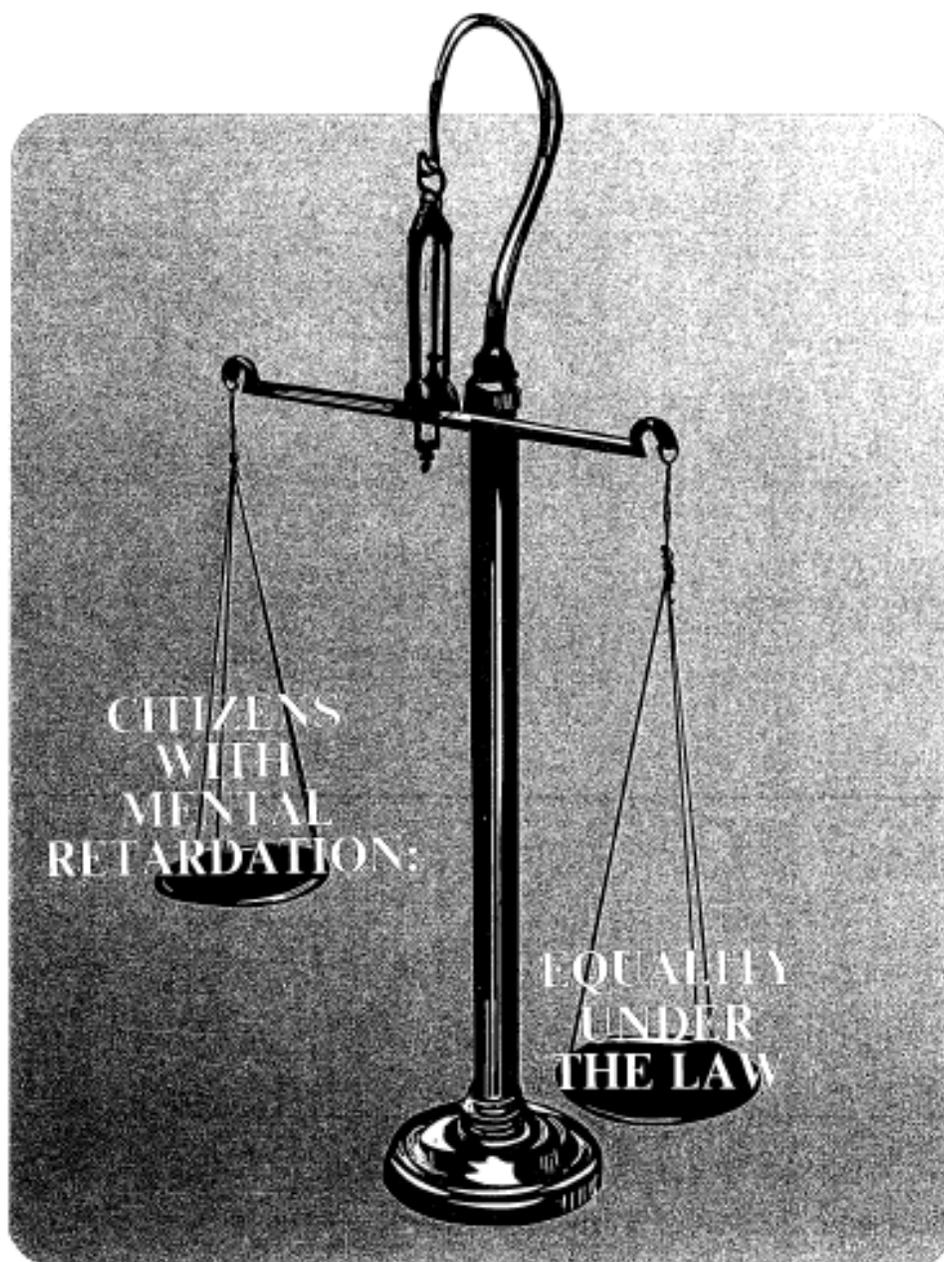


Report to the President



THE SECRETARY OF HEALTH AND HUMAN SERVICES
WASHINGTON, D.C. 20201

The President
The White House
Washington, D.C. 20500

Dear Mr. President:

I am pleased to transmit to you the report of the President's Committee on Mental Retardation entitled *Citizens with Mental Retardation: Equality Under the Law*. The report focuses on many important aspects of the law and mental retardation. It addresses recent and current legal issues and needs, including the role of local and State government, least restrictive environment, self-advocacy, right to survival, and family and community living.

The content of this report includes the contribution of participants, who were invited experts in the field of law and mental retardation, attending the Second National Conference on Legal Rights for Mentally Retarded Citizens held in March 1985; and selected resolutions passed by the membership of the President's Committee on Mental Retardation, relating to the subject of law and mental retardation.

The relationship between law and citizens with mental retardation was addressed by the President's Panel on Mental Retardation over twenty years ago. The First National Conference on Legal Rights for Mentally Retarded Citizens was held twelve years ago. The present report is an update on the subject of law and mental retardation, spanning the twelve years between the two conferences.

It is my hope the information in this report proves useful as we as a nation work to develop strategies for the attainment of full citizenship by citizens with mental retardation and developmental disabilities.

Sincerely,

Otis R. Bowen, M.D.
Secretary

Report to the President

Citizens with Mental Retardation: Equality Under the Law

President's Committee on Mental Retardation
Washington, D.C. 20201

Preface

For over 20 years, beginning with the President's Panel on Mental Retardation, and continuing with the President's Committee on Mental Retardation (PCMR), the Committee has monitored the relationship between citizens with mental retardation and the law with great interest. The Committee's diligence in monitoring this relationship is built upon an acute awareness that although citizens with mental retardation have the basic rights of Life, Liberty, and the Pursuit of Happiness, American society has frequently denied mentally retarded citizens full access to these rights. The intent of this Special Report to the President is that it will serve to strengthen the awareness of public policy makers and the general public regarding this dichotomy as well as to the need to ensure continued availability of Federally protected rights for citizens with mental retardation.

The information and recommendations contained in this Report to the President are the result of the Second National Conference on Citizens with Mental Retardation and the Law held March 14-16, 1985. The Conference was sponsored by the President's Committee on Mental Retardation, the Office of Special Education and Rehabilitative Services of the U.S. Department of Education, the Resident Home for the Mentally Retarded of Hamilton County, Inc., Ohio, and the City University of New York Law School at Queens College. The focus of the Conference was to assess the accomplishments and the problems in the legal rights area since PCMR sponsored the First National Conference in 1973, to consider current trends, to define a base for the efforts in this area and to develop a scenario through the end of the century.

