). Title I authorized federal grants to the States for allocation to school districts having children in low income families. "Educationally disadvantaged children included the handicapped. Through amendments of P.L. 89-313, non-educational State agencies directly responsible for educating handicapped children became recipients of federal assistance. Institutionalized handicapped children, for the first time in many cases, began receiving educational training.

The Johnson Great Society expanded in 1966 with the passage of P.L. 89-750, the Education of the Handicapped Act (EHA). EHA became a new Title VI of ESEA. Title VI B grants were allocated to the States to initiate, expand and improve programs and projects for the education of handicapped children at preschool, elementary, and secondary levels.

P.L. 89-750 also established the Bureau of Education of the Handicapped (BEH) and the National Advisory Committee on the Handicapped. This too was significant. In 1961, President Kennedy had appointed a



Division of Handicapped Children and Youth within the Office of Education (OE) but this was disbanded through an OE reorganization in 1965. A central bureau with responsibility solely for the handicapped had finally been established through federal statute.

The next four years witnessed the expansion of the Education of the Handicapped Act. In 1968, P.L. 90-538 created the Handicapped Children's Early Education Assistance Act. The federal government initiated experimental preschool and early education programs for handicapped children. 1969 saw the establishment of the National Center on Education Media and in 1970, a program of comprehensive research and training activities was undertaken as well as the creation of model centers for the education of children with specific learning disabilities.

On August 21, 1974, President Ford signed into law the Education Amendments of 1974. P.L. 93-380 strengthened the existing authorities of the Elementary and Secondary Education Act as it relates to the handicapped but did not change the federal role significantly. The basic federal strategy remained to use federal funds as a catalyst to State and local development. Primary responsibility and financial obligation remained rested with the States and localities.

However, the federal goals and objectives were clarified to emphasize a potentially larger service role in the future. The title VI B program was revised incorporating an entitlement formula sponsored by Senator Charles Mc C. Mathias (Md.). Under the Mathias amendment, each state would be entitled to an allocation based on multiplying the total number of all children in average daily attendance within the State's public schools by \$8.75. The entitlement would continue to be used for initiating, expanding, and improving programs but would last only for one year. The current political environment indicates that there may be little funding of the Mathias Amendment.

- The Education for All Handicapped Children Act

In November 1975, the "Education for All Handicapped Children Act" was signed into law as P.L. 94-142.

- (1) Purpose of P.L. 94-142

P.L. 94-142 declares that "it is the purpose of this Act to assure that all handicapped children have available to them, within the time periods specified..., a free appropriate public education which emphasizes special education and related services designed to meet their unique needs, to assure that the rights of handicapped children and their parents or guardians are protected, to assist states and localities to provide for the education of all handicapped children, and to assess and assure the effectiveness of efforts to educate handicapped children."



(2) Definitions of Crucial Terms

Central to understanding the full implications of P.L. 94-142 is a comprehension of crucial terms. The following definitions are crucial:

(a) Special Education. "Specifically designed instruction, at no cost to parents or guardians, to meet the unique needs of a handicapped child, including classroom instruction, instruction in physical education, home instruction, and instruction in hospitals and institutions."

(b) Related Services. "Transportation and such developmental corrective, and other supportive services (including speech pathology and audiology, psychological services, physical and occupational therapy, recreation, and medical and counseling services, except that such medical services shall be for diagnostic and evaluation purposes only) as may be required to assist a handicapped child to benefit from special education, and includes the early identification and assessment of handicapping conditions in children."

(c) Free Appropriate Public Education. "Special education and related services which (a) have been provided at public expense, under public supervision and direction, and without charge, (b) meet the standards of the State educational agency, (c) include an appropriate preschool, elementary, or secondary school education in the state involved, and (d) are provided in conformity with the individualized education program required..."

(3) Annual State Plan Requirements

In order to qualify for federal funds, every state must develop an annual State Plan which must contain certain conditions and provisions:

(a) The State has in effect a policy that assures all handicapped children the right to a free appropriate public education.

(b) The State establishes the goal of providing full educational opportunity to all handicapped children, a detailed timetable for accomplishing such a goal, and a description of the kind and number of facilities, personnel and services necessary throughout the state to meet such a goal.



