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**ADVOCACY SYSTEMS FOR
THE DEVELOPMENTALLY DISABLED**

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**RESEARCH AND TRAINING CENTER IN MENTAL RETARDATION
TEXAS TECH UNIVERSITY, LUBBOCK, TEXAS**

ADVOCACY SYSTEMS
FOR THE
DEVELOPMENTALLY DISABLED

Proceedings of the National Conference on
Establishing Statewide Advocacy Systems
as Required by the Developmentally
Disabled Assistance and Bill of
Rights Act

March 31-April 2, 1976
Dallas, Texas

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Forward

The Developmental Disabilities Services and Facilities Construction Act (PL 91-517) was passed in 1971. This Act focused upon those handicapping conditions which occur during the developmental period of life and which require services similar to those necessary for the mentally retarded. The Act was unique in that it sought to coordinate the multiple services required by the developmentally disabled as well as to provide for adequate planning for the service delivery system. In order to help assure widespread input in the planning effort, the Act mandated consumers, or spokesmen for consumers, be represented on the state councils.

During the interim period of four years prior to the passage of the Developmentally Disabled Assistance and Bill of Rights Act (PL 94-103), in 1975, the consumer movement grew tremendously. As a result of litigation, the human and civil rights of the handicapped became more clearly established. Federal, state and private organizations began to establish standards relative to the facilities, programs and manner in which these services were to be provided. As a result of increasing scrutiny, it became apparent that some type of protective system was required to monitor the quality of services to the handicapped and to assure that the life-long needs of the developmentally disabled were provided at the time they are required. The Developmentally Disabled Assistance and Bill of Rights Act requires that each state shall institute a system to protect and advocate the rights of persons with developmental disabilities and that this system will have the authority to pursue legal, administrative and other appropriate remedies to insure the protection of the rights of such persons with developmental disabilities.

Advocacy is certainly not new with this bill. Broadly defined, it includes any activity which involves a person acting on his own behalf or on

the behalf of others to secure responses to perceived needs. Early advocates might have been family members or the extended family of nomadic tribes. Although the concept of advocacy is simple, it becomes complex when one considers the wide range of functions which might be designated to advocacy programs: advocates can act as friends, parents, legal guardians of persons or estates, and case managers. These responsibilities have been designated to parents, relatives, public officials and agency personnel prior to the passage of this Act and will continue to be provided by a variety of people and agencies.

The Developmental Disabilities Office of the Office of Human Development was interested in obtaining as much input as possible regarding various models of advocacy, preliminary plans by the states for developing advocacy programs, and the concerns that various groups have regarding the way in which a statewide advocacy system would interface with other systems and interests already operational. Because of the earlier work the Research and Training Center in Mental Retardation had done in the area of advocacy and its current interests in the changing patterns of advocacy and their impact on the adjustment of the developmentally disabled, a jointly sponsored conference was planned.

In order to obtain information relative to the "state of the art" in advocacy at an early date, conference planning had to be brief. An attempt was made to publicize the meeting by sending announcements to the three organizations most concerned with advocacy, namely, the Association for Retarded Citizens, the Epilepsy Foundation of America and the United Cerebral Palsy Association. A mailing list for the National Society for Autistic Children was not available although the Texas organization was notified. In addition, the state coordinators for the mentally retarded and developmentally disabled, executive directors of the state developmental disability councils and the

chairpersons of the councils were invited to participate.

An attempt was made to solicit information and advice regarding the program format, content and speakers. Budgetary and time limitations did not make it possible to respond to all of these requests. It was the hope that national representation could be obtained with conference participants representing various groups and points of view. The goal was to have frank and open discussion of these points of view and to have the critical discussion oriented to solution rather than to division. It is the editors' view that these goals were fairly well achieved.

We wish to express our appreciation to the speakers, who did an excellent job of providing helpful content for fruitful discussion in the small group sessions. The skill and effort of the group leaders, Ron Attkisson, Charles Acuff, Fred Girardeau, Marjorie Kirkland, Michelle Morrison and Iverson Riddle resulted in lively but meaningful discussions. The small group discussions enabled us to reach conclusions and to make recommendations for the development of advocacy programs. We would particularly like to thank the R&T staff who served as reporters for the groups: Pam Bernanke, David Chapman, Jan Chapman, Carolyn Rude, and Carol Sigelman. Jan Chapman and Teresa Dailey cheerfully and competently typed the manuscript. Finally, we greatly appreciate the support of the Regional and Washington Offices of Human Development and the Developmental Disabilities Office for their assistance in making arrangements for this conference and for providing meaningful participation during the conference.

Opening Remarks

Tommy Sullivan
Assistant Director
Office of Human Development, Region VI

Probably one of the most pleasant things that I get to do as Assistant Regional Director of the Office of Human Development is to meet with groups such as this and welcome you not only to conferences but to Dallas. So on behalf of the Assistant Secretary for DHEW, Mr. Stan Thomas, and our Regional Director, Mr. Stewart Clark, I would like to extend to you a very warm and cordial welcome--not only to the Conference on Advocacy and Protective Services, but also to Dallas, Texas.

Both Mr. Thomas and Mr. Clark are well aware of the problems that this group is faced with. Many times it seems we have systematically and persistently excluded many of our neighbors from ordinary events and activities which most of us take for granted. We should no longer deny individuals their human rights, their human needs, their human potential, simply because of an incidental disability. We have a piece of new legislation, PL 94-103, "The Developmentally Disabled Assistance and Bill of Rights Act," which makes a number of changes in the programs of the DDO. One of the most important changes to me is a somewhat expanded role for the state council, which I think is a very positive role.

Probably the most important thing to me this morning is to make a plea to this group not to expect this piece of legislation--neither the rules and regulations, nor the guidelines--to bring about improved services to those that are disabled. Only you and the people working with you will be able to bring about the kind of results that the drafters of this piece of legislation envisioned. Too many times I feel we rely on rules, regulations, guidelines, legislation, to solve our problems. I am hopeful that the rules and regulations that have been developed and will be discussed here are very supportive of the endeavors that

you undertake. Your participation in this conference should assure us that a strong, workable piece of legislation does indeed exist. Your participation re-emphasizes that we work in partnership, playing somewhat different roles at times, but each making distinct and necessary contributions to the advocacy and action necessary to restore disabled people to an active involvement in our society.

We've worked very hard within the Office of Human Development to emphasize that we are a service organization. Sometimes we are a little hesitant to mention that word "service." At this time, it's not too popular in some circles. I feel very deeply about it; part of our job as a service organization is to assist you as best we can in the development, the planning, and delivery of services, the best services that are possible, to individuals who have a right to expect the very best, the developmentally disabled. If this office can be of assistance to you during the conference or in the days ahead, remember--we do believe in service. I hope you leave this conference with two things: one, with better information about the specifics of this piece of legislation; and second--probably more important--with some basic ideas for improving within each state a system that protects and advocates for the rights of each developmentally disabled person.

It has been a pleasure to be here this morning and to meet with you briefly. I look forward to attending some of your sessions later on this week. I mean very sincerely, a very warm welcome to Dallas, and I think by noon it will be that way. Thank you very much.

Advocacy and Protective Services--Where are We Coming From?

Elizabeth M. Boggs
President's Committee on Mental Retardation

Advocacy! What is it and who needs it? All of us need it some of the time and a few of us need it all of the time. The ability to advocate for one's self is one of the marks of maturity. It is an essential component of what we call "social competence." The development of self-advocacy skills is one of the objectives of education for all of us. One aspect of such skill, indeed, is the ability to perceive one's need for advocacy by another and to proceed to seek and enlist the assistance of an appropriate advocate. By instinct, by social custom and by law, the family is a mutual advocacy society, whose members spontaneously advocate for one another as needed. In particular, spouses advocate for each other and parents for minor children.

Obviously the development of self-advocacy skills in persons we call developmentally disabled is one of the primary objectives of any individual habilitation plan. If we could realistically anticipate success in this venture in all cases, it would not be necessary to have any specialized systems of advocacy for the developmentally disabled, and the new Section 113 in the Developmental Disabilities Act would not be there. The self-advocacy skills of a developmentally disabled person are likely to need supplementation for two main reasons. First, by the very nature of developmental disability there is likely to be an impairment of the individual's own ability to advocate for himself. The majority have some "impairment of adaptive behavior." All have had an atypical experience during the critical developmental years. Even those whose "substantial handicap to such person's ability to function normally in society" is not associated with intellectual impairment are usually at some disadvantage in asserting themselves in situations where people without such handicaps manage to hold their own.

The second reason that persons we call developmentally disabled are likely to need advocacy more frequently or more continuously than other people lies in the complexity of the array of services which they require. It is part of the common wisdom of most of us to know where to find the so-called generic services--how to get health care, call a policeman, negotiate a loan, find an apartment or even choose a lawyer. But what will suffice for your needs or mine may well not suffice for the needs of a developmentally disabled person. He may need an accessible apartment, which is much harder to find. An uninformed police officer may view him more with suspicion than with concern for his protection. We are all aware that the array of services is painfully incomplete, but we are also aware that there is often more out there than the disabled and their families are able to link with.

Let me say it once and for all: advocacy should not inhibit any appropriate level of self-determination. Indeed, it should enhance such opportunities. Nevertheless, by very definition, those with developmental disabilities, particularly those with the most serious forms of impairment of adaptive behavior, will need special advocacy, and it is to the definitions of such varieties of special advocacy that we are here to address ourselves.

Some Thoughts on Elephants and Bees

The word "advocacy" means different things to different people. Already people are jockeying for recognition of this model or that model, usually the one they are already practicing. One is tempted immediately to invoke the image of the proverbial elephant as seen by the various blind men who respectively grasped his tail, his ear, his trunk or his leg. However, I do not like this image because, despite his many virtues, the elephant is ponderous. Rather I would like to draw an analogy with the bee. The bee is, as advocacy should be, small and nimble.

Bees are also seen variously by different people. If you live in Utah, you think of the bee as industrious--the busy bee, producing a useful product. Some one else thinks of the bee as wide-ranging and fast flying, very mobile in proportion to its size. Students of entomology are fascinated with the social structure exhibited by the bees, and more particularly by their extraordinary communications. A bee who discovers a new clover patch is able to summon his colleagues. (One successful "right-to-treatment" suit, when well publicized, leads to many others.) Some people associate the word "bee" with "sting." However, to the human race, it appears, on careful reflection, that the most important contribution of the bee is not his honey or his sting, but his role in the ecology. If bees stop making apple blossom honey, farmers will stop harvesting apples. Bees put it all together.

Bees, of course, exist in the wild state, but man can also domesticate bees to some extent. A person can attract bees by providing a favorable habitat--a well-designed bee-hive. He can even hold bees captive for a brief period. He can order a package of queen and worker bees from a mail order house, and transplant them to a new location on his own compound. But he cannot confine them inside a fence. The would-be bee-keeper must play by the bees' rules. The bees must go free if they are to live and to provide humans with honey and pollinize the blossoms. Finally, if you are a bee-keeper, knowing your bees will range widely, you are under some obligation to see that your management of them does not increase the natural hazard which they may represent to other people, for bee-keepers have indeed, on occasion, been held liable for the pain caused by their bees.

Like bees, advocates have been available wild in the community for a long time. Now we are talking about cultivating them--making hives. Indeed, some of the participants in this conference are aspiring to be bee-keepers.

There are, of course, varieties of bees and there are varieties of advocacies. Marie Moore of the UCP Advocacy Project has made a useful chart of different kinds of advocacy (see her paper below, page 113). A recently issued report of the President's Committee on Mental Retardation discusses "personal representation," which certainly describes several forms of individual advocacy. Various special and general forms of advocacy will be discussed throughout this conference, although our emphasis, since we are gathered to consider the implementation of Section 113, must be on advocacy and protective service systems, i.e. organizations for individual advocacy.

Types of Advocacy

I believe that it is important to distinguish conceptually between individual advocacy and collective advocacy, but to recognize that the two are interactive. A system of advocacy for individuals and individual rights will inevitably identify systemic barriers to the realization of such rights. The removal of such barriers becomes a task for collective advocacy. Within the framework of both collective and individual advocacy, I believe there are three mutually supporting types, all of which must be present in a truly effective system. The first I will call professional advocacy, by which I mean advocacy by persons with professional competence in relation to human services needed by disabled people. It is fashionable nowadays among some attorneys to deprecate the professional advocate, since professional advocacy, like judicial advocacy, has not always been effective in the past. However, if we fail to recognize a role for professional advocacy, we will deprive the developmentally disabled of something they need, and even impose on them some rights they do not need. The second type is lay advocacy; lay advocates include parents, guardians, concerned citizens and specifically defined models of individual advocacy, as exemplified in the "citizen advocate." Finally, we have

legal advocacy. Legal advocacy is as old as the practice of law, but legal advocacy which is effective in meeting the special needs of the developmentally disabled has, until recently, been relatively under-developed.

In my opinion, all individual advocacy should focus on the needs and rights of individual clients. At the same time, the advocate must be conscious of the implications for the class of which the individual client is a member, and also must act in a way which recognizes that all of our rights are not absolute but contingent on an equitable recognition of the rights of others.

The developmentally disabled are by no means the only group of people with needs for special kinds of advocacy. Society has long recognized the need for special protection for children, especially for those who are in one way or another deprived of the natural advocacy of parents. Persons who become mentally ill as adults are prime candidates for advocacy, as are many elderly people. People who are uninformed, work long hours, have little money, speak only a foreign language or are imprisoned are all at a disadvantage with respect to self-advocacy, and may need special instrumentalities to provide advocacy for them.

A word should be said here about guardianship of the person. Among the most important rights to be protected is the right to choose--where to live, how to occupy one's time, whether to accept or refuse treatment, and by whom, whether to seek remedies by litigation, and if so, by whom to be represented. Among the developmentally disabled there are individuals who can make these choices and others who do not have the capacity to do so in their own best interests. It is not up to self-appointed advocates, legal or otherwise, to make such decisions for them. The parent has this responsibility for a minor child unless he or she has been found unfit or has relinquished this role. The recent federal legislation on education of the handicapped (PL 93-

380) recognizes this need by providing means for the appointment of a "parent surrogate" to act for the child in educational decision-making when no parent or guardian is available (Aveson, Bolick & Hass, 1975, chap. 4). More generally, the law has provided means whereby an impaired adult may be provided with an authorized individual spokesman to act on his behalf on a continuing basis in those matters which are beyond his own ability to decide. A guardian, like a parent, is a lay advocate. The right to have a guardian, if one is needed, is one of the most neglected rights in our field. Advocacy is not guardianship, but advocacy without attention to guardianship (and thus without individual advocacy for those who cannot voice their own wishes) will be incomplete.

In Wyatt v. Stickney, George Dean was the leading legal advocate, but Ricky Wyatt was the plaintiff. It was his guardian, who happened also to be his aunt, who had to decide to bring suit.

Section 113 calls for a system to "protect and advocate the rights of persons with developmental disabilities." This requirement emerged, in part, out of outrage at the abuses exposed in some of our residential institutions for the retarded. Protection against abuse is an essential part of advocacy for rights.

Although it may sometimes seem as though we were discovering the need for protective services for the first time in the past decade, in fact, the advocacy idea did not and could not spring full-fledged from the head of some Congressional Jove. All legislation is evolutionary and basically incremental. Viable legislation reflects the evolving convictions and societal response to secular changes in the social scene. Thus, Section 113 represents an event with visible antecedents going back for nearly a century.