The Report includes selected resolutions passed by the President's Committee on Mental Retardation which relate to the subject of the Report. These are the only items in the Report which represent the official position of the Committee.

Albert L. Anderson, D.D.S.
Vice Chairperson
President's Committee
on Mental Retardation

President's Committee on Mental Retardation

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3 - Chairperson, Full Citizenship Subcommittee

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I. Introduction

Role of the President's Committee on Mental Retardation in the Legal Rights Area and in the Development of this Report

The President's Committee on Mental Retardation has an unique responsibility. Its charge is to focus on a single area of national concern—mental retardation—and to make its recommendations to the President of the United States, and to the Secretary of the Department of Health and Human Services. Our society's view and treatment of persons with mental retardation continually changes. These changes are reflected in policy shifts among different agencies at the Federal, State and local levels.

The relationship of citizens with mental retardation and the law initially was addressed by the President's Panel on Mental Retardation over twenty years ago. Issues related to the rights of this portion of our population were brought to the attention of families, care givers, policy makers, professionals and the general public. In the intervening period, the President's Committee on Mental Retardation has continued to focus attention on the rights of individuals with mental retardation.

We do not "give people their rights". Individuals either have rights or they do not. The unfortunate thing that we often do with rights is to take them away from certain groups or classes of citizens. Rooted in the Constitution and in the Declaration of Independence are the rights of **Life, Liberty, and the Pursuit of Happiness.** We must remain alert to ensure that persons with mental retardation are able to enjoy their full rights of citizenship.

In terms of their right to **Life**, protections must be in place to ensure that decisions will not be made to deprive individuals of life because of diagnoses of mental retardation. President Reagan's clear support of this position is reflected in his statements on the "Baby Doe" issues. Further, we must be alert to prevent efforts to devalue the life of persons with mental retardation. The strength of a society is reflected in its willingness to safeguard the rights of *all* of its citizens.

As a nation, we have fought to protect our right to **Liberty.** Full application of this value requires an end to the presumption that there is a need for segregation of persons with mental retardation from the rest of society. Historically, application of this presumption has resulted in the construction of large, usually isolated residential facilities; in the

segregation of students in schools; in the denial of access to generic service agencies; and in efforts to limit full and equal access to appropriate living arrangements and employment within the community.

Parents' groups have been a major force in advocating the **Liberty** rights of citizens with mental retardation. The efforts of parents' groups at the national, state and local levels have resulted in educational mainstreaming, establishing and maintaining community living settings, legislation and court rulings limiting discrimination in employment, and in the growth of a strong protection and advocacy network. Group efforts have significantly advanced the **Liberty** rights of citizens with mental retardation.

Individuals with mental retardation have a basic right to the **Pursuit of Happiness.** This right can be exercised best when the individual is functioning at an optimal level of independence and can choose from among the options generally available to citizens of this society. To allow optimal choice, a full range of services should be available to each individual with mental retardation and his or her family. These services include prevention, early intervention, nutrition, health care, education, vocational training and employment, recreation, social services, housing, and transportation.

Though these services may seem costly, investments in them are appropriate and fiscally responsible when considered against the benefits of reduced need for life-long services, reduced drain on families and increased opportunities for persons with mental retardation. Providing this support base to the **Pursuit of Happiness** allows citizens with mental retardation to move from being tax consumers to the socially integrated role of being working, and tax contributing Americans.

The President's Committee on Mental Retardation has maintained a national spotlight on the specific needs of this population. The Committee has disseminated information on the most recent scientific advances, on model programs and on changing policy and service patterns. The Committee has sponsored studies to consider what may be expected in the future for our society overall, and for the individuals with mental retardation within that changing society. A hallmark of the Committee's efforts has been in the legal rights area.

In 1973, PCMR convened the First National Conference on the Legal Rights of Mentally Retarded Citizens at Ohio State University in Columbus, Ohio. The purpose of the 1973 Conference was to review the historical development of legal and civil rights in this area, to consider both the recent progress and the practical and conceptual obstacles to full realization of these rights, and to set an agenda for the coming decade. The Conference brought together hundreds of parents, decision makers, legislators, lawyers, advocates, university faculty, mental retardation professionals and students. As the first meeting of its kind, it represented a milestone in the history of people with mental retardation in the United States.

The Conference accomplished a number of major achievements. First, it provided the stimulus for lawyers and advocates to recognize that mental retardation is an appropriate and exciting area for legal study and activities. Second, it created a heightened awareness for mental retardation professionals of the potential within the legal system for securing needed and legally mandated services. Third, it served to identify lawyers active in the mental retardation field. Finally, publication of the text, *The Mentally Retarded Citizen and the Law*, based upon Conference proceedings, provided the first extensive exploration of the personal, civil and community rights of citizens with mental retardation.

Twelve years later, in 1985, a small group of legal scholars, educators, parents, mental retardation professionals and advocates met at the Grailville Conference Center in Loveland, Ohio, for the Second National Conference on the Legal Rights of Mentally Retarded Citizens. The Resident Home for the Mentally Retarded of Hamilton County hosted the Grailville Conference and co-sponsored it with the President's Committee on Mental Retardation, the Office of Special Education and Rehabilitative Services of the U.S. Department of Education, and the City University of New York Law School at Queens College.

The Second Conference was a marked contrast in size to its predecessor. Participants at Grailville were selected for their expertise and active involvement as outstanding representatives in the legal rights area of the mental retardation field. A major difference in 1985 was the great increase in the size of the pool of knowledgeable, talented and experienced individuals from which participants could be selected. The

Grailville Conference was designed as a working conference so that every participant would play an active role in the Conference sessions, presenting either papers or formal reactions, facilitating sessions or participating in the group discussions. Grailville's seclusion and retreat setting provided an atmosphere conducive to fruitful dialogue.

The First Conference focused considerable attention on developing recognition, through legal avenues, that citizens with mental retardation share the same basic rights as other citizens. Educational exclusion and deinstitutionalization were major topics. At Grailville, these and related issues were viewed as historical phenomena. Superseding them were questions related to the quality of life; the provision of life sustaining services; self determination, the type, setting and value of educational and work-related services, and the community integration of those citizens with mental retardation who could function in a variety of small, appropriate, family sized residences. New issues, not foreseen in 1973, were the focus of much intense discussion. Of particular importance were the Baby Doe cases and self-advocacy by persons with mental retardation.