(c) The State assures that a free appropriate public education will be available for all handicapped children, ages 3-18, no later than September 1, 1978 and ages 3-21 no later than September 1, 1980 except this requirement shall not apply to any state where this would be inconsistent with state law or court order.

(d) The State has identified located, and evaluated all handicapped children and has designed a practical method to determine which children are currently receiving or not receiving needed special education and related services.

(e) The State Plan is available to parents, guardians, and other members of the general public.

(f) The State has established priorities for providing a free appropriate public education first to children who are not receiving an education and second to children with the most severe handicaps.

(g) Each local educational agency in the State will maintain records of the individualized educational program required for each handicapped child.

(h) The State has established procedural safeguards to assure, to the maximum extent appropriate, handicapped children are educated with children who are not handicapped (least restrictive environment).

(i) The State shall develop and implement a comprehensive system of personnel development.

(4) Procedural Safeguards

P.L. 94-142 requires every state to assure that handicapped children and their parents or guardians are guaranteed procedural safeguards with respect to the provision of free appropriate public education. These safeguards relate to (1) the opportunity to examine all relevant records with respect to the identification, evaluation, placement, and service provision; (2) the protection of rights of any child whose parents or guardians are not known, unavailable, or the child is a ward of the state; (3) written prior notice whenever identification, evaluation, and placement is to be initiated or changed; (4) provide such notices in the parents' or guardian's native language where feasible; (5) the opportunity to present complaints; and (6) the opportunity for an impartial due process hearing.



(5) Funding Formula

P.L. 94-142 provides a gradually increasing federal fiscal role for the education of handicapped children. For fiscal years 1976 and 1977, the current formula of multiplying all children in average daily attendance within a state's public school system by \$8.75 is continued. This formula is subject to an authorization ceiling of \$100 million in 1976 and \$200 million in 1977. In fiscal year 1978, a new formula will be adopted by targeting federal monies for handicapped children by paying a specified percentage of the average per pupil expenditure multiplied by the number of handicapped children receiving special education and related services in a state. The specified percentage will gradually increase, beginning at 5% in F.Y. 1978 and moving to 40% by 1982 and thereafter. In determining the allotment of each state, the federal government may not count handicapped children in any state which is greater than 12% of the number of all children aged 5-17 in such state.

The Council for Exceptional Children (CEC) has estimated, on the basis of the current national average per pupil expenditure, the following authorization ceilings for the first five years of the new formula:

Fiscal 1978.....\$387 million (on the five-percent factor)
Fiscal 1979.....\$775 million (on the ten-percent factor)
Fiscal 1980.....\$1.2 billion (on the twenty-percent factor)
Fiscal 1981.....\$2.32 billion (on the thirty-percent factor)
Fiscal 1982.....\$3.16 billion (on the forty-percent factor)

P.L. 94-142 addresses the potential threat of "overcounting" children as handicapped in order to generate the largest possible Federal allocation. The measure prohibits counting more than 12 percent as handicapped served within the total school-age population of the State between the ages of five and seventeen.

(6) State Education Agency - Local School District Relationship

P.L. 94-142 requires that the State educational agency be responsible for ensuring that all requirements of the Act are carried out, and that all education programs within the State for all handicapped children, including all such programs administered by any other State or local agency, must meet State educational agency standards and be under the general supervision of persons responsible for the education of handicapped children. This provision establishes a single line of authority within one State agency for the education of all handicapped children within each State.



As finalized, P.L. 94-142 contains a substantial pass-through to the local school districts. In the first year of the new formula, 50 percent of the monies going to each State would be allocated to the State education agency, and 50 percent would be allocated to the local education agencies. In the following year, 1979, the LEA entitlement would be enlarged to 75 percent of the total allocation to a given State, with the SEA retaining 25 percent. This 75-25 arrangement commencing in fiscal '79 becomes the permanent distribution arrangement. The current State-control of all funds is retained for the remainder of fiscal 1976 and fiscal 1977.