A Retrospective View of Advocacy Concepts and Practices

It was before the Civil War that Dorothea Dix first spoke out as an advocate for the rights of "insane and idiotic men and women" (1843). It was in the latter part of the nineteenth century that there emerged a strong movement of child advocacy. The child protective thrust in the nineteenth century was a direct response to evidence of widespread neglect and abuse of children. "Protective services" were established with both the standing and the capability of pursuing legal remedies. Child abuse became a crime. Child labor laws were enacted. Children's aid and humane societies were formed and especially licensed to act as interveners and were given certain kinds of quasi police powers, such as rights of entry. These agencies were also empowered to accept responsibilities as individual personal guardians of children left without natural guardianship. In the years since then, most of the authority and responsibility originally vested in these bodies has been transferred to public agencies. Since the model of the separate private corporation which might be empowered with the authority required under Section 113 is one of those being proposed now for possible implementation at the state level on behalf of the developmentally disabled, I believe it behooves us all to study the reasons why such models are today no longer very important in the child welfare field.

Concern for dependent and neglected children had become so strong by 1910 that President Theodore Roosevelt took the unprecedented step of calling the first White House Conference on Children. This was the beginning of the decennial conferences with which we are all familiar and led directly to the establishment of a Federal Children's Bureau, an entity with a clear collective advocacy mission which survived intact until 1968. It still exists as a legal entity whose residual child advocacy responsibilities are now vested in the Office of Child Development.

The convocation of the first White House Conference was well-timed. Braced by the community of concern there expressed, many states moved forward in the child welfare field in the following decade. Of particular note to us is the creation in 1917 in Minnesota of a state Children's Bureau with "special units for dependent and neglected children, boarding homes, unmarried mothers and the blind" (Thompson, 1959). Within this Children's Bureau there was created a Department for the Feeble-Minded and Epileptic. This agency was responsible not only for screening admissions to the then already existing state residential institutions for the mentally retarded and epileptic (separate institutions) but also had important responsibilities for community supervision and for guardianship of the person (child or adult) who was so "mentally defective as to be incapable of managing himself and his affairs, and to require supervision, control, and care for his own or the public welfare." This department, later called a bureau, was headed from 1924 through 1959 by a very remarkable woman, Miss Mildred Thomson, whose account of the duties she first assumed and of the interplay between the courts, the social work profession, the mental health agencies, legislature, and the governors during the subsequent years appears in a book called Prologue.^{*} The Minnesota program of assigning individual case workers working out of the county welfare board offices to assist parents of children living at home, to assure them of the state's continuing concern (through its guardianship program) in the event of the parent's death, and its capacity to maintain a professional advocacy staff for over 5,000 children and adults in the community, emerged in the early fifties as a unique model in the country. Necessary liberalizing changes have

^{*}A few copies of this book are still available for \$2 from the Minnesota Association for Retarded Citizens, 3225 Lyndale Avenue South, Minneapolis, Minnesota, 55408.

since been made. As other states progress, the system seems less remarkable now than it did in 1955, but there are lessons to be learned from its longevity and its recent revitalization.

Minnesota's leadership in protective services for children and adults who were mentally retarded or epileptic was paralleled in certain other states with respect to rights to education. The first mandatory special education legislation, applying to the mentally retarded, deaf and blind, was passed in New Jersey in 1912, and a very similar law was passed in Massachusetts the following year. More such children were identified for service in the public schools in New Jersey in 1918 than in 1945! The growth of special education and the advocacy by special educators continued strong through the late twenties.

Then ensued an event the impact of which on our field is, in my opinion, inadequately appreciated by many younger workers. The period of the Great Depression and World War II, from 1930 through 1945, was one in which all human services, and especially those for the handicapped, suffered from fiscal constraints which are hard for those under 40 to imagine. During the early thirties there was a bulge in the school population attributable to the post-World War I baby boom. This hit the schools precisely at the time when revenues were plummeting. School construction came almost to a stand-still. Class size necessarily increased and special classes came to be viewed as a luxury. Schools which had heretofore accommodated children whom we later came to call "trainable" began to exclude them on the basis of a rationale (which even then had no constitutional basis) that they were "ineducable." A child was defined as "ineducable" if he did not make progress in reading, writing and arithmetic. Since the duty of the schools was to educate, it was argued that they had no duty toward the "ineducable." The families of these "ineducable" children were referred to the institutions.

The impact of the great depression on state residential institutions for the mentally retarded and epileptic was just as dramatic. The most common age at admission (6-9) corresponded with the age group which was exceptionally large in population. Court commitments continued despite the fact that the accommodations were not expanded appreciably; no new public facilities were established during the depression and war years. Moreover, the economic effects of the depression on many families and on the employment prospects for the mildly retarded themselves was such as to encourage the admission of mildly retarded adolescents to public institutions. The effects of these external stresses were very apparent in the demographic profile of residents of such institutions which some of us began to study in the early fifties.

Recruitment of new employees was slowed down and a vicious circle was generated. The educational leadership which had been demonstrated earlier in these institutions gave way to programs of bare survival. Working conditions were such that attracting creative new staffs became more difficult, even when an occasional job-slot opened up. For many facilities the obvious deterioration and obsolescence of the physical plant was paralleled by an even more invidious degeneration of the internal social structure and dehumanization of the professional and especially the direct care employees. Some institutions retained enough residual resilience to make a come-back in the post-war period as resources gradually became available again, but others have never quite recovered.

I make this point, in part, because it could happen again. Our human services structures are fragile at best. Some, such as advocacy services, are less visible to the untutored eye than schools or workshops, and thus likely to be the first to succumb to those shifts in social priorities which inevitably occur when the fiscal going gets rough.

The depression and war also had an inhibiting effect on voluntary action. When people work fifty hours a week, and have gas rations enough only for the most essential travel, committee meetings become very difficult. Thus the post war period between 1945 and 1950 saw a great reawakening in voluntary advocacy, especially lay advocacy. A new post-war baby boom generated new pressures on schools and residential waiting lists. The organization of United Cerebral Palsy, NARC, and NAMH in 1950, and the rapid growth in professional organizations such as the Council for Exceptional Children and the American Association on Mental Deficiency were indicative of a social recovery and a renewed advocacy which this time included parents of developmentally disabled persons in a new and very vigorous role.

The Post War Years

The decade of the fifties was characterized by collective advocacy focused on education in the public schools, improved conditions in state residential facilities, and elimination of the long waiting lists, which clearly violated "equal protection." The strategy was state legislation. There is scarcely a state which did not make significant changes during these years in the options, mandates and funding affecting local school boards' obligations to handicapped children. NARC enunciated a "right to education for all retarded children" as early as 1954. By 1960 considerable progress was noted in extending school programs to the "trainable," but it remained for the courts, followed by Congress, in the early seventies, to make the principle of "zero reject" official. In addition to declaring exclusion unconstitutional, the court cases, such as PARC and Mills, have brought "due process" to the schools, when a child is to be reprogrammed in a special class or track (Abeson et al., 1975).

Another independent but confluent development during the fifties and sixties related to the elderly. As life expectancy increased, the proportion of

older people in our population also increased; a significant proportion of these persons were bereft of spousal and other family advocacy at the same time that their capacity for self-advocacy was declining. Thus concern for protective services for older persons became more general and was expressed in nationally commissioned studies and in public policy. A careful study of the evolution of the Social Security Act will show that issues beyond income maintenance per se were frequently addressed. These developments were important for our cause because in many respects the "model" of protective services for the elderly is more appropriate for the adult disabled than is the child protection model (Lehman & Mathiasen, 1963).

The subjects of right to education, protective services, and guardianship plenary or limited were among many addressed by the Task Force on the Law of the President's Panel on Mental Retardation in 1962. The Task Force was chaired by Judge David L. Bazelon, who is credited with the first "right to treatment" decision. Its report bears rereading at this time. The President's Committee on Mental Retardation picked up many of these themes and made them the subject of a landmark conference in 1973 (Kindred, 1976). Meanwhile, during the decade of the sixties, United Cerebral Palsy (lead by Dr. Elsie Helsel) took the lead nationally in examining the issue of protective services as applied to individuals disabled in and from childhood, and, with the active cooperation of NARC, convened two working conferences (UCPA, 1967, 1969). Results of these discussions are reflected in the specification for "protective and other social and socio-legal services" in the 1970 Developmental Disabilities Act. They also led to Ohio's guardianship and protective services legislation. This, in turn, led to establishment of its legal rights service, which now offers a model for consideration by other states working toward an advocacy system.

Wolf Wolfensberger, seeing this debate as becoming overly legalistic, countered with a proposed model for "citizen advocacy" (1973). This emerged at about the same time that the Joint Commission on Mental Health of Children came on with a proposal for more "child advocacy" (1970). Although these two concepts were, in fact, based on different premises (JCMHC being more interested in collective advocacy), demonstrations of both received funding under the same HEW initiative, as described by Laverdia Roach later in this conference (see her paper below, page 70). The UCP and NARC advocacy projects, represented here by Marie Moore and Max Addison, have now gained considerable momentum. They have demonstrated that lay advocacy has a contribution to make alongside legal and professional advocacy. Kurtz (1975) has evaluated progress in effectuating the complementary roles.

As a background to these developments is an eight-year sequence of international events beginning with the Stockholm Symposium of the International League of Societies for the Mentally Handicapped in 1967. This led, first, to the UN Declaration of Rights of Mentally Retarded Persons in 1971 and then to a similar declaration on the behalf of the disabled in 1975. The 1971 declaration was cited in Senate reports on the developmental disabilities legislation in 1974.

On the legal side the "War on Poverty," following closely on the Civil Rights Act of 1965, was bringing legal services to the poor, including in some instances, the disabled (President's Committee, 1974). The Harvard Center for Law and Education, for example, one of the legal services "back-up centers," contributed to several "right to education" suits. It was a legal services lawyer in New Hampshire (Daniel N. O'Shaughnessy in *Boisvert v. Heilier*, 1971) who established that a disability need not have a provable physical basis in order for a mentally retarded person to qualify for disability assistance in that state.

Meanwhile, physically handicapped adults were becoming more vocal on their own behalf. "Access" became a battle cry, and the handicapped joined minorities and women as groups requiring "affirmative action" by federally impacted employers. The Epilepsy Foundation was particularly active in relation to employment and driving rights.

The creation of the Subcommittee on the Handicapped within the Senate Committee on Labor and Public Welfare in 1972 brought education for the handicapped, vocational rehabilitation and developmental disabilities together in a way which explains why client participation, individual programming, focus on the severely handicapped and "rights" are themes recurrent in recent legislation in all three areas.

Congress was responding in part to the crescendo of court suits spearheaded by pro bono legal organizations, the National Legal Aid and Defenders Association, ACLU, the Mental Health Law Project and individual lawyer-parents. These in turn were also reflected in the formation of committees within the American Bar Association, the publication of books and periodicals, and running accounts of concurrent court battles, with which many of us are familiar.

The 1970 developmental disabilities legislation abetted these efforts in a small but seminal way by providing funding both for the National Center for Law and the Handicapped as a "project of national significance" and (via the states and HEW regional offices) for undertakings such as the Minnesota Legal Services project and the University of Maryland Law Clinic, both represented at this conference. DD funding also augmented Professor Michael Kindred's activities at Ohio State University. Now Temple and Georgetown Universities are joining in.

The advent on the scene of law schools close to university programs preparing service personnel for the field of DD is especially timely, because it must be admitted that the spate of litigation in the seventies overtook a pro-

fession not fully prepared to meet the challenges of so complex a human problem. Indeed, until recently, if one mentioned the subject of the "law and the mentally retarded" to an attorney the feedback usually addressed only two issues: (1) commitment to institutions, and (2) criminal responsibility.

A word or two should be said here about the first. As late as 1965, the most usual route to admission to a state institution for the retarded was via a court order. Someone believing admission of an individual to be desirable had to apply to a designated court, demonstrate that the individual was "dangerous to himself or others" and obtain from the court an order of commitment, i.e. an order authorizing the institution to detain the individual. Such detention is, of course, a deprivation of liberty. Although the texts of the statutes covering these procedures were replete with "due process" stipulations, in practice these protections were considerably eroded by routinization, and waivers were invoked almost automatically. Judicial review became perfunctory in most instances. Most admissions of retarded or autistic persons were and are for minors; the parents were forced to go through a sometimes humiliating, even if pro-forma, adversary procedure, only to find in the end that their powers under law to reverse this procedure had been curtailed.

A significant case illustrating this point was decided in Wyoming in 1967. An eleven year old boy, Charles W. Parker, was committed in 1946 to the Wyoming state institution, following court action on the application of his parents. In the mid-sixties, his parents sought his discharge and were refused. The law appeared to support the authority of the institution. A suit was brought; the attorneys for the parents chose the tactics of attacking the original commitment proceeding on the grounds that the boy had not had benefit of representation by an attorney at the time of admission. The court ordered that he be released and that all similar cases be reviewed for adequacy of such representation. (Apparently the issue of periodic review of

need for care was not raised.)

In the fifties the ever broadening interpretation of "dangerousness to self" as a justification for court ordered commitments to mental hospitals was seen, in the context of changing treatment patterns for the mentally ill, as injurious to patients and a deterrent to early treatment. As psychiatrists and mental health associations successfully developed the model of voluntary admission for adults with forms of mental illness which did not meet the "dangerousness" test, so in a number of states NARC's state associations moved to authorize the alternative of voluntary admission of children on the application of parents. Thus the responsibility for reviewing appropriateness of admission was transferred from the courts to the professionally staffed intake machinery of the responsible state agency or facility. Under these new rules in most states parents retained legal custody and were in a better position to secure release if it appeared desirable and to assert the rights of their minor child while he remained.

Even more importantly from a policy point of view, the residential facility was put into perspective as a part of the service continuum rather than as a place of detention. Both of these principles (emphasis on voluntary admission and use of the residential facility as a habilitation resource) were affirmed by the White House Conference on Children and Youth in 1960 and were reflected in the detailed standards for residential facilities as the latter were evolved over the years by AAMD (1964) and later by the Accreditation Council (1971).

The Developmental Disabilities Act Amendments of 1973-75

These accreditation standards eventually received Congressional imprimatur when they were embodied en bloc in S. 3759 (later S. 458), the Javits "Bill of Rights for the Mentally Retarded" introduced in 1972. It ran well

over three hundred pages. In 1974 the same text was reintroduced as Part C of Title II of S. 3378 (Randolph et al.) and again in 1975 as part of S. 462. Title I of S. 3378 and S. 462 consisted of extending legislation for the 1970 Developmental Disabilities Act. Senator Javits' support for the DD extender was understood to hinge on Senate acceptance of his "Bill of Rights" as a rider. Among other things the "Bill" stressed the right to independent external guardianship for selected residents.

Both these successive bills passed the Senate containing specific language favoring voluntary admission to residential and non-residential programs alike, based on thorough evaluation of the disabled person's needs and a review of program and placement alternatives. Most professionals and parents see such a process as normalizing, comparable to admission to camp or college for siblings. However, to the new-found legal advocates of the seventies, the professional review which is part of voluntary admission of children on the application of their parents (or adults on their own or on application of their guardians) appears to be deficient in "due process" protections; the advocacy of parents is regarded as suspect because of "inherent" conflict of interest. (The assumption is that the parent gains advantages through such "divestiture.") Thus the court role is being reactivated. It is not appropriate to elaborate here on the recent cases in this area, notably *Bartley v. Kremens*; but the water is very muddy at present. The area is one which exemplifies the problems that will confront the new advocacy systems.

The 1974 and 1975 Senate bills referred to above incorporated additional material, not contained in the original Javits bill. "Alternative criteria" recommended by the Consortium Concerned for the Developmentally Disabled included requirements for (1) individualized written habilitation plans for developmentally disabled persons in both residential and non-residential settings,

(2) a program coordinator for each such individual to see that the plan was implemented, (3) a set of minimum standards, and finally (4) a "system of protective and personal advocacy to protect the human and legal rights of each developmentally disabled person." Its powers and duties as proposed by the Senate were fairly detailed and elaborate. How most of this paraphernalia was streamlined and compressed into PL 94-103 in the course of the House-Senate Conference late in 1975 is told by Jack Andrews (see below, page 32).

And so, as the saying goes, "We've come a long way, baby." The hopes and fears of many years are met in Section 113. It cannot bear them all; it cannot be all things to all people, even all developmentally disabled people. But, like the honey bee, it can make a difference.