This report draws on the positions and actions taken by the President's Committee on Mental Retardation from 1982 to 1985 which are related to major national concerns about the legal rights of citizens with mental retardation. Further, relying on the 1985 Conference, the report integrates the Conference's presentations, reactions, and discussions of these issues. It also presents resolutions by the President's Committee on Mental Retardation, passed between 1982 and 1985, that related specifically to the legal rights area. These issues are on the cutting edge of efforts to ensure the rights of individuals with mental retardation while meeting the needs presented by these persons, their families and other advocates.

The President's Committee on Mental Retardation has played an important role in highlighting issues central to the legal rights of citizens with mental retardation. By bringing these issues into a national arena for debate and discussion, the Committee intends to focus the attention of policy makers and the general public on the needs of these citizens. This permits consideration of the issues and goals, and encourages development of strategies to impact on future developments.

II. The Population of Citizens with Mental Retardation

Identification and Description of the Population of Citizens with Mental Retardation

The meaning of the term mental retardation has changed with some frequency over the years. Some words which originally had specific, professional meanings in the field of mental deficiency/mental retardation were, incorporated into the general language, used as pejorative and then gradually replaced in professional use. Different professions defined mental retardation in terms of each profession's view of human development. As our view of mental retardation changed, different professions became dominant in the field. Over the years, medical, psychiatric, psychological, educational and rehabilitation personnel each have had the primary role in determining how we view the people who were labeled as mentally retarded.

Professional terminology established classifications which described the degree of intellectual deficit. Persons were described as having borderline, mild, moderate or severe mental retardation. As recently as 35 years ago, the I.Q. score was widely accepted as fixed, and persons with I.Q.'s below 50 were deemed not able to profit from educational services and in need of long term care and custody. Education and rehabilitation services for this population were not generally available. Instead of diagnosing or describing, classifications set limits. We did not expect higher levels of performance and behavior, and we did not get them. Unfortunately, some professional and many lay persons dismiss the significant advances and demonstrated successes of the past three decades and believe that the above limits are, in fact, a true reflection of the needs and abilities of persons with mental retardation.

Changes in our belief system started to accelerate when parents organized to advocate for services for their children. Their advocacy was a grassroots effort to help themselves and other families and to define the problems of mental retardation from the reality base experienced by the families. The classification system was modified to redefine and to establish mild or educable; moderate and severe or trainable; and profound levels of retardation. Slowly, public schools opened classes for trainable students as new approaches and technologies were developed to meet the needs of this population. Students were benefiting from these programs and were remaining in the

community.

Behavioral teaching techniques served these students in educational, vocational and social settings. Professionals in sheltered workshops and in other pre-vocational and vocational programs were learning how to structure the program and the environment so that adolescents and young adults with mental retardation could function socially while meeting the demands of relatively complex vocational activities. Concurrently, these individuals with mental retardation were demonstrating their abilities to live and function in a variety of community based, residential settings. The lack of performance and the failure of earlier generations of persons with mental retardation were more the result of limitations set by our belief and by our inadequate training programs, rather than by the actual abilities of these individuals.

For students who were labeled as borderline or as mildly mentally retarded, it became apparent that as adults, once they were out of school, they were integrated into the general population. Labeled and treated as retarded during their school years, they apparently had the capability to function as adults in ways that did not differentiate them from their peers. Thus, they were able to lose the stigma of the label "mentally retarded". This situation was vividly brought to the attention of the nation by the President's Committee on Mental Retardation when it published a report of a 1969 conference, *The Six-Hour Retarded Child*.

As more was learned about the true performance potential of persons with mental retardation, movement toward community placements and community based services became more pronounced. Building upon the concept of normalization, leaders and advocates in the field worked to make the patterns and conditions of the general society as available as possible to individuals who were classified as mentally retarded. This movement was incorporated in major national efforts, including programs such as deinstitutionalization, the transfer of residents from large, often isolated public facilities to community settings; mainstreaming, the provision of educational services for students with mental retardation within regular classes and school settings; integration, the involvement of persons with mental retardation in programs, services and activities enjoyed by the general public; and community living, establishing residences which are family sized and are located in neighborhood residential areas.

that normalization facilitates and supports the fullest development and independence of the individual with mental retardation. Normalization tailors programs and services to the needs of the individual and measures options in terms of the alternative least restrictive to the person.

In 1973, Congress established a national priority of serving the most severely disabled persons when it passed the Rehabilitation Act. The Education for all Handicapped Children Act of 1975 incorporated the standard that all children with disabilities can benefit from a free, appropriate education; that, to the maximum extent possible, children with handicaps are to be educated with children who are not handicapped; and that parents are to have an active role in the educational planning for their children. Some educational and vocational programs, striving to address the challenges and the vision of these laws, have created and implemented model programs. These programs have demonstrated the value of the new approaches and their positive impact on the lives of persons with mental retardation and their families. Services provided through these programs meet individual needs and encourage growth and the highest possible level of independent, adult living.

Unfortunately, these achievements are not consistent across the nation. What one community actually accomplishes with educational, vocational and social programs may be seen as impossible by a neighboring community. Federal and State laws and constitutions provide to individuals with disabilities many of the same rights provided to the general population. Included are access to mainstreamed educational programming, integrated community living arrangements, transitional educational-vocational programs, and health, social and recreational services. Availability and use of these services and facilities vary as professionals, family members and other advocates debate what research demonstrates, how broadly experiences and successes can translate from one setting to another, what is the least restrictive alternative, and which programs or approaches are in the best interest of the person with mental retardation.

By the 1970's, Federal court rulings defining and establishing a right to treatment were complemented by the Education for All Handicapped Children Act and the Rehabilitation Act. Growing militancy within the disability

community and the demand for appropriate services, for options and for self determination followed and paralleled civil rights developments in the racial field.

Legislation which established specific civil rights for citizens with disabilities encouraged these individuals in their personal advocacy. They were no longer willing to permit others to make decisions for them. Legislators, policy makers, service providers as well as relatives and neighbors were challenged as persons with disabilities demanded their rights and demonstrated their abilities to represent themselves. Initially, leadership in the disability community was provided by articulate individuals who had various physical disabilities. These persons advocated for themselves and their peers. Unfortunately, there was little contact with persons who were advocates in the mental retardation field.

Many individuals believed that people with mental retardation were unable to advocate for themselves and needed parents, guardians or others to advocate for them. While the need for an advocate is apparent for newborn retarded infants, or for individuals at any age who are severely limited in their ability to communicate, there is a growing appreciation of the ability of most persons with mental retardation to advocate for themselves and to be active participants in the advocacy effort. The success of self help groups regularly demonstrates this ability. People First, a national organization created and run by individuals with mental retardation, is an excellent example of the self advocacy movement.