(7) Private School Considerations

Every State is required to develop policies and procedures related to handicapped children in private schools. Each State is to provide for the participation of handicapped children enrolled in private schools in programs assisted or carried out under P.L. 94-142. The state must assure that handicapped children in private schools will be provided special education and related services, in conformance with an individualized educational program, at no cost to their parents or guardians, if such children are placed in or referred to such schools by the state or appropriate local educational agency as the means of carrying out the requirements for free appropriate public education for all handicapped children. States **shall** determine whether such private schools meet standards and that the rights of children and their families in such schools are observed.

● Federal Administration

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HOUSING AND COMMUNITY DEVELOPMENT ACT

The "Housing and Community Development Act" was signed into law as P.L. 94-383 in August 1974. The Housing and Community Development (HCD) Act is a complement to general revenue sharing with primary decision making and priority setting resting with states and localities. Local government, operating under loose guidelines, are granted much flexibility and independence.

The HCD Act is aimed primarily at helping those living in urban areas with emphasis placed on local governmental units representing 50,000 population or more. The federal administering agency - the Department of Housing and Urban Development (HUD) - heavily relies upon designated SMSA's (standard metropolitan statistical areas) for allocation of funds.

The priority objective of the HCD Act is the development of viable urban communities with emphasis on decent housing for persons of low and moderate income. Low income families is specifically defined to include disabled persons including the developmentally disabled.

● Community Development Program

Title I of P.L. 94-383 - the Community Development Program (CDP) - attempts to assist local government agencies to develop viable urban communities including decent housing, suitable living environments, and expansion of economic opportunities for low income persons. Eighty (80) percent of CDP funds are allocated to metropolitan areas.

Title I applications and annual plans must provide assurances that prior to their submission citizens have received adequate information about funds to be applied for and public hearings have been conducted to obtain the views of citizens. Citizen participation is a mandated requirement of each community applying for CDP funds.

Title I is not a housing program but many of its activities are complementary to developing community based housing for the disabled. Funding of special projects directed to the removal of material and architectural barriers which restrict the mobility and accessibility of the disabled are specially earmarked. In addition, acquisition, construction, reconstruction, or installation of neighborhood facilities, parks, playgrounds, and other recreational facilities open to the disabled are permitted fundable activities.



The Title I annual plan has a direct and immediate impact on housing programs. The act mandates that each plan accurately surveys the condition of the housing stock and assesses the housing needs of the disabled. This is a mandated requirement which every applicant community must meet.

- Housing Assistance Program

Title II of P.L. 94-383 is the housing program of the act. It is permissible legislation in that the means and mechanisms to serve the disabled are authorized but are not mandated. Each community must submit a Housing Assistance Plan reviewing its priorities and objectives. The Housing Assistance Plan must specifically address the priorities and activities as identified in the Title I Community Development Program.

Section 8, authorizing rent subsidy payments (known as housing assistance payments), is the backbone of the Title II program. The rent subsidy will pay the owner of rental property monthly rents based on the family's or individual's income. Each eligible person or family will pay more than 25% of their monthly income for rent. Persons with high medical costs may only have to contribute 15% of their income towards the rent.

- Construction Funds: Section 202 Program

The Section 202 program, as amended by Sections 209 and 210 of P.L. 93-383, permits HUD to make direct federal construction loans to non-profit developers of housing programs for the elderly and handicapped.

The Section 202 program is targeted on "rental housing structures suitable for dwelling use by elderly or handicapped families and includes structures suitable for use by residents of the housing structures as cafeterias, dining halls, community rooms or buildings, workshops, infirmaries, inpatient and outpatient health facilities, or other essential service facilities."

HUD regulations require that only projects which receive contracts for Section 8 rent subsidy payments would be eligible to participate in the Section 202 program. Though neglected in the regulations, P.L. 93-383 requires all Section 202 projects for the disabled to be in support of and supported by the applicable State Developmental Disabilities Plan.

- State Housing Agencies

With the exception of the Section 202 program, housing construction funds are not authorized under P.L. 93-383. Section 802 of P.L. 93-383 encourages the formation and effective operation of State housing



finance and development agencies. The main function of these state housing agencies is to use the bond financing mechanism with a tax exemption to provide loans with below the market interest rates to developers of housing.