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Overview: Legislative Activities of the
Subcommittee on the Handicapped

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The Subcommittee on the Handicapped is a standing, i.e. permanent, Subcommittee of the parent Committee on Labor and Public Welfare, U. S. Senate. It was established in the final months of the 92nd Congress, and its existence as a permanent Subcommittee is an indication of the importance which the Congress has attached to legislation affecting handicapped individuals. It was established in order that such legislation have more visibility and coordination; for it is charged not only with developing federal legislation, but also with formulating national policy regarding such issues as education, vocational rehabilitation, employment and related subjects such as architectural barriers, transportation barriers and adequate housing.

The Subcommittee has specific jurisdiction over the Education of the Handicapped Act (including the Education for All Handicapped Children Act of 1975); the Rehabilitation Act of 1973, as amended; the Developmental Disabilities Services and Facilities Construction Act, as amended; the Randolph-Sheppard Act; and the Javits-Wagner-O'Day Act. In addition, the members and staff of the Subcommittee work with other Committees on matters relating to the lives of handicapped persons, but over which the Subcommittee has no direct jurisdiction. The Subcommittee has cooperated with the Public Works Committee on the effects of an energy crisis on handicapped persons and on accessible transportation; with the Banking, Housing and Urban Affairs Committee on housing, transportation and low-cost loans for handicapped persons; with the Post Office and Civil Service Committee on support personnel for handicapped Federal employees; and with the Appropriations Committee in order

to get the maximum possible funding for the programs authorized by the Subcommittee.

The members of the Subcommittee are: Jennings Randolph of West Virginia, Chairman; Alan Cranston of California; Harrison A. Williams of New Jersey; Claiborne Pell of Rhode Island; Edward Kennedy of Massachusetts; Walter Mondale of Minnesota; John Durkin of New Hampshire; Robert Stafford of Vermont; Robert Taft of Ohio; Richard Schweiker of Pennsylvania; and J. Glenn Beall of Maryland. Although Senator Jacob Javits of New York is not a member of the Subcommittee, the members and staff work very closely with him as the ranking minority member of the full Committee on Labor and Public Welfare.

During the 94th Congress, the Subcommittee has worked primarily on the Education for All Handicapped Children Act of 1975 (PL 94-142); the Developmentally Disabled Assistance and Bill of Rights Act (PL 94-103); and the Rehabilitation Act Extension of 1976 (PL 94-230). With these major pieces of legislation enacted, the Subcommittee during the last months of the 94th Congress is turning more toward oversight of the implementation of existing legislation as a basis upon which to knowledgeably formulate any future amendments. During the spring of 1976, Chairman Randolph held eight days of hearings on the implementation of the Rehabilitation Act of 1973; other oversight hearings on education and developmental disabilities are tentatively scheduled before the end of the 94th Congress. In addition, the Subcommittee is carefully reviewing all regulations promulgated by the administering agencies to insure that Congressional intent is clearly reflected in these regulations.

Rather than giving detailed explanations of these recently enacted laws this paper will deal with basic legislative trends over the last few years; for as one examines the bills and laws with which the Subcommittee has dealt, certain trends become apparent.

A non-handicapped person does not even stop to consider his personal freedom; he takes it for granted. A non-handicapped person assumes that he will always live in an environment that allows for self-determination and self-expression. Most of the developmentally disabled citizens in this country have not had this opportunity. A non-handicapped person has considered it his right to have a free, appropriate public education. However, a handicapped child may, at worst, be denied any education at all or, at best, be shuffled off to a separate class where an inadequately trained teacher simply does not know how to plan activities which meet his special needs. A non-handicapped person who interviews for a job for which he is well qualified will feel confident that he will get it; a handicapped person may be unable to even be interviewed because of communications, architectural and transportation barriers; if he does, he may not be hired simply because of his handicap. The list of injustices is long; fortunately, recent federal legislation has tried to address some of these problems by emphasizing the concepts of (1) advocacy systems and due process procedures; (2) individualized planning; (3) non-discrimination on the basis of handicap; (4) least restrictive environment; and (5) barrier-free environment.

Historically, handicapped children and adults have had little protection from abuses resulting from inadequate care and education. Both the Developmentally Disabled Assistance and Bill of Rights Act and the Education for All Handicapped Children Act have placed in effect or strengthened mechanisms to protect the rights of handicapped individuals.

The Congress has recognized 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, most particularly those who are unable to adequately

protect their own rights. It was for this reason that PL 94-103 mandates that the states, as a condition for receiving funds, must have a system to protect and advocate the rights of persons with developmental disabilities in effect no later than October 1, 1977. The Secretary may not make an allotment of federal funds to a state for fiscal year 1978 and thereafter unless the state has in effect such a system. The system is to be independent of any state agency which provides treatment, services or habilitation and is to have the authority to pursue both legal and administrative remedies for developmentally disabled individuals.

The Education for All Handicapped Children Act of 1975 strengthened provisions in existing law relating to due process protections for handicapped children. The local educational agency or the state educational agency (if the state is a provider of direct services to the child) must provide prior written notice to the parents or guardian if that agency proposes to initiate or change the identification, evaluation, or educational placement of the child. Furthermore, the agency must provide prior written notice if it refuses to educate the child. A parent or guardian has the right to present a complaint concerning the identification, evaluation or educational placement of the child or the provision of a free, appropriate public education; if they wish, they also have a right to an impartial due process hearing. This hearing must not be conducted by an employee of the agency which is involved in the education or care of the child. Other protections strengthened by PL 94-142 include the establishment of procedures to insure non-discriminatory testing and evaluation procedures, the requirement that all materials and procedures used must be provided and administered in the child's primary home language or mode of communication, and the establishment of procedures to provide parents or guardians the opportunity to examine all relevant records.

Additional protections added by PL 94-142 that relate to the impartial due process hearing include (1) the right to counsel and to be advised and accompanied by persons with special knowledge, training or skills with respect to the problems of handicapped children; (2) the right to present evidence and confront, cross-examine, and compel attendance of witnesses; (3) the right to have a written or electronic verbatim record of the hearing, and; (4) the right to have written findings of fact.

The Rehabilitation Act, the Developmental Disabilities Act, and the Education for All Handicapped Children Act all reflect yet another legislative trend--individualized written plans. These individualized programs as set out in the respective laws have in common the following requirements: (1) the plans are to be developed jointly by the counselor (or representative of the agency primarily responsible for delivering the services, or the teacher), the handicapped person, and parents or guardian (where appropriate); (2) the plans are to include a statement of specific services to be provided; (4) they are to be reviewed at least annually; and (5) they are to include the projected date for initiation and anticipated duration of services to be provided. Such plans are to serve primarily as a tool for the development of the individual; however, they can also be used as a means of evaluating the quality and performance of the program.

The problem of discrimination against handicapped persons has been outlined in three sections of the Rehabilitation Act: section 501 (Employment of Handicapped Individuals); section 503 (Employment under Federal Contracts); and section 504 (Nondiscrimination under Federal Grants). Section 501 mandates the establishment of an Interagency Committee on Handicapped Employees within the Federal government; this Committee is to provide a focus for handicapped employees within the Federal government and is to review, in coopera-

tion with the Civil Service Commission, the hiring, placement and advancement practices of federal agencies. Section 503 relates to employment under federal contracts; any contract in excess of \$2500 entered into by any federal department or agency shall contain a provision requiring that the party contracting with the government shall take affirmative action to employ and advance in employment qualified handicapped individuals. The Office of Federal Contract Compliance Programs of the Department of Labor is charged with investigating any complaints from handicapped individuals regarding employment discrimination; the regulations for this provision have been issued and are in effect.

Section 504 is perhaps one of the most far-reaching sections concerning handicapped persons ever enacted. It states: "No otherwise qualified handicapped individual in the United States . . . shall, solely by reason of his handicap, be excluded from participating in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance." Although it is placed in a vocational rehabilitation law, section 504 clearly extends its coverage to all handicapped individuals, regardless of their need for or ability to benefit from vocational services; thus, it affects approximately 25 million handicapped individuals. The Office of Civil Rights of the Department of Health, Education and Welfare is charged with the implementation of this section (the language is based upon that in Title VI of the Civil Rights Act). The Subcommittee has expressed a great deal of concern because the regulations for this section have not yet been issued, although OCR has submitted a draft copy for review by the Secretary. In the interim, enforcement is being done primarily on a complaint basis by the staff of the OCR.

Both the Developmental Disabilities Act and the Education for All Handicapped Children Act include sections relating to affirmative action in the

employment and advancement of handicapped persons; clearly the population served by both measures is covered under section 504.

It is now almost 50 years since experts in the field of mental retardation first began to discuss alternatives to large institutions. Unfortunately, progress in developing these community alternatives continues to be slow, and the care provided in most institutions nearly always leaves much to be desired. The Developmental Disabilities Act reflects the belief that every effort should be made to assist developmentally disabled persons to maximize their ability for self-care, to live normal lives, and to live in the least restrictive environment conducive to their maximum development. PL 94-103 requires that each state in its state plan contain a plan "designed (A) to eliminate inappropriate placement in institutions of persons with developmental disabilities, and (B) to improve the quality of care and the state of surroundings of persons for whom institutional care is appropriate." Furthermore, not less than 10% of a state's allotment in 1976 and not less than 30% of the state allotment for each succeeding fiscal year must be used by states to develop and implement plans designed to eliminate inappropriate placement in institutions of persons with developmental disabilities.

The state must also provide assurances of how it will "support the establishment of community programs as alternatives to institutionalization and support such programs which are designed to provide services for the care and habilitation of persons with developmental disabilities, and which utilize, to the maximum extent feasible, the resources and personnel in related community programs." In Title II, the law states that 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."

The Education for All Handicapped Children Act also strengthens provisions relating to "least restrictive environment" in existing law. The states are required to establish procedures to assure that handicapped children, including children in public or private institutions or other care facilities, are educated with children who are not handicapped, and that separate schooling, or other removal of handicapped children from the regular educational environment, occurs only when the severity of the handicap is such that the education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily.

Another trend is the increasing visibility given to the need to remove architectural and transportation barriers to handicapped individuals. Both the Developmental Disabilities Act and the Education for All Handicapped Children Act contain provisions to assure that any construction or renovation will be done in conformance with standards promulgated pursuant to the Architectural Barriers Act of 1968. (These standards are presently being reviewed by Syracuse University in order to correct any deficiencies and identify any omissions in them.) In addition, PL 93-112, the Rehabilitation Act of 1973, established an Architectural and Transportation Barriers Compliance Board to enforce compliance with these standards as well as identifying any existing barriers contained within housing and transportation systems.

Senator Randolph, Chairman of the Subcommittee, has often expressed gratification that the work of the Subcommittee has produced legislation that is beneficial to many handicapped persons. It is clear that this could not have been accomplished without the support of handicapped individuals and of organizations serving handicapped persons. A great deal remains to be done to insure the full implementation of these enacted laws and to correct any inadequacies and problems which will be manifest in the future. By serving as

a legislative focus for these efforts, the members of the Subcommittee will continue their work to insure equal rights for all handicapped Americans.

The Evolution and Congressional Intent
of the DD Legislation

Jack Andrews
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I will start by stating that I am very happy to have the opportunity to be here this morning. Marvin Layne mentioned that I've been involved with lots of legislation; that is true. But I want you all to know that I am pleased to be here about this piece of legislation because I very much plan, at some point in my life, to be able to go back through some old files and look at the work on this particular bill and still be proud of it. Of all the things I've worked on, PL 94-103 is the one that I like the most. So, now you know my bias.

I picked up that bias slowly, not instantaneously. I picked it up through Senator Javits to a large degree and from those in the developmental disabilities field who showed so much interest.

It's my understanding that we're looking this morning for the Congressional intent of the Developmental Disabilities Assistance and Bill of Rights Act as passed and signed into law. I would rather trace how we ended up with the present law from the original gigantic document.

I first became associated with something known as the Bill of Rights for the Mentally Retarded approximately four days after I became minority counsel to the Labor and Public Welfare Committee in the United States Senate. It was handed to me in a galley print. A galley print is simply a draft print of a piece of legislation. It weighed about six pounds and was about four hundred and fifty pages long. I was scared to death.

I came to this job from having been an attorney in government, working with regulations, doing the standard government lawyer sort of thing. I had no background whatsoever in teaching special children. I had no back-

ground in mental retardation, or the field of the handicapped in general. I don't today, except with respect to some of the legislative aspects. I looked at the original Bill of Rights to see if I could teach myself what it was intended to do.

It was 1974. So far as I could discover, there had never been one piece of federal legislation that stated, "The mentally retarded have a right to proper care, treatment, and habilitation"--not one. Just as a layman and as a lawyer, that struck me as insane--how could that be in 1974?

I decided that I'd better try to figure out what the Bill of Rights was all about--and, I proceeded to try to do that. A month or so later, the first time I was ever called to speak in front of a group about the Bill of Rights for the Mentally Retarded (which by that time had already been added as Title II to the DD Act), I found myself still not knowing exactly what all those pages and all that weight of this gigantic document really meant, yet expected to explain it. And, I remember afterwards Elizabeth Boggs came up to me with a very anguished look on her face that seemed to ask, "What are you doing to my DD program?" She was very unhappy with this dinosaur Title being attached. Now, these four hundred pages, the Bill of Rights, consisted of every conceivable detail and standard that JCAH and other groups had thought would be appropriate for institutionalized mentally retarded patients. And, here it was tacked on to the DD bill. Dr. Boggs probably had very good reason to have that anguished look.

Well, I figured out, after defending this thing long enough to help get it through the Senate in October 1974, that it really was a turkey. So the task then fell to me to go to the author of this bill and say to him, "Senior United States Senator, your bill which you and twenty other Senior Senators have been associated with for three years is a turkey." I was still new at

my job and that prospect made me very nervous. I decided that rather than just saying that it was a turkey, I would have to try to figure out for myself before I went in to discuss it with the Senators what they were trying to accomplish.

The best I could do was come up with a fifteen-page outline of the five essential elements of the bill. The elements that emerged from the hundreds of pages in a process of several months of endless conversations, skull sessions, arguing, and fights with various Congressional staff, Dr. Boggs, and many others representing various groups in the field, were as follows:

1. a statement of the rights of the developmentally disabled;
2. minimum standards;
3. protection and advocacy of individual rights;
4. individualized habilitation plans;
5. program coordination.

At any rate, I did my best to put something down on paper and approached Senator Javits. Before I could say, "Senator, your four hundred pages is a turkey," he said to me, "I bet you're going to tell me we've got to do something with this four-hundred page document." And, I said, "Yes, Senator, we do." And he said, "There are three things I care about: one, that there be a statement of the rights of the mentally retarded; second, that there be an advocacy system; and third, that the document include the concept of minimum standards. Give me that--that's all I want." I said, "Here it is." He said, "I want this; it's important."

We went to work. The next trick was to keep the pressure on the House of Representatives. Both the members of the House and staff who had to deal with this legislation were terrified, and I think rightfully so, of this four-hundred page document. In order to keep the pressure on them, we had

to pass all four hundred pages through the United States Senate a second time. Between October of '74 and January of '75, a new Congress had begun. Bills have to be reintroduced in each new Congress. Well, we did so, and we made it to House-Senate Conference with all four hundred pages.

The Conference reported the three pages of the Bill of Rights, now such a vital part of PL 94-103.

Thus, one of the essential things in this four hundred page document was the statement of the rights of the developmentally disabled. Today PL 94-103 affirms those rights, and that's vitally important. Program coordination was considered very important. So was system of advocacy. Minimum standards-- another important concept. Keep in mind that the bill was originally geared for the institutionalized mentally retarded.

Now I'd like to talk a little about advocacy systems. Earlier, I counted maybe ten or fifteen lawyers here. I'm glad to see that there are that many lawyers here. "Advocacy" is a term that lawyers get accustomed to hearing, using, and thinking of as referring to their work. Advocacy does not have to be legal advocacy. It can be much broader than that.