As we approach the remaining years of this century, our society will continue to be challenged to meet the needs of its citizens with mental retardation. Reduced resources demand that we make wise choices and decisions. The creative use of public programs and public-private sector partnerships will help guarantee that the rights of these persons are not violated. Current estimates set the number of persons with mentally retardation at over six million. Health surveys continue to report increases in this population, particularly persons with severe retardation. We must ensure that the millions of citizens with mental retardation are integrated into society as fully as possible. These efforts will result in productive, useful citizens who participate in and contribute to the American society.

III. Citizens with Mental Retardation as Part of the Community

The value of Community Integration of Citizens with Mental Retardation to the Individual, to the Family and to the Society

Recommendation: Continued emphasis on programs and services which support opportunities for citizens with mental retardation to live as part of the community and, insofar as possible, to function as contributing members of society.

There has been vigorous discussion across the nation about the validity of an approach that works toward the norm of full community integration of individuals with mental retardation. Some people cite the value of placement in improved, large facilities; others cite concerns of reduced land values when persons with mental retardation move into the neighborhood. Many advocates emphasize the value to the individual and to the society of community placement and look for the best techniques for achieving this goal while minimizing or eliminating the use of large residential settings. Some ask if it ever is necessary to segregate persons with mental retardation from their families and communities.

Questions are raised about the generally held assumption that legislation and litigation should provide the primary tools for promoting the well-being of all citizens with mental retardation. The keynote speaker at the Grailville Conference suggested that community "beneficence" can create a good and normalized life for people with mental retardation and that litigation might jeopardize this benevolence. His remarks posed a real challenge to the participants, most of whom had actively sought and achieved gains through both legislation and litigation and whose experiences suggest the lack of community beneficence. Participants agreed that, although thorough efforts should be made to educate the public, reliance on benevolence at the expense of rights would perpetuate the stigma of charity. The result would be fewer opportunities for persons with mental retardation to exercise and enjoy their full rights as citizens.

There are clear and desirable alternatives to dependence on community benevolence. Whether identifiable by race or class or mental retardation or any other characteristic, we are inescapably members of the same community and all benefit from its diversity. Given that, some advocates argue that there is a priority to the value of community over the values of

liberty and equality. **Under this viewpoint, community placement of individuals with mental retardation is seen as valuable, not only to those individuals, but also to the community as a whole.**

The concept of a single community can be integrated with an emphasis on individualism, provided the rights of the individual are protected. Recent legislation has supported the role of parents and the family in programming decisions for their children and has supported the value of community based services. Throughout the core of our personal and social values is the concept of a single community, where all citizens can live, learn, work and play. Yet, ideals of liberty and equality represent other basic constitutional values, which sometimes are in conflict with community. Because of the conflict in these basic values, reasonable, not total, accommodation of special needs should be our goal. Accommodation must be guided by the intent to further the participation of citizens with mental retardation as members of the general community.

Public Law 94-142 and Section 504 Resolution of the President's Committee on Mental Retardation

Whereas, disabled children and adults have historically been denied the right to obtain a meaningful education, appropriate vocational training, and access to basic human services, and have been relegated to a role of dependency and a loss of human dignity; and

Whereas, the Education of All Handicapped Children Act, Public Law 94-142, was passed into law to guarantee disabled children a right to a free public education provided in conjunction with specific related services which would allow them to have an equal educational opportunity; and

Whereas, Section 504 of the 1973 Rehabilitation Act guarantees that as these disabled children grow into adulthood, they will be provided with equal access to the educational, training, employment, social services, transportation and housing services available to the nondisabled; and

Whereas, the implementation of both of these laws

through Federal regulations over the last five years has resulted in greater opportunities for meaningful educational programs for over 4 million disabled children throughout the country, and uncounted numbers of disabled adults from lives of total dependency and low self-esteem to productive lives through increased employment and training opportunities and expanded avenues to social services and community life; and

Whereas, the premise that some disabled persons would not be able to benefit from meaningful educational and training opportunities, and that a determination should be made regarding the extent to which disabled people would either benefit from or contribute to the operations of a program in a manner which would be "socially beneficial" to all parties, speaks to age-old prejudice against the disabled, denies them basic human dignity, and is antithetical to the concept of equal citizenship; and

Whereas, these two laws were passed because

similar protections were not and are not available through existing State statutes;

Therefore, Be It Resolved that the President's Committee on Mental Retardation reaffirms their strong commitment to retaining the existing laws and regulations pertaining to Public Law 94-142 and Section 504 in substantially their present form, and encourages the President to take a positive and public stand to halt all efforts to change these laws through regulatory and legislative reform that would adversely affect mentally retarded citizens. Through these laws, the way has been cleared for preparing a large segment of our society to move from lives of dependency to greater independency by becoming tax-paying citizens. Public Law 94-142 and Section 504, and their implementing regulations constitute an investment, rather than a burden, to society.

IV. New Federalism

Relationship of State Laws and Courts to the Federal Role as a Source of Rights of Citizens with Mental Retardation

A. Litigation

Recommendation: Extend the use of State courts as well as Federal courts to protect and expand the interests and rights of citizens with mental retardation.

Much of the advocacy effort on behalf of persons with mental retardation has been conducted at the Federal level, using class action suits to obtain constitutional and statutory rights. Strong efforts must continue at this level to ensure the continued availability of Federally protected rights. At the same time, the new Federalism suggests increasing our attention to and reliance on State level remedies and guarantees for citizens with mental retardation.

Recent experience demonstrates a growing emphasis upon local control and decision making. This suggests the value and desirability of looking to the State level for relief. State constitutions and laws provide a wide panoply of protections beyond those in the Federal arena. Our Federal system allows citizens of States to invoke State laws for additional protection; Federal law only sets minimum requirements.

Careful documentation of existing State constitutional guarantees, particularly those that go beyond Federal levels of protection, will greatly assist advocates for the rights of citizens with mental retardation. For example, in several States, handicapped persons have been designated a suspect class entitled to heightened scrutiny under the State's equal protection clause. In other States, guarantees of equal protection have no State action requirement.

We must encourage advocates to develop creative approaches to legal rights litigation at the State level. At the Federal level, information about actions and decisions receives rapid, national distribution. Unfortunately, information may not easily cross State boundaries. We should encourage systems of information exchange such as that of the national network of State Protection and Advocacy agencies. At the same time, however, we must continue to use Federal courts to protect the rights of citizens with mental retardation.

Strategies should be reassessed to maintain our

gains in advancing the rights of people with mental retardation and to identify methods that would be successful through the remainder of this century.