The Section 802 program authorizes HUD to guarantee obligations of a state housing agency issued to finance development activities. HUD is permitted to cover 33-1/3% of the interest on obligations assumed by a state housing agency. HUD is also permitted to provide technical assistance to state housing agencies to carry out the purposes of Section 802. With the current scarcity of federal housing construction funds, it is the state housing agency which potentially can provide construction funds for developing housing programs for the disabled.

● Federal Contact

Each of the above discussed programs are administered by separate divisions within HUD, none of which contain identifiable staff for the disabled. HUD has established a special office as the liaison with outside constituency groups. The office has no direct program authority.

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TRANSPORTATION

There is no coherent federal policy regarding transportation for persons with disabilities. There are federal programs for the disabled and those programs are fragmented, incomplete, and largely ineffective. They have made little impact on increasing the mobility and independence of persons with disabilities.

Existing federal transportation statutes related to disability revolve around public transportation accessibility policy statements, reduced fares for the disabled on public transportation, and support on non-profit agencies serving the disabled. Each of these approaches are targeted on a single aspect of the transportation needs of disabled persons. Unfortunately, both physical difficulties and travel barriers occur in combination. Hence, the elimination of one barrier, regardless of its importance, will not make the system accessible to a large portion of the disabled population.

(1) Federal Laws Relating to Accessibility

There are five existing federal statutes which relate to accessible public transportation for the disabled.

(a) "Federal - Aid Highway Act of 1973"

Section 165(b), P.L. 93-87: Mass transit projects receiving federal financial assistance must be designed to be accessible.

(b) The Secretary of Transportation shall assure that projects receiving Federal financial assistance under (1) subsection (a) or (c) of section 142 of title 23, United States Code. (2) paragraph (4) of subsection (e) of section 103, title 23, United States Code, or (3) section 147 of the Federal-aid Highway Act of 1973 shall be planned and designed so that mass transportation facilities and services can effectively be utilized by elderly and handicapped persons who, by reason of illness, injury, age, congenital malfunction, or other permanent or temporary incapacity or disability are unable with special facilities or special planning or design to utilize such facilities and services as effectively as persons not so affected.

(b) "Federal - Aid Highway Act of 1973"

Section 228, P.L. 93-87: Streets constructed with federal funds must have accessible pedestrian crosswalks.

Curb Ramps for the Handicapped

Sec. 228, Paragraph (1) of subsection (b) of section 402 of title 23, United States Code, is amended by adding at the end thereof the following:



"(F) provide adequate and reasonable access for the safe and convenient movement of physically handicapped persons including those in wheelchairs, across curbs constructed or replaced on or after July 1, 1976, at all pedestrian crosswalks throughout the State."

(c) "Amtrak Improvement Act of 1973"

Section 6, P.L. 93-146: The National Railroad Passenger Corporation must take all necessary steps to insure rail accessibility by the disabled.

Section 6, Section 305 of the Rail Passenger Service of 1970 (45 U.S.C. 545), relating to general powers of the Corporation, is amended by adding at the end thereof the following subsections:

"(c) The Corporation is authorized to take all steps necessary to insure that no elderly or handicapped individual is denied intercity transportation on any passenger train operated by or on behalf of the Corporation, including but not limited to, acquiring special equipment and devices and conducting special training for employees; designing and acquiring new equipment and facilities and eliminating architectural and other barriers in existing equipment and facilities to comply with the highest standards for the design, construction, and alteration of property for the accommodation of elderly and handicapped individuals; and providing special assistance while boarding and alighting and in terminal areas to elderly and handicapped individuals.

(d) "Department of Transportation and Related Agencies Appropriations Act, 1975"

Section 315, P.L. 93-391: Department of Transportation assisted facilities must be designed to meet the mass transportation needs of the disabled.

Mass Transportation Facilities

Sec. 315. None of the funds provided under this Act shall be available for the purchase of passenger rail or subway cars, for the purchase of motor buses or for the construction of related facilities unless such cars, buses and facilities are designed to meet the mass transportation needs of the elderly and the handicapped.