This bill is drafted in such a way it drives lawyers crazy because there is so much flexibility in it. That was the intention. You define advocacy as is most appropriate in your communities and in your states.

Fran Lynch, Director of the DDO, is charged with the duty of coming up with regulations under which the advocacy system will be administered from the federal level. His draft regulations have received a considerable amount of review and criticism. Many people have suggested that he is not regulating enough. In other areas, specifically with respect to the state DD councils, some think he is over-regulating.

It's my feeling that so far as just the advocacy system is concerned, the less regulation, the better. This program is a small one with very

little money and must have a chance to get off the ground. It must have flexibility to be useful in fifty different states and hundreds of different communities. It doesn't have the money, or the support yet to survive being regulated into a narrow parameter. This advocacy system, which defies definition a little too much to make some people happy, will never have the chance to assist the developmentally disabled if it's killed by inflexibility at the start.

Another danger, perhaps small but real, is that the system could be perceived as another bold attempt by the federal government to finance pro-bono legal action against the very states that are trying to provide the service. Everybody familiar with the federal legal aid legislation and issues is aware of how explosive such a perception can get. I hope that this advocacy system will not be perceived as a system whereby the federal government subsidizes trifling with state and local government. I don't think this will happen. I think the bill is in good hands. Your hands.

The bill reads that "the state will have in effect a system to protect and advocate the rights of persons with DD." "The states will have in effect"--that's the public, the state government. That's very important.

I know that in at least one state, and probably several others, there's a big drive to have this system contracted out totally by the state government or governor to a private group, with only a contracting officer at the state level. I would suggest that that is not what the law intends. Nor is that result what those in the field would want. If the system is totally contracted out--let's envision "Consortium Systems, Inc." on the door--it no longer has the imprimatur of the state government or of the public. The important thing is the public--state government, local government, the community--meeting a public responsibility. The law says very clearly that the state must assume

the responsibility of the advocacy system.

I am also aware that in many states the best people to carry out the responsibilities of this system will be private groups. This is permitted, even encouraged, by the law, and I don't think there's anything wrong with that. But I would suggest that before the system is just shuffled out the door by contract, there should be at least one paid state employee somewhere, whose responsibility is to personify the public responsibility for this system.

I believe that the draft regulations respecting how the system may be set up, and how advocacy services are contracted out, almost invite the states to dump this public responsibility in the lap of private groups. I hope that does not happen. I hope you all will think very seriously about these concerns I've mentioned and that you will demand in your state that the advocacy system be a state system with some state employee in charge.

As the discussion of PL 94-103, of planning and implementing the advocacy system continues, let us not lose sight of our goal--to better meet the public responsibility we have to assist developmentally disabled citizens.

The Developmentally Disabled Assistance
and Bill of Rights Act

Francis X. Lynch
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Developmental Disabilities Office

Much has happened in developmental disabilities during the past 15 years. Organizationally, you might say, the country is ready to do some accelerated work on behalf of developmentally disabled persons. Certainly, we don't lack the knowledge for this work.

We are learning that disabled persons are entitled to be treated as individual human beings with basic rights. They are not for warehousing. Their problems are not solved but become more severe when we erect a wall around them.

Last October, the President signed into law the latest amendments to the Developmental Disabilities Act: PL 94-103.

This provides for a three-year extension of our program of the state formula grants to assist in planning and implementing programs for developmentally disabled persons. Among other things, the legislation authorizes continued support for the university-affiliated facilities, it makes numerous changes in the state plan requirements, and it modifies the definition of "developmental disabilities" by adding autism and severe dyslexia to the existing list of mental retardation, epilepsy, and cerebral palsy.

A principal addition of the amendments is Title II, a section in individual rights. Now, some of our beliefs have been translated into law. Increasingly in recent years, the advocates of disabled persons have been saying that all people, including the disabled, should have equal access to community programs; that children who have disabilities have a right to grow up in typical settings with their typical peers; that institutions often isolate and dehumanize people; that most decisions involving disabled persons are not scientific questions to

be solved by professionals so much as they are political and moral decisions to be made by the entire society; that all persons, including disabled, have a right to equal treatment; and that the problem of serving persons with disabilities is not essentially a problem of facilities or of money, but of our prejudice and discrimination.

How does Title II help those who are advocates for developmentally disabled persons? It makes these findings respecting the rights of disabled persons:

- . Persons with developmental disabilities have a right to appropriate treatment, services, and habilitation.

- . The services should be designed to maximize the developmental potential and be provided in a setting that is least restrictive of the person's liberty.

- . The federal government and the states have an obligation to assure that public funds are not provided to any institutional or other residential program when treatment is not appropriate and when minimum standards are not met in diet, medical care, safety, visiting hours, and personal treatment, including use of physical or chemical restraints.

- . All programs for persons with developmental disabilities should meet standards which assure the most favorable possible outcome for those served.

Another part of Title II gives these individual rights some structure by requiring that states develop a habilitation plan for each developmentally disabled person receiving services under the Act. The individual habilitation plans are to be reviewed each year.

The Act stipulates that the individual plans are to be in writing; developed jointly by representatives of the service-delivery organization, the disabled person, and the disabled person's parents or other representative; provide for evaluation of program; and contain a statement of specific services to be provided, identifying personnel and agencies involved and duration of services.

It is possible that there will be pressures in some areas to either water down this part of the law or to delay implementation. Several states have taken action in individual rights for disabled persons, and they might have experienced these tactics in getting their state laws passed.

There also is the school of thought that human rights should be strictly a matter of local discretion, but I suggest that the local and state expression has already been made through national representatives in the U.S. Capitol. The representatives, after lengthy debate and compromise, have translated these expressions into law, and it has been determined that disabled persons have certain minimum rights.

I also want to suggest that those of us who make a living by serving disabled persons should consider it a privilege to see that they obtain these rights and that they are, at the least, protected from neglect and overt abuse.

Our advocacy work is taking its place in history. America, as we are continually reminded on our birthday, is built on the principles of freedom--that is, the rights of individuals. But the rights have been won slowly and are obtained through force of law, not necessarily through feelings of brotherhood and generosity on the part of fellow citizens. During our history, advocates in the full sense have been few in number. Some of them, such as pamphleteer Tom Paine, have found life less than ideal after making their thoughts known. Slowly, painfully these rights have been extended to all people of all races, religions, sexes, and handicapping conditions, such as developmentally disabled persons.

Today, we are recovering from the Willowbrook case in New York state. The purpose here is not to single out one institution. The indignities suffered by youngsters there have occurred elsewhere. But we should remember this sad story the way we remember Pearl Harbor, because there are just as many lives involved. One of the important outcomes of Willowbrook has been the additional recognition

from the courts that the lack of meaningful help can be as damaging as overt cruelty in turning children into vegetables.

Judge Judd of the District Court approved a consent decree last year (May 5, 1975) securing the constitutional rights of the residents of the institution to protection from harm. Judge Judd added a memo of his own. It relates to constitutional rights and to our social policy. He said,

The consent judgment reflects the fact that protection from harm requires relief more extensive than their court originally contemplated, because harm can result not only from neglect but from conditions which cause regression or which prevent development of an individual's capabilities.

He accepted the argument of plaintiffs that in an institution for the mentally retarded, it is impossible for the condition of a resident to remain static. If his functioning is not improving, it will deteriorate. Thus, to keep the residents from being harmed, it may well be necessary to provide the full range of affirmative relief, which has been ordered in some court cases, under a theory of right to treatment.

For safe custody, we have the theory of right to protection from harm. This was set forth in 1973 and is based on the Eighth Amendment's prohibition against cruel and inhuman punishment. For improving the habilitation, we have the theory of right to treatment. This is based on the Fourteenth Amendment and relates to the clauses on equal protection and due process.

So much for legal precedent, which helps us turn good intentions into deeds.

The provisions on individual rights meld naturally into our basic desire for normalization, which is one of the keys to our thinking in developmental disabilities. As you know, this is the concept of helping the disabled person obtain an existence as close to the normal as possible, making available patterns and conditions of everyday life that are close to the norms and patterns of the mainstream of society.

There has been new interest in the total quality of life rather than merely the length of life, in the positive elements of good health rather than the absence of disease and infirmity. This is reflected in the work now going on throughout the country to make it possible for people with developmental disabilities to lead fuller lives. There is more stress on proper diet, especially during the younger years. The school system is making education available to everyone, including the retarded and otherwise handicapped children. This relates to academic, vocational, and social skills which enable them to live up to their greatest potential.

Recreation is no longer busy-work to fill a void but an end in itself that provides people not only with therapy but several forms of satisfaction.

The physical environment finally has become important, and a person's relationship to his environment now is a major concern of architects, urban planners, behavioral scientists, and social workers.

On the one hand, there are efforts to enrich the lives of persons who must remain in institutions, and on the other hand to make it possible for many persons in institutions to someday return to relatives and friends in a home environment.

I won't underestimate the amount of work ahead of us, but these are some of the pieces which are falling into shape throughout our society which might help us in implementing the new amendments to the Developmental Disabilities Act.

Definitional Aspects of Advocacy and Protective Services

Dennis E. Haggerty
Advisory Board
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Introduction

The constituency of the developmentally disabled has literally created a new industry. In the not too distant past, parents sent their children away to institutions located away from population centers and staffed by personnel that was not at all exceptional or well-trained, from the Administrator and medical doctor on down to the attendants.

Then came a time when the parents decided to trot out of the closets their problems with the developmentally disabled, including the retarded. They organized, formed committees, and started looking at institutions and changing things. They succeeded in changing the medical model and encouraged the unionization of attendants and other staff. They started grasping at concepts of normalization, deinstitutionalization and institutional reform.

In the meantime, what have we done? Looking back, as I have said, we have created new monsters. We have created a more aggressive and intelligent top management of institutions. We have unionized staffs so that sometimes they are more interested in feather-bedding and protecting their own job slots than in improving the quality of care or even understanding the clients whom they serve. We have made many of the not-so-rich rich, and we have succeeded in creating much confusion. We have moved from the single headings we used to use, like the "mentally retarded," the "cerebral palsied," the "epileptic," the "autistic," and refer now to the developmentally disabled, asking ourselves such questions as where during the developmental years the neurological deficit is.

I. Advocacy: What It's Not

Parents are the natural guardians of their offspring until the child reaches the chronological age of adulthood, which in some states is eighteen and others twenty-one. But whenever, the idea of guardianship seems no longer necessary once adulthood has been reached. Legal advocacy for the retarded is not that.

The parents draft a Will and name therein guardians for their minor children. These are referred to as testamentary guardians and they are usually further distinguished as guardians of the estate of the minors that the parents leave behind, and guardians of the person, the latter being the guardians who would take over the role of the parents and indicate where the child might reside, go to school, church, etc. These guardians are not to be confused with trustees, who usually manage money matters solely. Testamentary guardianship is not, however, legal advocacy for the retarded or for the developmentally disabled.

If the parents die before the child reaches majority, and if the Will does not name a testamentary guardian, the court would appoint a guardian for the minor children until they reach majority. This, too, is not legal advocacy for the developmentally disabled.

There are other types of guardians whom the court recognizes, such as guardian ad-litem, meaning there is a guardian for someone under a disability during a court proceeding involving that individual, or there is a guardian for the incompetent of an estate, who is appointed after the declaration of incompetency of the person who has an estate to manage or a personal life to manage. This kind of guardianship has no relevance to age of the ward. This, too, is not legal advocacy for the developmentally disabled.

In some of the roles that we just mentioned, there may or may not be some advocacy involved. Some persons, because they are under the disability

of minority or incompetency, may not be advocated for as developmentally disabled persons. And further, their needs may or may not be different from the needs of a normal individual.

II. What is Advocacy

The word advocate is synonymous with lawyer. To advocate means to actively support a cause--to speak in favor of--to recommend--to support or defend--to plead on another's behalf. Its derivation is from the Latin ad, meaning to, and vocare, meaning to call, to vocalize for, or to give evidence.

III. History of Advocacy in the Field of the Developmentally Disabled

Volunteer Movement

When the parents' movement was organized in 1950, some twenty-six years ago, it borrowed generously from the civil rights movement. Association representatives on local, state and national levels structured committees to move forward to providing a better life for the developmentally disabled. There were several movements, but all were trying to act in the particular interests of those with the developmentally disability that they represented. The organizational effort seemed to go very well, but the parents' movement was not an effort in legal advocacy.

A few typical examples show the false starts in the area of advocacy. Lawyers who were parents or interested in movements supporting the retarded and other developmental disabilities were bogged down with assignments to create by-laws and be concerned with Robert's Rules while Rome burned. Or worse, having cared for their own children in the best setting because they could afford it, they were no longer deeply interested in the overall good of the movement.

Educators in special education certainly were interested in seeing it

improved. But they were intimidated by their second-class citizenry in their own chosen field. They were ineffective when priorities or budgets were seriously approached and seemed to be resigned to an attitude of being happy to get anything.

Appointments to committees and to chair committees were interesting. For example, one would find chairmen of Residential Care Committees whose children were in the best programs of the residence. They were hardly in a position to be effective in advocating for the rest of the children to receive the same kind of care their own children were getting.

Chairmen of insurance committees worked for insurance companies and did not really force the issue of why there is not realistic criteria to justify not covering developmentally disabled children from birth.

And of course, there was the ever present professional parent volunteer too taken with his or her own importance to be running anything. The content of any program or any committee function was of secondary importance.

And so it went--and sometimes still does. As a legal advocate, it didn't seem to me any way to run a railroad.

Litigation Effort

Advocacy has been multi-faceted in its approach since the first class action, which was instituted in the Pennsylvania Association for Retarded Children's suit for the right to education. To realistically look at what has happened in the field we must take a look at how that case developed. It was not just a lawsuit. It involved the association for the mentally retarded on the state and local levels, and the cerebral palsy organization on the state level. Together with the Junior Chamber of Commerce these groups moved ahead to investigate large institutions in a large state. The setting was an institutional setting. Effort was concerted by all three groups. The action was

informative to members. It was informative to the general public, having hit the news media in the exposes which followed as the investigation got under way. It was an educational effort for all concerned, and particularly for political aspirants. It resulted in the education of a person who was to become governor of that state and in a position to assist in a consent decree at a later date. Further, it was an education for the opponent who did not win the governor's chair but soon found himself on the Federal Court and one of the judges in the historic Right to Education suit. Finally, it was more than all this. It involved a little showmanship for a state convention to get a commitment from a state for funding. Literally, the national associations had turned down for a number of years requests for funds to hire counsel to address some of the major issues, such as education, treatment, peonage and the like. And also, literally, such an organizational effort, even on the state level meant that the state was dragged kicking and screaming into the area of legal advocacy as a complaining party. I don't think it is any secret that the national associations had not appreciated the opportunity or the possibilities of such a class action approach in the courts.

However, once the little red wagon started rolling it was hard to keep those jumping on from falling off due to overcrowding. There rapidly followed class action suits and litigations all over the country. At one point, the suits in process totaled nearly 150. The national associations serving the developmentally disabled saw the possibilities. Soon lawyers got involved broadly as the American Bar Association took note and set up first a committee and then a commission to address the problems. Federal funding of the National Center for Law and the Handicapped to assist as a legal shop for the constituency was one of the other direct results of the class action litigation.

The law case approach has limitations. While the parents' organizations were at first hesitant to move into the courts, they are now hesitant to move away from them. It must be remembered that courts are supposed to be forums of last resort, and the parents now seem to be attempting to use them as one of first resort. In my opinion, courts will react when issues are properly presented to them. We are not clearly presenting to the courts such issues as what is treatment, and certainly cannot expect a proper response by the courts until we do.

We in the legal advocacy field should be interested at this time in defining our terms and moving ahead from this basis in sound definitions. We should certainly be interested in the secondary and tertiary areas of establishing clearly what a due process hearing is regarding an educational setting for a child and what the proper prescription is for said child, the composition of those who hear due process cases in the educational setting, and proper education for all litigants in such sessions.