Conference participants considered alternatives. Given the success of integration and normalization, some participants believed that legal efforts should be directed toward small scale interventions on individual cases rather than large scale, class action suits. Conversely, others offered the hope that the Conference would provide the impetus for a new spurt of litigation. Toward that end, a catalogue of alternative legal bases was presented for continued pursuit of rights litigation through class action suits.

B. Legislation

Recommendations: At the Federal level, renewed emphasis should be placed on fulfilling the goals expressed in Section 504 of the Rehabilitation Act and PL 94-142, Education for All Handicapped Children Act, and on the removal of categorical labels from Federal legislation. At the State level, emphasis should be on enacting laws that recognize the rights of persons with mental retardation.

Every listing of landmark disability legislation features Section 504 of the Rehabilitation Act and the Education for All Handicapped Children Act. Each of these important pieces of legislation presented and continues to present a positive, changing and optimistic image of persons with disabilities. It is noteworthy that during the legislative process, individuals with disabilities were in the forefront, advocating for these laws and for the regulations necessary for their implementation.

Handicapped Children's Protection Act Resolution of the President's Committee on Mental Retardation

Whereas, the President has expressed his concerns that the educational needs of handicapped children be met; and

Whereas, earlier this year in the case of *Smith vs. Robinson*, the U.S. Supreme Court concluded that, where both statutes are applicable, the Education for All Handicapped Children Act (EHA) supercedes and preempts Section 504 of the Rehabilitation Act of 1973, the Fourteenth Amendment and other

Federal Statutes in establishing a basic guarantee of a free appropriate education for school age handicapped children; and

Whereas, the practical effects of this decision are both to eliminate Section 504 as a vehicle for protecting the rights of mentally retarded and other handicapped school age children to a free appropriate public education, and to prevent the award of attorney's fees to parents who successfully challenge the denial of their children's rights in Federal court; and

Whereas, the award of attorney's fees is an important and just incentive for parents to actively protect the rights of their children in cases where parents overturn improper administrative decisions or where school systems appeal proper administrative decisions;

Now, Therefore be it Resolved that the President's Committee on Mental Retardation strongly endorses S2859, the Handicapped Children's Protection Act of 1984, which is designed both to restore the free access of parents of mentally retarded and other handicapped children to Federal courts under Section 504, and clearly to authorize Federal judges to award attorney's fees to parents where litigation by parents challenging schools district action is successful in the Federal courts under either or both Section 504 or the Education of All Handicapped Children Act.

The needs of society are met best when children are prepared to be active, contributing adults. Evidence establishes that children with special needs are served best in integrated programs with appropriate services and the full involvement of their parents in program planning and placement. Families are strengthened when all family members are supported and maintained in the home community. The Education for All Handicapped Children Act builds on these values. It guarantees the right of every disabled child to a free, appropriate education in the least restrictive environment. Community based programs increase the probability that the individual will be able to function at an optimal level as an adult in the community.

The Rehabilitation Act also strongly supports the community participation of people with disabilities. The right of access, guaranteed in the Act, presumes public participation by people with disabilities. Handicapped parking spaces mean that people with disabilities drive and are able to come to concert halls, stores, shopping centers, movies, schools and court houses. Bans on job discrimination mean that people with disabilities can and do function competitively in the American workplace.

Some advocates argue that some interpretations by the courts and the implementation of these interpreta-

tions by the administering agencies have fallen short of the potential in the Federal legislation. Further, there are advocates who observe that certain fiscal patterns set in law and regulations may favor one program alternative over another. In some situations where program implementation is based on funding rather than on the individual's needs, the result may be inappropriate or segregated services and programs. The person with mental retardation may be deprived of an opportunity to experience integration within the community.

Particularly in the area of education, once compliance with Federal requirements is assured, program directions are determined by State laws and regulations. For example, it may be cheaper for a local school district to send a disabled student to another district, perhaps even out of state, rather than to establish an appropriate program in the home community. Funds may be available to support placement in large residential settings, but not to maintain the child in the home. Children who are exposed to other children with disabilities grow in understanding and acceptance. The entire community gains from this.

Leadership in support of community placements has been demonstrated by a number of States. Michigan was cited as an example of a State which recently enacted legislation to provide funds directly to the families of children with disabilities. These funds are intended to assist families in their efforts to maintain their disabled children in the home and to prevent institutionalization. Comparable actions in other States support the view of the State level as the active arena for advocacy for innovative legislation.

There is additional justification for advocates to work on a State by State basis to insure that appropriate educational experiences are available in each student's community. One can cross the country and identify examples of outstanding programs. These programs can serve as models of successful approaches which assist very difficult to serve students. Yet these programs are not available to all of the students who could benefit from them.

Application of state-of-the-art principles will promote the goals represented in innovative programs that are supported by State level legislative enactments and regulations. State-of-the-art programming means that if one child anywhere is able to remain at home because school officials have figured out how to provide needed education and family support services, then any child with similar needs should have the same opportunity to remain in the family setting and the home community. The use of state-of-the-art technology also applies to providing adults with requisite support for successful employment, for a rang

of social, health and recreational opportunities, and for community based, family sized living arrangements.

Historically, there has been relatively little contact between advocates representing persons with chronic, life-long disabilities and activists representing disabled veterans and groups of physically disabled individuals. Linkage with the broad, national, disability rights movement and with advocates representing older Americans will expand the horizons of persons with mental retardation and will provide them with a sense of belonging. Such linkages also will help other disabled persons understand the needs and strengths of individuals with mental retardation. One aspect of a cross-disability movement is the strong de-emphasis on categorical labels. A strong, negative stigma is attached to most labels, particularly to the term "mentally retarded". Participation in a larger movement encompassing many different kinds of people focuses on our common humanity and on our strengths.

Consider Elizabeth, a young lady with autism, who attended a series of special elementary

schools to which she traveled on special buses. In an interview, Elizabeth stated: "Elementary school made me retarded!" Elizabeth's exclamation communicates a wealth of information about her view of the stigma attached to the school situations that she experienced. If segregation in special schools can so devastate a child who later joined her peers, imagine its impact on the self- image of children either totally excluded from school or forced to attend special residential schools far from home.

Educationally and socially, a label becomes a self- fulfilling prophecy of limited expectations and of imposed isolation. Categorical labels should be removed from both Federal and State legislation. The need for classification for data collection and funding should not be permitted to legitimize the labeling and stigmatizing of children. Approaches which avoid this problem should be explored in state-of-the-art programs. Successful techniques should be incorporated into guiding principles for education, other service systems, and for living accommodations.