(e) "The Federal-Aid Highway Amendments of 1974"

Section 105, P.L. 93-643: Mass transit programs receiving federal funds must be planned, designed, constructed, and operated to permit accessibility.

Transportation for Elderly and Handicapped Persons

Section 105. (a) It is hereby declared to be the national policy that elderly and handicapped persons have the same right as other persons to utilize mass transportation facilities and services; that special efforts shall be made in the planning, design, construction, and operation of mass transportation facilities and services so that the availability to elderly and handicapped persons of mass transportation which they can effectively utilize will be assured; and that all Federal programs offering assistance for mass transportation (including the programs under title 23, United States Code, the Federal-Aid Highway Act of 1973, and this Act) effectively implement this policy.

(2) DOT Implementation of Statutory Accessibility Requirements

Accessibility requirements and programs for the disabled do not have a single responsible administering agency within the federal government. Each agency is responsible for assuring compliance with statute only in its limited area of jurisdiction.

(a) Urban Mass Transportation Administration

Because most existing federal laws relates to accessibility on public transportation, the single most important agency is the Urban Mass Transportation Administration (UMTA). UMTA administers a host of programs. However, two are of foremost importance. The UMTA Capital Assistance program provided \$1 billion in 1975, on an 80-20% matching ratio, to local public transit authorities to construct new systems and purchase equipment and facilities. The UMTA Planning Assistance program provides grants, also on an 80-20% matching formula, to local government to develop short and long range urban transportation plans. These plans must address programs needed by the elderly and disabled.

On February 26, 1975, UMTA issued proposed regulations to codify existing requirements and establish new requirements consistent with statute related to service for the elderly and handicapped. The



response to the regulations were so complex, detailed, and technical with major concerns expressed by consumer based organizations, that UMTA has yet to issue final regulations. The proposed regulations address the service and hardware aspects of public transit and require local transit operators and planners to identify travel requirements and develop specific plans and programs to meet those requirements. Three major problems are involved with issuance of UMTA regulations: (1) UMTA refuses to commit the resources necessary to require both an accessible mass transit system and a specialized door through door transportation service. Spokesmen for the disabled are divided with some advocating that priority should be placed on one approach over the other. (2) UMTA is reluctant to require manufacturers and transit authorities to immediately utilize existing technology to solve transportation problems of the disabled. (3) UMTA has laid the responsibility on the disabled constituency with the statement that very little is known about the mobility requirements, program options, and numbers of transportation handicapped persons requiring services.

(b) Interstate Commerce Commission

On July 17, 1975, the Interstate Commerce Commission (ICC) issued proposed regulations requiring special assistance and terminal facilities for disabled passengers of Motor Common Carriers. The regulation declares that "no carrier shall deny transportation to any person on the basis of a handicap, physical disability, or blindness or because that person cannot board a bus without assistance, provided that such person can occupy a seat without disturbing other passengers."

(c) Architectural and Transportation Barriers Compliance Board

The Architectural and Transportation Barriers Compliance Board (A&TBCB), established by the "Rehabilitation Act of 1973" (P.L. 93-112) is mandated to investigate and examine alternative approaches to the transportation barriers confronting disabled individuals, especially in the area of public transportation. The Secretary of the Department of Transportation must be a member of the Compliance Board. The Board is to determine how and to what extent transportation barriers impede the mobility of disabled individuals and to consider ways in which travel expenses in connection with transportation to and from work impede use of mass transit systems or need special equipment in private transportation.

(3) Reduced Fares

Section 5(m) and Section 108 of P.L. 93-503, the "National Mass Transportation Assistance Act of 1974," requires mass transit programs receiving federal financial assistance to charge reduced fares to the disabled during non-peak hours.



"(m) The Secretary shall not approve any project under this section unless the applicant agrees and gives satisfactory assurances, in such manner and form as may be required by the Secretary and in accordance with such terms and conditions as the Secretary may prescribe, that the rates charged elderly and handicapped persons during nonpeak hours for transportation utilizing or involving the facilities and equipment of the project financed with assistance under this section will not exceed one-half of the rates generally applicable to other persons at peak hours, whether the operation of such facilities and equipment is by the applicant or is by another entity under lease or otherwise.