The challenges are many, but until we in the field struggle with the perimeters of what is good for our constituency, we will not get the courts to effectively address these issues, nor should they. This is not to say the courts are shy, since they will deal in areas which are well defined and need redress. The courts have always promptly addressed the issues of abused children, and certainly the developmentally disabled would have the same kind of success. I recall a Florida case where the father had made his whole life's work attempting to have his daughter become an olympic swimmer. At the age of eleven she died by breaking her neck after a dive from a board into a pool. He was prosecuted criminally. During the 1930s when Hollywood decided to center publicity around a small group of child stars, it did not take the parents too long to find out their children were much wealthier than they were,

and it did not take the courts too long to put some brakes on the parents and encourage legislation, which was special to that time, preserving for the children whose labors earned the funds most of the funds until they reached adulthood. Later, legislation addressed the battered child and the battered child syndrome.

As we move into the field of what is proper treatment, we might concern ourselves with the word treatment to see if it really covers what we are talking about. Aren't we talking about the preservation of the constitutional rights guaranteed in this our 200th birthday, namely, the right to life, liberty and the pursuit of happiness? And does not that pursuit of happiness mean a delivery of a quality of life which was heretofore unheard of in an institutional setting?

IV. Definitional Goals

Those who speak for the retarded should be ready to stay in the legal advocacy field, but have to examine first whose rights they are protecting, and who makes the moves to so protect. We should struggle to define what the quality of life should be for any given citizen, institutionalized or in the community. Doing so will require reexamining our attitudes, namely, the "not in my block" syndrome. We must determine who are we moving for. Are we with our fixed attitudes attempting to hold onto lifestyles for our children and grandchildren that have been meaningful for us but have long since lost their relevance? Cannot we remember how our normal children rebelled by the middle of their teens against some of the attitudes of their parents and grandparents? Yet we expect to preserve for our retarded citizenry or those who are developmentally disabled habits and lifestyles which may not be in vogue a generation from now. Are we truly moving for our children and grandchildren, or for ourselves?

The who that moves is also important. Are we as parents too close and too emotionally involved to make a proper legalistic approach or advocate approach for our constituency? If so, whom should we turn this trust over to? Certainly, we cannot turn it over to those who run programs, such as administrators of state schools and hospitals or of county or state programs. If we have learned nothing else we should have learned that lesson. To be an advocate for and to speak for the rights of our constituency certainly would rule out those who argue for the funding necessary to run the institutions and community programs, and worry about their own salaries, their own pension plans, and their own struggle to the top of the professional heap. The two concepts--advocating for persons and controlling their lives--are mutually exclusive.

We are probably searching for a person whose job has not been completely described at this time. However, we should not allow the mistakes of the past to continue into the future by giving up the effort of struggling with these problems of definitions and guidelines in favor of allowing the institutional head or program head to become the guardian or advocate by default.

I leave to the next speaker the implementation of legal advocacy.

A National System of Legal Advocacy for Disabled Persons

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Part I. Introduction

I am delighted to have the opportunity to discuss the implementation of Section 113 of the new Developmental Disabilities Act of 1975, which requires that each state establish an advocacy system. First, I would like to suggest some definitions and explanations about terminology that I will be using in my paper. Secondly, I would like to suggest some of the essential components of the legal advocacy system and thirdly, I would like to suggest some specific criteria that each state must consider before it implements an advocacy system. But before I do any of those things, I would like to explain to you my background so that you can better understand the context in which I set forth the information in my paper.

I have been a practicing attorney in the field of the legal rights of handicapped citizens for approximately five years. I established the law office at the National Center for Law and the Handicapped in 1972. I was with the Center for several years and did some major litigation in the field of the legal rights of the mentally disabled person. However, my activities at the Center included teaching a law course at the University of Notre Dame entitled, "Law and the Handicapped"; I supervised a legal education program and did a great deal of public speaking and public education on the rights of the handicapped citizen. I am currently the Director of the Regional Developmental Disabilities Law Project, housed at the University of Maryland Law School. The Regional DD Clinic essentially does three things: first of all, on the state level, we give legal advice and legal education to the Maryland Develop-

mental Disabilities Council. Secondly, we run a law clinic at the Maryland Law School, where we train law students in this new, developing field; and we work with the Bar Association to sensitize them to some of these legal issues. Thirdly, we have a responsibility on the regional level to establish a legal advocacy unit in each of our surrounding states, which include Delaware, Pennsylvania, District of Columbia, Virginia and West Virginia. The concept behind this DD Project is a new one, and it is somewhat experimental. I find it to be exceptionally exciting, especially because I had the experience on the national level of working on the legal rights of handicapped persons. I realized quickly that what was really needed were some advocacy resources at the grassroots level and that there was clearly a limitation on what could be done from the national level. Therefore, I saw the regional DD Clinic as a marvelous way to implement and set up, on the grassroots level, statewide legal programs that were designed to advocate the rights of the developmentally disabled person.

The concept behind the DD Project was that most of the work that had been done in the advocacy area was litigation-oriented. Our charge was to take these good court decisions and the good legislation and implement the declaration of rights so that the everyday lives of handicapped individuals were actually changed. In order to accomplish this end, our activities are concentrated on the administrative and the legislative plane. Let me give you an example of what I mean. In Maryland we had a right to equal educational opportunity lawsuit that was successful, Maryland Association for Retarded Children v. State of Maryland, Equity No. 100/182/77676 (Circuit Ct. Baltimore Cty., Md., May 3, 1974). Even though there was a favorable opinion from a court and Maryland has fairly good legislation on the books, there are still children in Maryland who are either out of school or in inappropriate programs.

Therefore, we at the Clinic have undertaken several methods to actually implement the decision and the legislation. For instance, we have done some training of due process hearing examiners within the educational system. We have represented parents at due process hearings in order to better understand what problems the parents were facing. We have trained other advocates, members of various consumer groups like the State Association for Retarded Citizens or the various branches of the State Society for the Learning Disabled, so that they can help parents to obtain appropriate educational programs for their children. We have also helped draft some remedial legislation and some regulations to implement this right to education, and we have worked with the State Department of Education and local school districts to solve their problems as well.

In addition to our in-state activities, in light of the passage of Section 113, which requires the establishment of an advocacy system in each state throughout the country, our project has developed some materials which might be helpful to those persons in the various states who have the responsibility for setting up these units. We would certainly be most happy to work with anyone to acquaint them with the experience that we have had in Maryland and our regional projects.

Part II. Definitions and Problems

Now, let me turn to the key question, what is legal advocacy? Much has been written and said about terminology relating to the word advocacy. The basic question which needs to be addressed is, for what are we advocating? We are advocating for the legal and human rights of all developmentally disabled persons. All persons should be working together to accomplish this same goal. The citizen advocate, the lay advocate, the professional advocate, including

the lawyers, should be working to better the lives of handicapped persons. We are all trying to advocate and implement the legal and human rights of each one of the individual persons who happens to be developmentally disabled. It should not be, nor is it, legal advocacy versus citizen advocacy. In fact, since we are all advocating for that same thing, the legal and human rights of the developmentally disabled population, it is correct to view citizen advocates as part of a legal advocacy system just as lawyers, educators, social workers, medical doctors are all part of that same system.

One of the real difficulties that people must overcome in order to have this overview of advocacy is the underlying fear of lawyers and what they do. Often, the average person is not comfortable, because he views lawyers as primarily litigators--Perry Mason types. However, there are two points that should be made. First of all, it was through litigation and litigation alone that society formally recognized that the developmentally disabled person has the same legal and human rights as everyone else. Many of us know the history of the civil rights movement of the handicapped citizenry. We know the first major lawsuit was the Pennsylvania Association for Retarded Children v. Commonwealth of Pennsylvania, 334 F. Supp. 1257 (E.D. Pa. 1971) and 343 F. Supp. 279 (E.D. Pa. 1972). Since that time, we have had approximately 150 successful cases throughout every state and jurisdiction in the land which declare that handicapped persons have the same legal and human rights as everyone else. However, it should be clearly noted that litigation should be used as a last resort where other methods of achieving recognition of the rights of particular individual rights have failed. I say this because I have had experience as a litigator in this field, and it is clear to me that lawsuits don't solve all the problems. There are significant costs involved with lawsuits, not only financial costs but also the costs of social change. Oftentimes, we see that

in the process of changing society and the way that society views a particular class of persons, individuals get lost and get hurt in the process of change. An example of this problem is the move by various states to deinstitutionalize persons in institutions when no provisions have been made for appropriate community programs. Also, having a declaration of rights is not the same thing as having an implementation of those actual rights; implementation changes on the daily level the handicapped person's ability to do what he or she wants to do.

It is the actual implementation of these rights which I see the advocacy system trying to achieve. This means that there must be all different types of efforts by a variety of persons that include varying approaches depending upon the needs of the particular states. Lawyers will function in this advocacy system primarily as facilitators and catalysts to aid this entire population to see that they actually have implementation of their rights.

What kinds of groups are we going to affect by our advocacy? It is important to aim our impact at as large a group as possible. The system should advocate not only on behalf of particular individuals but also on behalf of groups. It should advocate on behalf of all age groups and not restrict its activities to children or to adults. The system should also advocate on behalf of those persons who are in community situations as well as in institutional settings.

With the enactment of Section 113, a fantastic opportunity exists to implement major social change. There are, however, probably some difficulties and problems that we are going to have to face in implementing Section 113, but I am extremely enthusiastic that we can do it, and we can do a good job. Not only can the advocacy system influence the implementation of rights for this population, but it can also impact on the services provided and it can have

significant constructive influences on the lives of developmentally disabled citizens.

Before I discuss the specific components of a legal advocacy system, let me mention the State Planning Council on Developmental Disabilities. It is very important that the advocacy system have a relationship or a role that works with the Council. It is important that this happen for several reasons. The Council is required by law to be an advocate on behalf of the handicapped or disabled person. The advocacy system has a responsibility to work with the Council to provide legal education and legal advice and to act as a resource to the Council so that it can better do its job as coordinator of state services and as advocate. On the other hand, as the advocacy system develops, the Council can be very, very helpful to the advocacy system. When the advocacy system is attempting to get new legislation passed that will better the lives of handicapped persons or even getting legislation that is on the books implemented, the Council through its contact with state agencies, private agencies and consumer groups can provide a solid base of support. The Council can be very helpful in persuading legislators and the general public that the changes are needed. I would strongly underline that there should be a good relationship with the Council in the state and that this relationship can be mutually beneficial not only to the Council but also to the advocacy system.

Part III. General Requirements for a State Advocacy System

Now let's turn our attention to what are the necessary components of an advocacy system. The intention behind the legislation, especially Section 113, was to provide as much flexibility to the states as possible. It is important that each state should be able to analyze its needs and design a system or a program that is based on those needs. There are some general

criteria, however, and some suggestions that can be very helpful to each state in capitalizing on the experience of those who have previously set up advocacy systems. I would like to review some of those components or general criteria that each state should consider in setting up its system.

1. The first requirement should be that the system should be a statewide system. The statewide advocacy system is important because you need to address all the problems of the state, not just those in urban areas but in the rural areas as well. I am very much aware of the fact that the federal government is providing somewhat limited resources to do this. Much can be done with the money that has been appropriated, and I think that it is important to require that the focus of the advocacy system be statewide and not just regional or local projects.

2. The system must be independent. The act specifically requires that the system be independent of any state agency which provides treatment, services or habilitations to persons with developmental disabilities. I would include in this independence requirement that the system must also be independent of the agency which is the legal representative of those state service providers, such as the Attorney General's office. I would suggest in addition that the system should also be independent of any private service provider. The reason for this is very simple. There is an inherent conflict of interest when an agency is providing services to the developmentally disabled population and at the same time attempting to advocate for the rights of this same group.

The system should also be independent of the agency to whom the service provider is administratively responsible or who represents the legal interests of the service-providing agency. I noted that this would clearly include the office of the Attorney General. However, it is very important to underline that the advocacy system should be a resource to the Attorney General's office

and wherever possible, the two groups should work cooperatively. Let me give you an example which might highlight the benefit which can be gained from working with the Attorney General's office. Oftentimes, there is a great deal of activity and many questions relating to the field of the legal rights of handicapped citizens. The Attorney General's office is responsible for providing this information to the state; however, it is realistic to say that in almost every state, the Attorney General's office is seriously undermanned, especially in the departments that deal with the developmentally disabled. In our own situation, our law clinic advocacy unit has been able to provide to the Attorney General's office a great deal of research and assistance which the Attorney General's office has then developed into Attorney General's opinions and/or positions on the rights of handicapped citizens. This method can accomplish some very significant goals without the use of undue pressure and without the force of using litigation. Also, goals can be achieved without a significant expenditure of time and money. Therefore, I suggest strongly that although the advocacy unit should not be placed within the Attorney General's office, the system should clearly operate as a resource to the State Attorney General's office.

3. The system should engage in all types of advocacy, which would include such activities as negotiations, counseling, individual representation, and legislative action--drafting of legislation, preparing expert testimony for various individuals testifying before the legislature, drafting rules and regulations to implement the laws, etc. Advocacy activities would also include administrative actions and participation in other decision-making forums regarding the rights of handicapped persons.

Advocacy functions do not have to be done solely by lawyers; and, although I have defined this as a legal advocacy system, I am using the broad

definition of legal advocacy, which includes all types of advocacy. The different types of advocacy activities--negotiating, counseling, legislative activities, and administrative activities--can be done by persons other than lawyers; that is, by citizen advocates and lay advocates as well as professional advocates.

4. The system should pursue remedies wherever practicable which do not necessitate legal action; however, the Act requires that the system has the authority to pursue all legal, administrative, and other appropriate remedies, including litigation, to secure the rights of persons with developmental disabilities. Wherever possible, the approach should be cooperative and helpful to all individuals, including those from state and private agencies. There will probably be times in the various states, depending on the development of the process of societal recognition of the legal and human rights of the disabled person, that litigation may be required. Therefore, the DD Act has specifically suggested that there must be the capability to pursue this remedy, if it is needed.

Again, we reiterate that it is in the spirit of the last resort that some would employ the tool of litigation. The possibility of its use, in most instances, will be enough to help the system implement the changes that it is working toward.

5. The system should cooperate and collaborate with the State Planning Council on Developmental Disabilities. This means that the system will be available for consultation concerning legislation, administrative rules affecting legal and human rights of persons with developmental disabilities, and court developments. As I noted before, this relationship should be open-ended, and the purpose should be to provide education and direct services to the Council and to help the Council better function in its role as advocate. This rela-

tionship can be mutually beneficial not only to the Council but to the advocacy system because of the support that the Council can provide to the system.

6. The system should train and educate lawyers, other professionals, para-professionals, and consumers in the state on the legal and human rights of persons with developmental disabilities. Because of the limited resources that have been dedicated to establishing the advocacy system, it is very important that we have maximum impact; one way that this can be accomplished is to require the system to have a training component so that the system can accomplish a multiplication effect. It should train new lawyers, professionals, and para-professionals, to help expand the impact of the system. At the end of the year or two years, through public and professional education endeavors, we will have expanded the efforts and the influence of the system. This will be true even though most states will have monies only to pay a limited number of full-time staff. I noted earlier that one of the examples of this multiplication effect is that we can use the educational and training component of the system to develop other individuals to provide advocacy services. Thus, there will be many people throughout the state who are familiar with representing and advocating the rights of the developmentally disabled citizen.

In Maryland, we have set up our training center within the law school at the University of Maryland. We have a multi-disciplinary staff, and we train social workers and other professionals in addition to law students. This type of component is something that should seriously be considered within each of the states as a method by which the multiplication of efforts can be very effectively accomplished. Approaches should be made to university law schools to persuade them to the idea of teaching a course and/or running a clinical education program for law students. This program may well be interdisciplinary and include social work students, education students, and other graduate students.