V. Least Restrictive Environment

Application of the Concept of Least Restrictive Environment to Provide Services and Rights for Citizens with Mental Retardation

Recommendation: Apply the concept of normalization to provide the least restrictive environment in education, housing and community participation.

Normalization is described in a 1969 publication of the President's Committee on Mental Retardation, *Changing Patterns of Residential Services of the Mentally Retarded*. Its goal is to permit persons with mental retardation to live as normal a life as possible by making available to them patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society. It does not mean to apply normal or usual treatment, but rather to use specially designed program approaches and modifications within the environment which help the individual live a life as close to the community norm as possible. A community based group home meets this standard when the residents are socially and programmatically integrated into its neighborhood and community.

In seeking the goal of providing as normal a life as possible, special treatment is required, particularly for those individuals with more severe mental retardation who have been deprived of opportunities to interact with non-disabled people. Under the standard of social and programmatic integration, experiences are made available which are appropriate for the age of the individual. Opportunities are necessary for education, work, independent living and leisure time activities. Normalization has stimulated efforts to establish the least restrictive setting for persons with mental retardation and has supported the strong efforts toward mainstreaming and residential placement in community settings.

A major thrust of normalization in education is functional programming. The idea behind the functional approach is to adapt the curriculum to accommodate alternative teaching strategies designed to compensate for particular skills deficits. For example, despite creative teaching, a student may be unable to tell time. This skill deficit would prove problematic to that student's ability to work in a factory setting. Yet the same student could be taught to respond to time-related social cues and, as a result, become employable.

The least restrictive environment in education is more than physical integration of children with

mental retardation into a regular education school building. It means social and program integration within the central core of the school's educational efforts to whatever extent feasible. Both disabled and non-disabled students benefit from integrated programming as each learns about the strengths and weaknesses, the quality of humanity, of the other.

The goal of functional programming is to develop skills so that greater independence and participation can be achieved. This goal extends beyond education to housing and community participation. These skills include learning to cross busy streets, to order food in restaurants, to use recreational and leisure time facilities, to work in actual work settings, and to use proper hygiene methods.

These skills can best be taught in settings that closely approximate the natural settings in which students will later function. For example, if a student is learning to cross the street, it helps to see other people doing the same thing, to hear the noises of car engines and horns, and to pick up on cues associated with safe crossings. Learning to work in a job setting exposes the trainee to the sights and sounds of the workplace, and to the model behavior of non-disabled workers carrying out their work assignments. Thus, a major means of applying the concept of the least restrictive environment is to use the community as the focus for educating its citizens with mental retardation.

In terms of residential living, the least restrictive environment means more than community placement. Programs and experiences must be structured to ensure that community facilities and services support the concepts of normalization. The location of the residence in the community, the number of residents in a home, their freedom to direct their own activities, the absence of dehumanizing rules and practices and the availability of appropriate program options all must be considered in determining that a community residence does, in fact, support normalization and provides a least restrictive environment. Such a setting provides for the social, vocational and political interaction of people with mental retardation with other individuals in the general community.

Advocates seek to combat efforts limiting the opportunities for citizens with mental retardation to live within residential areas in local communities. When a group home is proposed, some neighbors may be concerned and fearful. Their arguments may range from

the emotional to the legalistic. Some people work to exclude individuals with mental retardation from their community, frequently using zoning ordinances in their efforts to prevent, segregate or eliminate residences for persons with mental retardation from those communities. It is noteworthy that a growing number of State and local jurisdictions have used zoning ordinances and laws to establish that group homes for a small number of unrelated persons with mental retardation meet the standards set for the highest residential classification.

Cleburne, Texas, was the focus of national attention in a zoning case as it slowly worked its way through the appeal process. In *City of Cleburne, Texas v. Cleburne Living Center*, the United States Supreme Court was asked to determine the constitutionality of a municipal zoning ordinance that required a special use permit for the operation of a group home for people with mental retardation.

Resolution on the Cleburne Case by the President's Committee on Mental Retardation

Whereas: Mentally retarded persons have historically been subjected to State imposed exclusion from education, employment and housing and denied the opportunity to participate fully in American community life; and

Whereas: Systematic State imposed exclusion and hostile differential treatment continue to prevent mentally retarded persons from full enjoyment of the rights and opportunities guaranteed to other citizens such as the right to associate actively within the social and economic fabric of families, neighborhoods, and communities, unrestricted by prejudice or stereotype; and

Whereas: The zoning ordinance passed by the City of Cleburne, Texas, in 1929, excluding except by special use permit from apartment districts and other areas of the city where congregated living is permitted, "feeble minded" persons, is an integral part of this type of systematic State exclusion of and hostile treatment towards mentally retarded citizens; and

Whereas: The President's Committee on Mental Retardation has consistently supported all efforts to combat and overcome the effects of State

imposed exclusion and hostility toward mentally retarded Americans and to establish the right of mentally retarded persons to choose their living arrangements; and

Whereas: Group Homes currently are the principal community living alternatives for persons who are mentally retarded and the availability of such a home in communities is an essential ingredient of normal living patterns for mentally retarded persons; and

Whereas: The President's Committee on Mental Retardation has long recognized that mentally retarded citizens lack sufficient political power to effectively access or use the political and legislative process to assert and to protect their basic rights; and

Whereas: The President's Committee on Mental Retardation has vigorously supported both legislative and judicial action to ensure Equal Protection under the laws of States and localities; and

Whereas: The Fifth Circuit Court of Appeals has properly struck down the Cleburne Ordinance as contrary to the Equal Protection guarantees of the Fourteenth Amendment of the U.S. Constitution; and

Whereas: The Supreme Court of the United States now has before it a challenge to the application of this zoning ordinance under the Equal Protection Clause;

Now Therefore be it Resolved That: The President's Committee on Mental Retardation publicly express its view that the application of the Cleburne Ordinance to Americans with Mental Retardation represents a type of unlawful invidious discrimination existing across the Nation which is barred by the U.S. Constitution.

The issue before the Court was whether the zoning ordinance, on its face or as applied, violated the equal protection rights of potential residents of the Cleburne Living Center. The Court held that the ordinance was invalid because no reasonable governmental purpose was furthered by the restriction. Indeed, a combined reading of the majority and concurring opinions suggests that excluding people with mental retardation from the community is so irrational and so contrary to our constitutional values that such exclusions violate even the minimum rationality required under the equal protection clause.

VI. Self-Advocacy

Self-Advocacy as a Practice by Citizens with Mental Retardation to Enhance Their Role in Determining Goals and Strategies and in Choosing Among Options

Recommendation: Encourage self-advocacy and provide training in related skills so that citizens with mental retardation can play a prominent and an active role in determining and working for their goals.