Fares for Elderly and Handicapped Persons

Sec. 108. Nothing contained in this title shall require the charging of fares to elderly and handicapped persons.

(4) Grants to Non-Profit Agencies

Section 301 of P.L. 93-87, the "Federal-Aid Highway Act of 1973," authorizes federal grants to non-profit agencies serving the disabled by amending Section 16(b) of the "Urban Mass Transportation Act of 1964."

(g) Section 16(b) of the Urban Mass Transportation Act of 1964 is amended to read as follows:

"(b) In addition to the grants and loans otherwise provided for under this Act, the Secretary is authorized to make grants and loans--

"(1) to States and local public bodies and agencies thereof for the specific purpose of assisting them in providing mass transportation services which are planned, designed, and carried out so as to meet the special needs of elderly and handicapped persons, with such grants and loans being subject to all of the terms, conditions, requirements, and provisions applicable to grants and loans made under section 3(a) and being considered for the purposes of all other laws to have been made under such section; and

"(2) to private nonprofit corporations and associations for the specific purpose of assisting them in providing transportation services meeting the special needs of elderly and handicapped persons for whom mass transportation services planned, designed, and carried out under paragraph (1) are unavailable, insufficient, or inappropriate, with such grants and loans being subject to such terms, conditions, requirements and provisions (similar insofar as may be appropriate to those applicable to grants and loans under paragraph (1) as the Secretary may determine to be necessary or appropriate for purposes of this paragraph.



Of the total amount of the obligations which the Secretary is authorized to incur on behalf of the United States under the first sentence of section 4(c), 2 per centum may be set aside and used exclusively to finance the programs and activities authorized by this subsection (including administrative costs)."

In 1975, 30 community based agencies primarily serving individuals with cerebral palsy received Section 16(b)(2) grants to purchase buses and similar equipment. The total federal allocation for the program in 1975 was \$22 million. Although these grants will continue to be allocated to private agencies, UMTA maintains that "the regular transit operator still must play the lead role in satisfying the transportation needs of our elderly and handicapped people."

Under 16(b)(2), it is the responsibility of each State to select among projects, and, in turn, submit these to UMTA for review and approval.

(5) The Right to Travel by Air

The past several years have witnessed federal agencies attempting to make a judgement regarding the rights of the disabled to travel by air. The central question is do physically disabled persons threaten the personal safety of passengers on public air carriers to the extent that their personal right of access should be limited?

In October 1971, the Civil Aeronautics Board (CAB) asked the Federal Aviation Administration (FAA) for a determination of the relevant safety parameters associated with the carriage of disabled persons on the commercial airlines. Subsequent proposed rules were issued by the FAA on May 30, 1973, by the FAA on July 5, 1974, and by the CAB on August 14, 1974. Final regulations have yet to be issued. The basic FAA-CAB argument cites a survival accident in Denver in July 1961 whereby many of the passengers perished simply because the airplane was not evacuated soon enough. Because successful evacuation is directly related to the flow rate through emergency exits, FAA rules now require emergency evacuations within 90 seconds. The FAA argues that the number of disabled persons must be limited so as not to jeopardize their safety or that of others during evacuations. After all these proposed rules and the conduct of five regional hearings during the fall of 1973, no final policy has been developed. In the meantime, several court cases have been filed by disabled persons refused passage on a commercial airline.



(6) Federal Administration/Further Information

Urban Mass Transportation Administration policies regarding accessibility requirements and local transit authority planning requirements for the disabled should be addressed to Ms. Patricia Cass, Program Manager, Office of Transit Planning, Urban Mass Transportation Administration, 400 - 7th Street, S. W., Room 9307 G, Washington, D. C. 20410.

Questions regarding architectural barriers and accessibility should also be addressed to Mr. James Jeffers, Executive Director, Architectural and Transportation Barriers Compliance Board, Room 1004, HEW South Building, 330 C Street, S. W., Washington, D. C. 20201.

Information regarding Section 16(b)(2) capital grants is available by writing Mr. David Whiter, Director, Office of Capital Assistance, Urban Mass Transportation Administration, Room 9305 B, 400 - 7th Street, S. W., Washington, D. C. 20410.