7. The system should coordinate its advocacy activities with other legal resources in the state including the judiciary, the state bar association, the law schools, the state office of the public defender, the state office of the attorney general, public interest law firms, legal counsel to consumer groups, and other developmental disabilities legal advocacy projects. Not only should the system coordinate with the legal resources, but it should clearly coordinate its efforts with other advocacy programs that serve the developmentally disabled population.

8. In many senses, the prime role of the advocacy system is to coordinate all the efforts of the various agencies existing in the state and to sensitize them to the legal and human rights of the DD population. In addition to coordinating with legal resources and other advocacy programs, the system should coordinate its activities with the existing university-affiliated facilities or satellite centers within the state. At these university-affiliated facilities, there is a group of experts who are familiar with many of the problems and strengths of the developmentally disabled individual. The experts have come in very handy for our project in Maryland, and I am sure that they can be an excellent resource to the systems as they are established in other states. Therefore, the system should coordinate its activities with existing university-affiliated facilities and satellite centers.

9. Finally, the ninth criterion is probably the most controversial. Several people have already said to me when I mentioned this suggestion to them, that obviously I said it because I am a lawyer!! This suggestion is based on my own personal experience. I feel that it is important for a variety of reasons for the system to have a full-time staff that would be supervised by an attorney. I mentioned earlier that the purpose of the system is to advocate for the legal and human rights of the developmentally disabled

population. I think that lawyers are trained to recognize the legal and human issues that are involved and therefore are better able to advise and assist other professionals in implementing the actualization of these rights. I am sure there will be many states which will not follow this model and which will not have an attorney supervise the program. However, let me strongly suggest that such a system should rely on good legal counsel who will provide assistance in recognizing these rights and will help the advocacy system to be more effective. Lawyers can be cooperative and helpful to all the interested parties and need not be adversaries.

Part IV. Specific Criteria for Each State

In addition to the general criteria that a state should consider in establishing an advocacy system, there are some specific areas of concern that a state should analyze.

1. There should first of all be a thorough analysis and assessment of the status of the law in the state. This should include what the laws are and how they are implemented, and whether or not there are any court decisions, etc. The type of advocacy activities will depend on the needs of the state as determined by this survey.

2. There should also be an investigation of what components of an advocacy system are already functioning in the state. This would include a survey of what the state and private agencies are doing in this area, what the legal aid office is doing, etc.

3. The governors have by now been notified by Mr. Stan Thomas that they are to receive money to implement Title II, Section 113, of the Developmental Disabilities Act. The governor has the power to designate who will implement the system. This officially designated agency will have a strong influence on the character of the system. This designated agency should be a friend to

the developmentally disabled population and knowledgeable about the problems that disabled persons face.

4. The system should focus on both institutional and community problems. It would be a mistake to focus only on the institution, as this would not facilitate as much long-term change. What problems the advocacy system pursues will clearly affect the development of services, especially in the area of deinstitutionalization and community services.

Part V. Summary

Section 113 of the Developmental Disabilities Act calling for the establishment of an advocacy in each state is an exciting opportunity to implement not only rights of disabled persons but better programs and services for developmentally disabled individuals. It is important that each state analyze its needs and plan carefully for its advocacy system. However, there are many good programs throughout the country whose experiences both good and bad should be capitalized on in order to implement Section 113 as quickly and as effectively as possible in each state. The Regional Developmental Disabilities Project at the University of Maryland Law School stands ready to provide whatever information and assistance it can to help implement the wonderful challenge of Section 113 so that our disabled citizens can live happier, more fulfilling lives.

The Work of the National Center for
Law and the Handicapped

Kathleen Ursein
Educational Director
National Center for Law and the Handicapped

Speaking at an afternoon session on any program enlarges the responsibility of the presenter. The first speakers give information and suggest ideas which must be taken into consideration by subsequent presentors if the whole program is to make sense and to be useful to the audience. I mentioned this because although many of you may have come here thinking or feeling yourselves to be first "speakers" in developing advocacy programs under Section 113 of the DD Act, there are others who have "spoken" before: programs for legal advocacy for the developmentally disabled have been established and are operating successfully in many parts of the country. In fact, representatives of many of these programs are in the audience today and some will be speakers at later sessions. Therefore, we have not only the opportunity, but the obligation, to learn from the experiences of others, to coordinate our efforts so that we too can make advocacy meaningful for our "audience"--developmentally disabled citizens.

In his presentation this morning, Mr. Dennis Haggerty noted that advocates must be vigilant if the goal of equal citizenship is to be obtained. Too often, however, our misperceptions of the work that attorneys do cause us to feel that they are not vigilant but "vigilantes" of sorts. The attorney, the legal advocate, is seen as operating independently, not consulting established systems people, and having as his only goal the bringing of a lawsuit. In my own experience in working with the staff at the National Center for Law and the Handicapped, I've come to appreciate the variety of ways in which attorneys can work and do work in solving legal problems. All problems do not necessarily have legal solutions, however, and it is here that the attorney utilizes other resources to achieve change. The organization of the National Center for Law

and the Handicapped and its objectives help to illustrate the variety of ways in which a legal advocacy agency can work.

Established in July of 1972, the National Center for Law and the Handicapped has been jointly funded by the Bureau of Education, and as a project of national significance by the Division of Developmental Disabilities, Office of Human Development of the United States Department of Health, Education, and Welfare. The goal of the Center is to ensure or establish equal protection under the law for all handicapped individuals. The processes which we use in seeking to achieve these goals include the provision of legal assistance, legal and social science research activities, and programs of public education and professional awareness. The legal assistance which the Center provides may be through direct intervention in selected cases, or indirectly through consultation with attorneys, organizations and individuals considering or involved in litigation. Furthermore, the staff also provides assistance to attorneys and legislators working in areas involving disabled persons through consultation, legal research and the drafting of model pleadings and briefs.

The research activities of NCLH are multi-disciplinary in scope and are designed to facilitate legal reform as well as to answer specific questions on the application of existing laws to the handicapped.

In the area of public education and professional awareness, the Center conducts a wide range of activities designed to publicize and disseminate information about the legal rights of handicapped people and the progress being made in implementing those rights. Members of the NCLH staff have been active participants and presentors in state and national conferences, seminars, workshops and meetings sponsored by other organizations, as well as organizers and conductors of such activities. In November of 1975, the Center inaugurated publication of a bimonthly magazine, Amicus, designed to monitor and report devel-

opments in the law as they relate to the rights of the disabled, specifically significant court cases and legislation. Amicus is disseminated to both the legal and lay public.

Recognizing the need to train advocates in this newly emerging field of law and the handicapped, the Center has, since its inception, maintained an active clinical intern program with the University of Notre Dame/Notre Dame Law School. We have, however, included in our intern program individuals from other disciplines, such as psychology, sociology, business administration and architecture. The Center is concerned about the establishment and development of similar programs at other law schools, as well as the formation of legal advocacy programs in various communities.

If we are to be successful in securing equal rights and opportunities for handicapped individuals, however, other programs on state and local levels must be developed. The Center has found from its own experience that as awareness increases, so do requests for assistance. The need to provide disabled citizens and their representatives with the unique tools that only the legal advocate has is an exciting and positive step forward in our continuing move towards normalization for the disabled population. Before I joined the staff at the Center, I worked in state operated facilities for the retarded, with parent organizations, state government, and in other professional capacities. I was continually impressed and distressed by the need I saw to give some credibility, some unassailable basis, to what I and other professionals, parents and handicapped people themselves saw as the basic right to equal citizenship "with each other person." The entrance of the legal advocate into this field has provided that base. Legal advocates are only a part of the system necessary to achieve rights and secure programs and services, but an essential part of that system.

In the brief overview that I gave of our program, it is obvious that legal advocacy groups, like the National Center for Law and the Handicapped or any of the others in existence, can do and are doing much more than being involved only in direct litigation. The question which you are all asking yourselves now must be "What can the National Center do for you in terms of helping you to implement Section 113 of the new Developmental Disabilities Law?" It's a fact that the legislation has been signed and that it does require that programs of advocacy with a legal resource be developed in each state if the state is to receive other formula grant monies. Unfortunately, the amount appropriated directly to the development of such programs is small. However, this should not be viewed as a reason or excuse to limit your goals or the way in which you conceive your program. Other sources of funding may be available and should be considered.

To go back to a point I made earlier, there's also no need to feel that you must start from scratch in developing these programs. Other programs are in existence, some perhaps within your own state, which, in addition to being used as models, can also be used as the basis for a program to satisfy the legislative mandate.

But what exactly is the National Center for Law and the Handicapped doing and what will we be doing in the future to assist you in your planning? Approximately one year ago, the Center began, for its own purposes of referral, a project to identify other programs around the country which were involved in legal advocacy. We have surveyed these programs and are continuing to add to the list, in an attempt to learn not only who and where they are, but also to determine what clientele they serve, what their funding sources are like, and how they are basically organized. As an added dimension to this survey, we have also identified a number of citizen advocacy programs in the country.

Currently, this information is only available in list form, but we plan to incorporate it into a booklet which will be available for dissemination. As an additional part of this booklet, the Center plans to identify special categories of programs in order to help individuals appreciate the variety of ways legal advocacy programs can be established. Another dimension of the booklet will be a description of possible additional funding sources for programs. Again, these sources are being identified and will be described more fully, but as an indication of possibilities I would like to list the following:

1. Law Enforcement Assistant Administration Grants;
2. Private foundations;
3. Title XX monies under the Social Security Act;
4. Potential assistance from local Bar Associations, and the ABA Commission on the Mentally Disabled, which is currently conducting a pilot program on legal advocacy in Pennsylvania;
5. Monies available under the Formula Grant Program of the Developmental Disabilities Act;
6. Other sources of funding available through HEW, but potentially in other government agencies as well;
7. Revenue sharing funds; and
8. Pre-paid legal insurance.

Although there is no assurance that funds from each of these sources will be available to every program, the potential for additional funding does exist.

As a final consideration in the booklet, the Center plans to identify and explore those other established programs, such as the Legal Services Corporation, which may assist in the development of legal advocacy programs for the developmentally disabled, and suggest ways in which cooperative efforts with these programs may be useful in the establishment of advocacy for the develop-

mentally disabled.

In considering a system of advocacy for the developmentally disabled, the legal element, the legal resource is crucial. I recently attended a conference on developmental disabilities at which one of the speakers was discussing the origin of the development of attitudes towards handicapped people. He was describing the phenomenon called "breaking through" -- the time at which a non-handicapped person can approach and deal with a person who is disabled, who is "different" than he, without reacting only to that difference. "The law" can and does do this with the developmentally disabled and all other handicapped people. Working through the legal process, we have the greatest opportunity to establish the principles of equality that we want for all citizens in our country.

Developmental Disability Advocacy Projects

La Verdia T. Roach
Program Specialist
Developmental Disabilities Office
Office of Human Development

I am pleased to be here with you for this National Conference on Advocacy and Protective Services as related to PL 94-103, and to share with you some of my thoughts regarding several advocacy projects which are jointly supported by the Developmental Disabilities Office, the Bureau of Education for the Handicapped, and the National Institute of Mental Health. The new legislation has created many new possibilities which I find tremendously exciting, particularly in the area of advocacy. For almost half a decade now, the DDO has been both programmatically and fiscally involved in advocacy efforts, although prior to the enactment of PL 94-103 no formal mandate had explicitly dictated such involvement.

For the next several minutes, I will present to you what might most appropriately be called an "overview" of the DDO advocacy projects. I was interested to know that several participants on the program are intimately involved in at least three of these projects and are prepared to present a more detailed description of their particular efforts in the area of advocacy with you. One of these participants, Kathy Ursein, has immediately preceded me on the agenda. Two others, Ms. Marie Moore (of UCP) and Mr. Max Addison (of NARC) will speak with you tomorrow morning.

Before getting into specific descriptions of the individual advocacy projects, I'd like to tell you a little bit about their history and the kind of program interface and tripartite activities from which these jointly funded projects evolved. It was in the spring of 1971 that our office first learned that the Bureau of Education for the Handicapped and the National Institute of Mental Health had combined resources (fiscal and personnel) to support six

child advocacy projects. The close programmatic similarities between the mission and objectives of these two federal agencies and those of the DDO (at that time the Division of Developmental Disabilities within the organizational structure of the Rehabilitation Services Administration in the Social and Rehabilitation Services) caused the interest of our staff to be considerably heightened. Our interest was communicated to the appropriate persons affiliated with the Bureau of Education for the Handicapped and the National Institute of Mental Health Advocacy Efforts and we were consequently invited to attend their regularly scheduled meetings.

It has been my good fortune since the spring of 1972 to represent the DDO and the interests of persons who are developmentally disabled on the DDO-BEH-NIMH Subcommittee on Child Advocacy. Noteworthy is the fact that during the first year of the DDO's affiliation with the joint advocacy efforts, our support was purely programmatic. Upon request, we reviewed project applications, assisted in the drafting of policies and guidelines, and participated in on-site visit teams. Also noteworthy is the fact that, at that time, the advocacy efforts were basically child-oriented and expressed no particular objectives or strategies designed to advocate for the rights of persons who were handicapped or adults. Much of the emphasis on child advocacy, at the Federal level at least, was the direct result of four significant forces or antecedents:

1. The report of the Joint Commission on Mental Health of Children published in 1969, which recommended that the "Child Advocacy" concept be supported by Federal programs that establish an advocacy system at every level of society;
2. the establishment of the Office of Child Development in 1969;
3. the report of the White House Conference on Children in 1970, which stated the "urgent need for a national center for child advocacy within the Federal establishment"; and
4. the reorganization of the Office of Child Development, in 1971, with its provision for a national center of child advocacy, designated to

play a major role in the development and coordination of the federal advocacy effort.

It was in 1973 that the DDO first contributed fiscal resources to the joint advocacy efforts. It was also in this year that the three agencies emphasized the federal goal to assure the participation of a reasonable proportion of handicapped children in the program, and encouraged the inclusion of a handicap component to focus specifically on advocating for the developmentally disabled.

In addition to program support, each agency provides personnel and operating expenses to maintain monitoring, evaluation, and review of the projects. Each project is assigned a program officer and a project monitor. This and other pertinent information is included in a formal memo of agreement which is signed annually by the head of each component of the tripartite.

I'd like to pause here to express an idea which, during the last 3½ years, has become increasingly important to the advocacy movement. That idea is this: the success of any program (be it federal, state or local) which focuses on advocacy is largely determined by the clarity of the definition of the term, and by the extent to which it is understood and accepted by persons involved with, and affected by, that program. Very early in the history of our joint efforts, we realized the importance of agreeing on the definition of advocacy, understanding that, as a functionally definable term and as a concept, it is viewed in distinctively different ways. It can be viewed as:

A consumer-controlled outreach system.

A service program or approach directed towards changing systems and designed to improve life conditions for individuals by assuring that service delivery systems and institutions bearing most on their lives work for them rather than against them.

Providing a reaching out or counseling service, serving as mediator or gadfly between disabled persons and a service system that is un-receptive; or studying needs of the disabled or disadvantaged in what is called "health catchment areas" as a prelude to initiating or supporting new programs.

Political lobbying on behalf of children's services and needs or planning and coordinating services for children.

Intervention on behalf of the disabled in relation to those services and institutions that impinge on their lives.

The concept of advocacy adopted and popularized by the DDO, BEH, and NIMH is that it is "a system which intends to initially assess the needs of a particular target group; identify and assess the resources available to meet those needs; identify gaps between needs and resources; and determine essential strategies which will facilitate the satisfaction of those needs."

The basic purpose of all the advocacy projects supported by the DDO-BEH-NIMH is to demonstrate functioning systems of advocacy, evaluate their effectiveness, document them for purposes of replicability, and disseminate promising practices. A secondary aim is to develop procedures for making existing advocacy systems more efficacious in the obtaining of local, state, or national goals and objectives.

Let me share with you the federal program goals pertaining to the advocacy projects. Each project is expected to assure that its plans and activities assist in the accomplishment of these goals.