During the last half of this century, automobile accidents and the human devastation of wars have disabled many Americans. As an aftermath of these events, there has been a rapidly growing number of individuals with disabilities who live and work within the community in close contact with the general population. It is difficult to apply stereotypes about persons with disabilities to the next door neighbor you had known as a productive, able-bodied citizen, but who happened to lose an arm or a leg, or who now has to use crutches or a wheelchair.

Society has been learning to accept and integrate some of its disabled members. As these citizens with disabilities fight for their own rights, barriers to their integration slowly have been coming down. Individuals who became disabled as adults were accustomed to function independently, to make decisions about their lives, and to determine their own participation in society. They want to continue to do so.

The rising visibility of these individuals has challenged many traditional ideas about disability and activism. Such persons provide viable and useful models for the mental retardation field.

The driving force of many individuals disabled in an accident or in a war has been a desire to return as fully and as actively as possible to all areas of their lives. They wish to remain in their homes and communities and on their jobs. However, they were faced with the prejudices and barriers set up by architecture, attitudes, professional practices, laws, regulations and ignorance. Led by persons with physical disabilities, the anthem of the disability rights movement became self-determination. People with disabilities demanded control over their own affairs on every level, from governmental decision-making to personal care. Self-advocacy has become an important, central part of the drive toward self-determination. Self-advocacy groups have sprung up across the nation as persons with disabilities identified what they wanted and as they worked, lobbied and fought for their rights.

One of the primary benefits of self-advocacy

efforts is its positive effect on the advocates. Participants develop a growing awareness and understanding of the demands and rewards of community living and of the meaning and rights of citizenship. **The growing awareness that one has rights and the willingness to advocate for those rights in a public arena can lead to an appreciation of the Constitution and of Federal and State legislation.** And by speaking up on their own behalf, self-advocates teach the general society about the potential and capabilities of persons who may happen to have disabilities.

Self-advocacy came slowly to people with mental retardation. Many parents and other advocates initially made the assumption that advocacy had to be *for* rather than *by* a constituency of persons with mental retardation. Well intended advocates, acting on behalf of their clients, often assumed what was wanted and what was in the best interests of those individuals. When we ask their goals, we find that adults with mental retardation want interesting jobs, appropriate salary, living arrangements as independent and self directed as possible, variety and choice for leisure time activities, vacation opportunities, and the educational and vocational preparation which will permit them to reach those goals.

Grove City Resolution of the President's Committee on Mental Retardation

Whereas: the President, in response to the Supreme Court decision in *Grove City College vs. Bell*, stated his view that it was important to the continued protection of the civil rights of millions of Americans, including handicapped and disabled Americans, that the Congress act promptly to restore the interpretation of Federal civil rights statutes altered by the Court;

Now Therefore be it Resolved that the President's Committee on Mental Retardation endorses the current 504 Regulations on Federally assisted programs and the rights and remedies guaranteed within and urges the Congress to incorporate the basic concepts of these Regulations in appropriate legislation in order to ensure the effective protection of the civil

rights and full societal participation of 36 million handicapped and disabled Americans.

Unwilling to remain passive, some individuals with mental retardation started to form self-help groups, such as People First, to discuss issues they saw as important and to demand opportunities to speak for themselves. This movement has been growing and, in the last decade, examples of self-advocacy have become commonplace. Advocates with mental retardation demonstrated their skills by speaking out on services, facilities, communities and legislation. Their efforts have helped them achieve their goals while changing the view that others had of them.

The experiences of one self-advocate can serve as an example of the accomplishments of this activist group. Richard Sedor had spent sixteen years in institutions. Upon placement in a community residence, he labored through several workshops to regular employment. Upon hearing the admonitions of radio and television that prudent people open savings accounts, he went to a bank to open such an account. The supervisor refused his request. Mr. Sedor knew that he was being wronged. He complained to his local legislator about the bank that refused to take his money and open a savings account for him. The legislator arranged for him to testify before a committee considering antidiscrimination legislation. Richard Sedor's simple, straightforward story was a key element in the passage of this legislation in Connecticut. Appropriate training and related experiences enhance the effectiveness of self-advocacy. A

growing understanding of the needs and abilities of adults with mental retardation has resulted in the development of new approaches to support independent functioning. Advances in educational technology have made available reading-free workbooks, slide shows and audio tapes designed for use by persons with reading problems.

Community colleges and adult education programs have organized courses tailored to the special needs of persons with mental retardation and have accepted them in appropriate courses.

Self-advocacy offers much promise to enhance the gains of citizens with mental retardation, particularly at this time of budget-cutting and economizing. Encouragement of self-advocacy requires no extensive building programs and no new agency services which usually require large numbers of highly trained, professional staff. Yet self-advocacy can provide a powerful means to enhance public support and to develop true community integration by demonstrating the capabilities of individuals with mental retardation.

One of the strengths of the self-advocacy movement has been the networking which has occurred among advocates from various disability groups. Building on their broad base of common interests, shared experiences and common goals, members of disability groups coordinated their efforts and became a powerful political force. These same opportunities extend into the mental retardation field. Persons with mental retardation and the entire society will benefit as these efforts are continued and expanded.

VII. Right of Survival

Decisions on the Kind of Life and on Life Itself Cannot Be Based Solely on a Diagnosis of Mental Retardation nor on Projections about the Expected Quality of That Life

Recommendation: All mentally retarded people are to be free from the denial of medical service based on the judgment that the quality of life of a retarded person is less than that of other citizens or based on anticipated mental potential.

Two puzzles are relevant to this issue. First, we must consider why a dichotomy exists between the law on the books, which apparently outlaws the withholding of life-sustaining care, and the law in action, which fails to punish and thus apparently allows it. Second, we must consider why the lack of treatment of newborns with handicapping conditions has evoked a violent storm of controversy. Decisions which once were made in private have now become more public. Advances in medicine have made questions about how to treat disabled newborn infants more numerous and pressing.

The Infant DOE Resolution of the President's Committee on Mental Retardation

Whereas, the recent death of infant Doe on April 15th, 1982, in Bloomington, Indiana shocked the nation, by illustrating the reality that mentally retarded people continue to be treated as less than full citizens in the U.S.; and

Whereas, The President's Committee on Mental Retardation at its first meeting as a full Committee in 1982 reviewed the nature and this injustice; and

Whereas, the PCMR in its Annual Report to the President of the United States, in March 1976, addressed its concerns regarding the infringement of rights of mentally retarded persons over generations and the specific continued infringement of rights by a lack of equal access to quality health care and the denial of life-saving medical services; and

Whereas, the President of the United States has instructed the Secretary of Health and Human Services April 30th, 1982, to notify health care

providers to enforce Sec. 504 of the Rehabilitation Act of 1973, that forbids recipients of Federal funds to withhold from benefit or service ordinarily provided to persons without handicaps; and

Whereas, it has been six years since the President's Committee has gone on public record reaffirming its position of full citizenship status and legal rights for all mentally retarded citizens;

Be It Therefore Resolved, that all mentally retarded persons-including new-born infants, have the right to be free from the arbitrary denial of lifesaving medical services and that this right is premised on a recognition that mentally retarded persons must be allowed equal access to medical services to preserve their lives and such a right rules out any practice which would not allow retarded persons their right to life based upon a judgement that the quality of life of a retarded person is less than that of other citizens, or any routine policies or guidelines predetermining the withdrawal of life support from impaired newborn babies on predicted mental potential alone.

Disputes in this area often are couched in terms of the rights of the parents versus the rights of the child. Some decisions about treatment options have been made on the basis of the projected quality of life and the anticipated intellectual functioning level of the infant. Federal laws passed since the Infant Doe Case, such as the Child Abuse Amendments of 1984, have rejected the use of quality of life criteria to deprive disabled infants of medical care. These laws mandate medically indicated treatment for disabled infants with life-threatening conditions.

Child Abuse Prevention and Treatment Act Resolution of the President's Committee on Mental Retardation

Whereas: President Reagan has sought to protect handicapped newborns through Federal Law from the discriminatory denial of beneficial medical care; and

Whereas: State and local child protective services agencies have a responsibility under State law to act to prevent neglect and abuse of handicapped newborns who may be denied medically beneficial treatment; and

Whereas: Congress is considering legislation to insure that State and local child protective services agencies, which receive Federal funds, shall protect handicapped newborns who may become victims of abuse and neglect;

Now, Therefore, be it Resolved that the President's Committee on Mental Retardation urges congressional adoption of the Tentative Joint Explanatory Statement of the Committee of Conference on the amendments to the Child Abuse Prevention and Treatment Act and the Adoption Reform Act of 1978.

It is important not to limit the discussion about the right to survival to questions about medical treatment of newborn infants with disabilities. What we already know about prevention and treatment must be applied throughout the entire developmental period. Pre-natal care, including adequate nutrition and medical services to pregnant women, reduces risk to children. After the child is born, in order to minimize potential problems with mental retardation, there is agreement that early intervention programs, sound nutrition, and appropriate health, behavioral, educational, vocational, and social services all are necessary and cost effective supports for survival and a full life.

VIII. Future Strategies

Guidelines for Individuals in the Public and Private Sectors who are Concerned that Citizens with Mental Retardation Achieve their Rights

Progress during the past two decades has aided the growth and development of citizens with mental retardation in every aspect of American life. Legislative and judicial battles have been fought and won so that persons with mental retardation can assert their basic rights to Life, Liberty and the Pursuit of Happiness. Effective advocacy in the future will require strengthened efforts so that gains continue and additional barriers are eliminated. Social goals must be pursued so that individuals with mental retardation can exercise their rights of full citizenship.

Maximizing the probability that each citizen lives in an environment that promotes economic self-sufficiency, independence and dignity is a responsibility that is shared among the individual citizen, the family, as well as the private, public and volunteer sectors. The probability that citizens with mental retardation and other developmental disabilities experience an environment as described will be increased if strategies are developed jointly with all responsible parties. The points listed below are areas recommended to be considered as future strategies are developed.

- The general public must be educated through improved communications. In communication efforts, however, we must examine closely not only what is said, but also the underlying messages that are being delivered. The inherent value and dignity of the life of every person with mental retardation must be asserted strongly. It is important that we use terminology that will humanize the people about whom we are speaking. For example, we should refer to "persons or citizens with mental retardation," not to "the mentally retarded."
- The issue of community integration would benefit from redefinition. People are born integrated in their families. The issue is not whether individuals with mental retardation should be integrated in the community, but rather whether they ever ought to be segregated from it.
- Adult programs should be addressed in terms of economic self-sufficiency and the elimination of barriers to independence.

Unfortunately, the current adult day-care system affirms dependency. Positive economic implications result from supportive work programs and community living. These programs and services should be advanced aggressively as we communicate to the public the value and the contributions to our society of persons with mental retardation.

- We should develop coalitions with other groups which face the same biases, problems and restricted availability of services. In this area, we are not limited to coalitions with the traditional disability groups. For example, it is estimated that by the year 2000, approximately 45 percent of voting Americans will be over 65 years of age. Persons with mental retardation share several common issues with older Americans, including the limited range of community living alternatives, flexible and supported work strategies and access to needed medical services. Reforms in these areas often may be of advantage to Americans with mental retardation and with other disabilities, as well as to older American citizens.
- We should increase significantly the visible advocacy roles of persons with mental retardation. Direct public exposure to spokespersons with mental retardation would belie commonly held dehumanizing stereotypes. The end result would be significant progress toward an overall change in public attitudes, a prerequisite to full citizenship.
- At the Federal, State and local levels, legislative strategies need to be developed which will promote the achievement of the goal of full citizenship. In many instances, parallel efforts can and should be undertaken. These strategies would enhance the opportunities for citizens with mental retardation to secure personal independence, growth and security; to pursue the maximum range of options relating to community and family integration, living arrangements and social participation; to participate in sustained, productive and gainful employment; and to achieve social and economic self-sufficiency and advancement.

IX. Conclusion

*Creative Approaches to Ensuring Citizens with
Mental Retardation Equality Under the Law Will
Need Continued Development*

Citizens with mental retardation are, of course, no more homogeneous than the general population. What they do share in common as a group, however, is a history of enjoying less than full access to their rights of full citizenship. Over the past 20 or more years, significant advances have been made in ensuring continued availability of federally protected rights for citizens with mental retardation. These advances are due in large part to the efforts of parent and self advocacy groups and leaders in the field of mental retardation. These individuals have worked diligently to change American

society's belief system from one that presumed that it was necessary to segregate individuals from the general society as available as possible to individuals with mental retardation. This change in public attitude has been reflected in major national efforts, such as community living, mainstreaming, and the involvement of persons with mental retardation in programs, services and activities enjoyed by the general public.

In order to continue the progress made over the past two decades, into the remaining years of the 1980s and beyond, creative approaches to ensuring citizens with mental retardation equality under the law will continue to need development. It is hoped that the information contained in this report will prove to be useful as these national strategies evolve.

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