1. To demonstrate and evaluate disparate models of child advocacy.
 - a. Evaluate according to local objectives
 - b. Disparate in terms of having different
 1. Sponsoring agencies
 2. Types of targeted neighborhood
 3. Systems of child advocacy strategies and outputs
 4. Funding continuation plans
2. To continue child advocacy systems, if successful, after federal funding ends.
3. To package and disseminate widely the results of successful child advocacy systems.
4. To identify components of child advocacy which are exportable, singly or in combinations, to agencies wishing to establish other child advocacy models.

5. To identify aspects of advocacy programming which relate to advocacy legislation; i.e., identify what practices most efficiently affect legislative components
6. To discover unique child advocacy systems which need to be demonstrated and evaluated.
7. To develop a repertoire of needs-assessment techniques and instruments which are exportable.

In sum, these pilot projects are intended to strengthen resources and competence for facilitating optimal development of the target populations they serve.

The ultimate goal is to improve the total resources and the delivery of services for the physical, emotional, social, and educational development of all disabled persons or a class of disabled persons within a target area, with special emphasis on improving the environmental systems for individuals presenting developmental problems.

Another program goal is to effect and maintain a viable interagency collaboration with other agencies concerned with advocacy, particularly the National Institute of Mental Health and the Bureau of Education for the Handicapped.

Quite early in the life of the advocacy program, several program objectives were identified.

The first was to test a minimum of five major child advocacy model types (community, school, state, national organization, and legal) in at least the following target populations:

- | | |
|-----------------|-----------------------|
| (a) Ethnic | (e) Infant pre-school |
| (b) Innercity | (f) Family |
| (c) Rural | (g) Institutional |
| (d) Handicapped | |

The second objective was to monitor the activities of the child advocacy projects by site visits and evaluation of progress reports.

The third was to provide technical assistance, as requested or needed, to the projects.

The fourth programmatic objective was to contract for a third party evaluation of all child advocacy projects; and

The fifth was to provide for strategies to package and disseminate appropriate products at the termination of the program.

With this basic understanding of the kinds of program interface and formal agreements that the DDO has with the BEH and the NIMH; with a clear perception of the definition of advocacy as proposed by this tripartite; and with an appreciation of the federal program goals and objectives toward which each project focuses its efforts, we can now look at the model types which comprise this advocacy program.

The operational life of the child advocacy projects can be viewed as being composed of five phases. Some of these phases generally overlap at any given time for any particular project. The phases are: (a) development/planning, (b) demonstration/implementation, (c) evaluation, (d) packaging, and (e) dissemination. The length of time during which a project operates in any of these phases varies. It is expected, however, that all phases will be completed within the maximum funded five-year project period. It is also possible that, because of its performance, a particular project may be requested to concentrate intensively in any phase(s) at certain points in its life.

The six initial child advocacy projects have completed their fifth and final year. It was agreed during their first year that they would be funded no longer than five years.

There are currently being operated four advocacy projects, each of which has reached the packaging and dissemination phases.

All of the presently funded projects can be categorized into three basic model types: national, state, and community. Of the six initial projects, five were community-based models and one was a state model. The community-based models

included: the Philadelphia Urban League, Dede Wallace Mental Health Center, Prince George's Board of Education, the Mexican-American Neighborhood Civic Organization, and Central City Community Mental Health Center. The only state model among the initially-funded advocacy efforts was the George Peabody College for Teachers project.

Grantees which have already implemented community based-advocacy efforts include:

1. The Mexican-American Neighborhood Civic Organization (MANCO) in San Antonio, Texas
2. Central City Community Mental Health Center in Los Angeles, California
3. The Philadelphia Urban League in Philadelphia, Pennsylvania, and
4. Prince George's County Board of Education in Brandywine, Maryland

The only grantee to have completed implementation of a state advocacy model is George Peabody College for Teachers in Nashville, Tennessee.

Now, to tell you about the unique features of these disparate models of advocacy. The first model which will be described was a community-based model conceptualized and implemented by The Mexican-American Neighborhood Civic Organization (MANCO). The project title was "San Antonio Child Advocacy Project--Child Advocacy through Barrio Advocacy."

This project, unique in a Mexican-American community, was designed to bridge the gap between an educational system which had been irrelevant to Chicano educational needs and a family which had been deprived of meaningful participation in American society. The primary project goal was to act in behalf of the child whose family lacked resources to confront educational institutions.

MANCO, in its work with the community, developed a concept that the barrio's problems, particularly in reference to the neglected child, are only symptomatic of the more magnified problem. Consequently, it was believed that MANCO must treat the barrio as an entity before it could effectively help to advocate for

its children. This, hopefully, would help the child and his family to deal with institutions having responsibility for meeting their needs.

Because of the many education problems resulting from an ever increasing number of neglected children, what came to be known as a "scatter-gun" approach was used. This means that the child, the educational system that affected him, and the parent were dealt with simultaneously.

The San Antonio community child-based model concentrated on the educational system and the child. This strategy was believed to be important because programs that would deal with other problems in the community already existed. The child advocacy program complemented these programs in two ways:

1. It presented a united community-based effort where resources were coordinated in order to help a neglected community do something about its own needs.
2. The project directed its activities toward the child and the educational system, which was just one facet of the total problem of a barrio family.

The title of the community-based model conceptualized and implemented by the Central City Community Mental Health Center in Los Angeles was "Institute for Child Advocacy."

The basic purpose of this project was to identify the major problem areas pertaining to the development of children and to devise mechanisms by which to alleviate them.

The conceptual model involved the establishment of community task forces comprised of representatives from various child-centered agencies and representatives from community parent groups which had the function of identifying problems and initiating plans to alleviate them.

The establishment of an advisory board was an essential element of this project. Made up of high-level representatives from various child-centered organizations and the community, the board provided direction and expert task

forces. The director and a number of community workers served as intermediaries between organizations and community residents as well as between the professionals and non-professionals.

An ultimate goal of this community-oriented project was to establish permanent communication networks between all child-centered organizations and community residents. This network permitted persons close to the community to obtain needed help in their attempt to facilitate the development of children from infancy through late adolescence.

The Philadelphia Urban League titled its community-based project appropriately, "Philadelphia Urban League Child Advocacy Project."

It was the primary purpose of the child advocacy component in the urban league to help families maximize their strengths and work toward the removal of obstacles (be they emotional, social, or economic) in getting services for themselves and their children. It was toward this end that services were extended to families fo children in the program. The objectives of the model related to four basic areas.

1. Outreach--which included enrolling children in the program, keeping the community informed about available services, and playing an advocate role for families and children in getting complete services.
2. Information and referral--which included identifying existing community resources, informing families of these resources, and helping families obtain and effectively use such resources and services to their advantage.
3. Follow-up--which included contacting agencies to determine whether services were provided to families referred, and contacting families referred to determine their opinion of the services received.
4. Direct services--which included providing supportive counseling to enable families to strengthen their sense of worth as parents, handling problems such as arranging for child care or transportation, and providing information and guidance to parents that will help them to more successfully carry out their parental responsibilities.

The main idea of this model was that instead of making the individual the client, the community became the client. Project staff was of the opinion that

much of what was done in the advocacy role made the urban league an adversary of government agencies as well as a catalyst to private agencies and institutions. Through the program activities designed as preventive intervention, the project worked to improve treatment and promote services to meet needs and problems of children. It also worked for changes in attitudes of parents toward the use of community services and, at the same time, it worked to improve their effectiveness as parents.

The title of the Prince George's County Board of Education's Community Based Advocacy Model was "A Neighborhood Advocacy System."

The purpose of the project was to actively involve local consumers, youth, and agencies in the identification of their unmet needs and in the pursuit of solutions to them.

This project was mainly research-oriented. The approach provided community advocates with a planning method for progressing from the specification of system mission objectives to the achievement of these objectives. This procedure processed various types of problems and was characterized by the following essential elements:

1. Clear description of problems.
2. Clear description of goals and objectives.
3. Synthesis of alternate strategies.
4. Clear description of constraints related to specific strategies.
5. Testing of strategies.
6. Establishment of measures of effectiveness.
7. Implementation of specific strategies.
8. Continuous evaluation and feedback.

Another advocacy model, implemented by George Peabody College for Teachers in Nashville, Tennessee, was titled "County Agents for Children." It called for four general advocates in four rural counties, with a role modeled after that of county agricultural agents. They sought to identify unfilled expressive and instrumental needs of children in the counties, and to procure the satisfaction

of those needs by increasing the knowledge and understanding of child development by parents, families, community clubs and organizations, and by defining three sets of systems which the project described as "the key integrating systems of society," "the in trouble systems" and "the institutional care endeavors." The county agents worked to promote understanding of the findings of research in education and child development. These efforts were augmented by developing individual citizen advocates for individual child proteges, where needed.

Still another community-based advocacy model, conceptualized and implemented by the Learning Institute of North Carolina, was titled "Child Advocacy System Project." It involved:

1. Creation of a neighborhood system of advocacy for children to improve specific adaptive skills and maximize their potential;
2. Support of the development of ecological integrity to the mutual benefit of the child and his home, school, and neighborhood environments; and
3. Development of a more adequate understanding of the child and his ecology and the operations necessary to support both.

Specific goals of this project were:

1. To create or facilitate in a community or neighborhood intervention which reduced the stigma and subsequent exclusion of children from their regular environment.
2. To secure maximal gains for the child if he must be moved from one environment to another.
3. To create environments in which "fits" between the child and his environment are negotiated with increased participation of children and their parents, to the end that the needs of environment and the individual child are better met.

This involved developing a set of procedures designed to:

1. Monitor child and environmental fits to maximize child potential and environmental integrity.
2. Increase community awareness of the need to create environmental alternatives for children.
3. Create alternate child-related environments.

4. Create alliances among families, schools, and other community segments which have a primary interest in maximizing child environments and child potential.
5. Catalyze the existing programs.
6. Increase sensitivity to the process of stigma and exclusion as it is often occurred in the community.
7. Develop re-entry mechanisms in order that children extruded can be returned successfully to community living arrangements.

The title of the community-based project implemented by the Dede Wallace Mental Health Center in Nashville, Tennessee was "Child Advocacy Demonstration Project: The Linking Pin Model." The purpose of this project was to develop a pilot neighborhood child advocacy system to service preschool and elementary school age children living in the geographical area forming the school zone of Caldwell elementary school. Its basic goal was to strengthen the neighborhood's human service resources to provide for optimal emotional, social, and educational development of all children in this age range within the neighborhood. Specifically, the model sought to:

1. Develop systematic "early warning" techniques for children who were not yet exhibiting serious defiance, but who were likely to do so based on the history of similar children or children in similar circumstances;
2. Initiate growth-producing programs for children so identified; and to
3. Initiate treatment programs identified as missing by the child advocacy staff, and monitor and evaluate effectiveness of various components of the program.

The "linking pin" model was conceptualized to describe the functional interdependency of the advocacy demonstration and available community services for children, without having the advocacy function dependent on any single community agency. It was based upon overlapping group functions in such a way that all of the resources of one organizational level were available to the next level. The members of the child advocacy team, who were on the staff of the

child-serving agencies, were "the linking pins" representing the second level in the schematic relating the child advocacy team to one of the human services agencies involved in the demonstration. These staff persons supplied viable means for two-way communications between the demonstration and agency.

The project coordinator was similarly "a linking pin" between the staff and the neighborhood child advocacy board, and would be represented by the third level of the diagram. The members of the board were linking pins to the extent that they represented specific community/neighborhood groups.

The purpose of the linking pin model was to maximize the communication and effectiveness of staff and board members who served a mediating function between the child advocacy team, which actually worked with children in the community, and established agencies from the community at large, as well as state and federal agencies.

That concludes the description of the jointly funded advocacy projects which have already been implemented.

Of the four currently funded projects, three are national organization models and one is a state model. Grantees are: (1) the National Association for Retarded Citizens, (2) United Cerebral Palsy Associations, Inc., (3) The National Easter Seal Society for Crippled Children and Adults, and (4) The Kentucky Department of Human Resources (formerly the Kentucky Commission on Children and Youth). These projects will soon be entering their final year of participation in the program.

The National Association for Retarded Citizens is implementing a model with which many of us are familiar, titled "A National Citizen Advocacy Model for Mentally Retarded Children."

Initiated in August of 1972 to assist mentally retarded persons in safeguarding their legal and human rights and obtaining the services to which they

are entitled, this project aims to catalyzing the development of a nationwide volunteer advocacy program. The citizen advocacy model conceptualized and developed by Dr. Wolfensberger is used for providing child advocacy services. Local and state associations for retarded citizens serve as the implementation agencies. Primary objectives of the project include: (a) developing written and audio-visual materials to elicit understanding of, and commitment to, the citizen advocacy model; (b) developing a standardized training program to enable and facilitate the establishment of child advocacy boards and local and state advocacy offices, the identification of mentally retarded persons in need of advocacy services, and the training of citizen volunteers to serve as advocates for mentally retarded individuals; and (c) providing direct program consultation to assist NARC member units in establishing model programs. It is anticipated that this national organization model will have a significant positive impact upon the delivery of needed services and programs to the mentally retarded, as well as upon the overall environment within which these programs and services are provided. The advocacy services developed will provide a concrete national prototype which may be applied in efforts to obtain improved services for other developmentally disabled individuals.

I will not go into further detail regarding this project because Mr. Max Addison, of NARC, has been invited to present an in-depth discussion of it on tomorrow's agenda.

Our second national organization model was conceptualized and is being implemented by United Cerebral Palsy Associations, Inc. It is titled "Developmental Disabilities: 3 Child Advocacy Models." As is implied by its title, this project has established three models of advocacy for persons with developmental disabilities and their families in three areas in the east, midwest, and western sections of the U.S. These models are coordinated by the national organization.

The purpose of the project is to provide an advocacy program to assist the identified target population to obtain needed services and to make the best use of available resources. In addition, data of various kinds relative to service needs are collected and collated at the state and local levels and organized by the national organization. These data are used by the state, local, and national organizations to develop necessary legislation on all levels of government. Ms. Marie Moore, project coordinator, will discuss this advocacy model in greater detail tomorrow.

The third national organization model is being implemented by the National Easter Seal Society for Crippled Children and Adults. The project is titled "Demonstration Program of Advocacy for Physically Handicapped Children in Massachusetts." The basic purpose of this project is to establish and perfect a model of advocacy for physically handicapped children in Massachusetts that can be replicated by any affiliate of the National Easter Seal Society. Through the establishment of a child advocacy association and board, the project has brought together parents and interested persons from schools, public and private agencies, and the community to achieve change in legislation, policies, practices and attitudes which prevent physically handicapped children from achieving basic rights related to home, community, schooling, medical care, and legal rights.

The development of the model calls for the use of "four entry points" as targets of advocacy projects. They are categorized as individual, attitudinal, legal rights, and structural. From these "points of entry," the project office designs appropriate programs to support the strategies employed.

The only state model currently funded is being implemented by The Kentucky Department of Human Resources. The project is called "Advocacy for Exceptional Children--A Research and Demonstration Project." This state model is attempting to demonstrate the feasibility of establishing state and regional offices of

advocacy for exceptional children and youth. These offices develop mechanisms to insure the attainment of the following goals and objectives:

1. Formulation and advocacy of special legislation vital to the needs of exceptional children;
2. Provision of educational information and statistical data to state officials, the legislature, and the general public regarding the needs and problems of exceptional children;
3. Development and establishment of a unified policy framework within which statewide goals for exceptional children are formulated, service priorities established, existing problems kept in balance, and new program developed;
4. Improvement in the coordination of management of human and fiscal resources to avoid waste, duplication, conflicting programs objectives, and prevent gaps in existing services;
5. Evaluation of agency programs to assure maximum effectiveness for quality control and accountability.

This model serves as an appeals agency or ombudsman in dealing with the grievances of exceptional children and their families, and as a guardian of their rights.

That concludes the overview of the types of advocacy models comprising the advocacy program federally supported by the DDO, the BEH, and the NIMH. As has been noted earlier on the program by Ms. Ursein, two of these agencies, the DDO and the BEH, have also comingled fiscal resources to support the development of the comprehensive national legal advocacy center for law and the handicapped in cooperation with the University of Notre Dame Law School which is directed toward social and educational activities affecting the DD of all ages.

Although all of these projects represent a first step toward answering many of the basic questions concerning the establishment and maintenance of advocacy mechanisms in a variety of settings, numerous questions still remain. A few of these are:

1. How can an advocacy system best be developed, both locally and nationally, which meets the basic needs of children and adults, insures coordinated preventive and remedial services, and pre-

vents gaps in services?

2. Which models are most effective for which types of communities?
3. What types of new activities should be included in advocacy efforts?
4. What new professional, paraprofessional, and layman roles need to be developed, and how can training needs best be achieved?

Hopefully, in the near future, the evaluation of the advocacy efforts described to you today will provide answers to these and many other questions that exist. Presently, however, I'd like to leave with you what my colleagues at the BEH and the NIMH and I have generally observed and informally analyzed relative to these disparate models of advocacy.

1. There has been an inevitable tendency toward case advocacy.
2. Non-professional lay persons recruited to serve as advocates (especially when they were indigenous to the target area) have experienced difficulty implementing an approach geared to systemic change.
3. The models have contributed much to the strengthening of neighborhood resources and competence for facilitating optimal development of children.
4. They have evidenced increased progress toward the ultimate goal of improving the total resources and delivery of services for the emotional, physical, social, and educational development of classes of children and adults within a defined target area, with special emphasis on improvement of the environmental systems for children presenting behavioral or developmental problems.
5. The projects were able to deliver direct services or make services available to persons who had no access to them previously.
6. I don't believe that we have ever succeeded in our goal of systems advocacy. We had hoped that the projects would impact on the various social systems of the community but I haven't seen this really happen.
7. There has been a proliferation of child advocacy programs in the last few years. To what extent our projects may have been responsible is difficult to prove, but it is likely that we played a catalytic role.
8. In instances where we have been less than successful with the community projects, I believe that one reason is a heavy

reliance upon paraprofessional personnel. It may be that professional personnel with community organization "know how" and experience might have been able to do more.

9. With considerable caution, I add the observation that on the state level it is entirely possible to establish a child advocacy program which, either by design or by chance, accomplishes nothing. It is important to make certain that state programs do not get lost in bureaucratic red tape and become emasculated. This has happened to at least one of our state models.

For this reason, I think we must have constant monitoring of projects by an outside group. It is difficult for a state agency to serve as both the advocate and the "watch dog." We need citizen input at all levels.

On Humanistic Technology, Devalued People, Useless Occupations,
Advocacy, and the Economics of the
Developmental Disabilities Industry

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One objective of this paper is to illuminate the hypothesis that, on the one hand, development is a function of practice and training--e.g. intelligence is educable--and, that on the other, we organize programs for the so-called developmentally disabled, and we set priorities, in ways to illustrate that people do not change, that alternatives to segregated settings are not necessary, that special classes and institutions serve mankind well. It is hoped that program participants will consider the possibility that there is a very strong mental health/mental retardation monolith that exerts enormous influence insofar as the education, training, and treatment of disabled people are concerned. However, the monolith is not the special class, the institution, or other special settings. Rather, the monolith has been created and perseveres, because of the unavailability of alternatives for clients, families, and others concerned with the education and treatment of people with special needs. The monolith is a creation of the single way, no-option, ideological block of granite that we call "institutions" and "special classes."

Obtained during the course of my research and clinical activities, the following summarizes major considerations suggested for discussion:

1. Although there is little scientific evidence that permits definitive answers to the so-called nature-nurture question, there is enormous clinical evidence that man can change, that intelligence is educable. The Wild Boy of Aveyron, the Autobiography of Helen Keller, the work of May Seagoe, and our experiences are but a few of the many examples that lend cogent testi-

mony in support of this hypothesis. However, evidence aside, for reasons dealing with the mission of teachers and others in the helping professions, the aforementioned is the only defensible hypothesis.

2. As human beings, all people are equally valuable. Nirje's "Normalization" theory, the religious and ethical teachings and behavior of thousands of others since the beginnings of our civilization provide mankind with, at least, a glimmer of hope that we will one day take this concept more seriously than heretofore.

3. Man has a penchant to segregate, to separate, to stigmatize, to make pariahs out of other human beings and, unfortunately, more than ever before, we seem to be engrossed in such activities. One of the very key statements obtaining from the so-called Partlow decision in Alabama was the court's decision that people have the right to the "least restricted setting necessary for habilitation." It is not enough for government to offer services. Those services must not unnecessarily segregate or restrict.

4. Possibly, for the first time in our American experience, the myths of such terms as "mental retardation" and "developmental disability" appear to be partially understood. The efficacy studies, our nomenclature changes, the Black Revolution, and other scientific and social movements have led us to a better comprehension of what must be considered no more than an administrative rather than scientific term.

5. The work of pioneering educational psychologists causes us to consider the possibility that the child in school knows what's best for him, and curricula should be designed and implemented around that concept.

6. As John Dewey said many years ago, teachers own the schools as much as children, principals, and parents. It appears that only in the University, and sometimes not even there, do we take this important notion seriously.

7. The more things change, the more they remain the same. In our special field, we have confused activity, laws, buildings, new money, new converts as evidence that we have progressed, that the world for the so-called mentally retarded is better.

8. The problems we are facing in this field are very complex, as are the solutions. Possibly, our research has suffered from the inappropriate assignment of independent and dependent variables. Possibly, the world is too opaque, too mysterious and secret, and the most important problems facing mankind are those that have been most effectively concealed from public observation and consideration.

9. We must return some responsibility, some authority, some decision making, some priority setting to the consumers of services. As has been said in other contexts about other matters, education is too important to be given entirely to professionals and their interests. It isn't that professionals are less able or less trustworthy than consumers. They are different, with different agendas and priorities.

10. Why doesn't anyone ask the important S.S.T. question? Forget pollution for the moment: does a person need to travel to Europe in three hours? What good does the electric can opener do? There are machines that extend the human and those that make him useless.

Monopoly: A Proposal

Special Education is big business. The Rand Corporation reported recently that government agencies expend 2.8 billion dollars annually to serve mentally retarded youths (Kakalik, 1973). Mental health is big business. Governor Carey of New York has recommended a 924 million dollar Department of Mental Hygiene budget for the 1977 fiscal year, "part of the Governor's 10.7 billion austerity

budget..." ("Governor Carey Recommends," 1976). For those interested in the slope of data, the trend, the recommended Mental Hygiene budget may be contrasted with the 640.2 million dollars appropriated in New York State for fiscal year 1973. Institutionalization is big business. The 1975 appropriation for the Willowbrook Developmental Center is approximately 62 million dollars, more than a 20,000 dollar expenditure per resident. In contrast, the 1965 per capita expenditure at Willowbrook and at virtually every other state institution for the mentally retarded was less than 4,000 dollars a year. Even deinstitutionalization is big business, from those who are engaged in trust busting and monolith wrecking to others who create and manage community alternatives. There is no way to avoid the plain fact that special education/mental health/mental retardation IS big business. On a typical day, on almost any day, one can find in the New York Times front page stories, Sunday features, Sunday magazine section cover stories, items in the news section, and items in the business section, each in some fundamental way related to the big business that is the Handicapped Industry (Blatt, 1976).

And it is sacred business too! How many people noticed that candidate Reagan's ill fated 90 billion dollar federal budget cut proposal avoided assault on allocations for the handicapped. The Untouchables, our pariahs, have become holy Untouchables, for the most part segregated and without normal context and opportunities but surrounded by government and philanthropic agents committed to protect to the last their right to be different, with that right to be backed by the dollars. In this modern era we insist on creating certain problems and also expend whatever outrageous resources are necessary to support those problems. Shades of John D. Rockefeller, Standard Oil, and his Foundation welcome this new super philanthropy.

The handicapped are big business, but more like the game of Monopoly than

the work of people who sell or buy or grow or invent. Like Monopoly, the handicap business appears unreal, the money seems more like paper, the promises aren't really meant and few take them seriously, the monopolies are easily constructed and almost as easily destroyed, and this moment's idea is the next moment's joke, today's victory may well be tomorrow's embarrassment as it was yesterday's bit of pornographic imagination. When Rockefeller, Carnegie, Mellon, and the other boys invented the Philanthropy business--an industry that came to be almost as powerful, more influential, and much more beloved by the people than Standard Oil and U.S. Steel--their efforts led not only to significant changes in the curricula of our schools and universities, but in the extent and manner that government aids those in need. Prior to the turn of this century, most of the schools and all of the universities were uniformly devoted to the classics, the sciences, and the learned professions. Big business taught us that they could also be used to teach people how to do a job, how to earn a living, how to contribute to business, which one former President was wont to tell us is America's business. Big business has also taught us how to organize our philanthropies to serve the people and, furthermore, how to organize the people--the State--to serve both business and philanthropy.

This is America. There is enough for everyone, for the rich and the poor, the healthy and the sick, the sound and the unsound, the philanthropic person and the business person. What difference does anything make? This is America. We're all alike, philanthropist and businessman. Some data:

Item. In 1965 Governor Rockefeller embarked upon a five year 500 to 600 million dollar mental hygiene construction program, part of a master plan for the mentally disabled (Construction of Mental Hygiene Facilities, 1973; Persons Released, 1975). Forty major projects were approved at a construction cost of

320.3 million dollars. Furthermore, the program included an additional 188 million dollars for modernization of existing facilities, plus 100 million dollars to help construct community mental health facilities. As of 1972, 23 of the original 40 major projects had been completed or were under construction; these exceeded cost estimates by 50%, 94 million dollars, a discrepancy that construction inflation is unable to account for. When the revised total plan is implemented, 28 projects will have been completed at a cost of 343.5 million dollars, 23 million dollars over the original estimate for all 40 projects, and with but 48% of the original number of beds planned (not an unmixed curse, if you know what I mean). When everything is said, constructed, and explained--and if there are no further delays, inflations, union demands, or bright new ideas--the 7,500 beds that will be the basic products of Governor Rockefeller's master plan will cost the tax payers of New York State approximately \$45,000 per bed for construction and approximately 1 1/2 to 2 times that amount additionally (\$65,000 to \$90,000) to meet fund obligations, to pay off the banks and the foundations and the other bond holders who "own" those facilities. But that is another story.

Item. Recently, in Syracuse, New York, the Catholic Diocese constructed a facility for the aged, Loretto Rest. This was but one of several new county, not-for-profit, and for-profit facilities either already constructed or being planned in our community. I have learned that the cost for care at Loretto Rest is approximately \$24,000 a year. I have also learned from my colleagues in this new business, Gerontology, that it is estimated that three million "golden agers" will be in geriatric facilities by 1999. Extrapolating from the continued inflation predictions, it may be reasonable to estimate that what may cost \$24,000 in 1976 will cost \$60,000 in 1999. Who will pay the \$180,000,000,000 annual bill to care for the unwanted old? Probably no one.

Therefore, isn't it time we spoke the truth to each other? Isn't it time we admitted that America will have to do one of two things to deal with the increasing geriatric problem, a problem which America didn't have a hundred years ago in its prescientific era: we must change our policies and programs, ostensibly created on behalf of the aged, or we must consider euthanasia as a relatively inexpensive and painless solution to this problem. What do you think? Remember, there is a fair chance that you will someday have this disease, being old.

Item. A recently completed study by the New York State Department of Mental Hygiene, unpublished but documented, disclosed that residents in group homes for the so-called mentally retarded incurred expenditures of \$6,700 per annum, while institutionalized residents required \$34,000. That bit of data is difficult to believe, especially after visiting Camp Hill or L'Ache, or is any number of beautiful communities or homes, and then contrasting those visits with observations in Willowbrook, Belchertown, or even the spanking new Syracuse Developmental Center. "Segregation" isn't the only issue. Willowbrook is "segregated." So is Camp Hill. But so too are Austria and Switzerland. A recent report issued by the New York State Assembly Joint Committee to Study the Department of Mental Hygiene (Swift, 1976) revealed that family care requires approximately \$7 a day and residential services for the mentally ill or mentally retarded costs from \$50 to almost \$90 a day. And, although family care and other community placements may incur additional educational and other treatment services, just as frequently such services may be available from city, county, or state programs.

There are fixed costs, some of gigantic dimensions, not accounted for in the above discussions: pension costs, government and other grants, various kinds of interest rates, costs that are so hidden that even the most penetrat-

ing search has yet to uncover them. The question that returns to us again and again is: Why do New York State--and other states--continue to construct and support institutions and other segregated places? We commend you to think about the following: unions, for example, the 64,000 union employees of the New York State Department of Mental Hygiene, an increase of 10,000 in little more than three years; contractors, builders, architects, real estate entrepreneurs, many people anxious to be business associates of the most affluent--"best"--purchasers of construction in any state, the state itself; merchants, manufacturers, contractors, the folks in business and commerce who would rather sell carloads of merchandise than run corner five and dime stores; and who wouldn't?

In 1963, also at the behest of Governor Rockefeller, our legislature created the Health and Mental Hygiene Facilities and Improvement Fund, an organization that has had several name changes during the ensuing years but has remained steadfast in its mission to execute the construction program of the Department of Mental Hygiene (Construction of Mental Hygiene Facilities, 1973; Persons Released, 1975). Its beginning responsibilities involved the Fund in completing work on a \$350,000,000 Mental Hygiene bond issue. However, since its January 1964 take-over date, HMFIF (or you may use its new name, the Facilities Development Corporation), has spent over one billion dollars on mental hygiene construction. Financing is arranged through the State Housing Finance Agency, who issue bonds that are converted to the dollars necessary to construct our state schools and mental hospitals. Eventually, institutional and individual investors purchase these bonds because they are tax free and also because they provide the lender with a virtually fail-safe method to earn anywhere from 3 1/2 to 7% interest on his money. You must remember that these bonds are tax free (an important benefit to those in high

tax brackets) and very safe. The bonds are so safe that Standard and Poor and Moody have consistently rated them quite safe, even in the face of New York City's and New York State's various fiscal crises. One reason these bonds are rated highly is that all income to mental hygiene facilities--income directly from patients or their families and income from federal or third party sources, such as income from Title XIX of the Social Security Act--IS PLEDGED FIRST TO THE MENTAL HYGIENE FACILITIES IMPROVEMENT FUND: the bond holders must be paid first, as in any good business.

We have a problem. How do we convert segregated facilities for the handicapped and the elderly to useful purposes? How can these thousands of people return to normal community life without the state bankrupting itself in attempts to meet bond obligations and other commitments to the business community? First, we must recognize the depth and extent of involvement in the world of commerce of supposedly non-profit, philanthropic, and helping agencies. Secondly, we must seek to interest other clientele for the segregated facilities and programs we have erroneously created for the handicapped and the aged. A modest beginning may be to solicit discussion with penal officials and advocates for the reform of our penal system. The possibility exists that in the conversion of segregated facilities for the handicapped and the aged to open community opportunities there may be hope for the utilization of such facilities by individuals who are required by law to be segregated. Great strides may be made through such exchanges, both for current occupants and the new tenants. To complete the conversion plan, as each facility is evacuated by so-called mental patients, state school residents, and the aged, institutional operating budgets would follow the clients to the community as new agencies would pick up program costs for the new tenants, then advocates for prisoners would meet bonding obligations, satisfy the unions

and the merchants, the builders, and all the others who play the big business and monopoly game. It's simple justice.

In the beginning, the people created the state. Then the state did foolish things. Now the voice of the people must be heard.

Vox populi. Time is running out.

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Advocacy: An Examination of its Interaction
with the Human Service Delivery System

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Introduction

An advocate, simply defined, is one who is trying to maintain or promote a cause. From an individual perspective, advocacy is acting in behalf of, or pleading a cause, for another. It often involves fighting for someone who can't fight for himself. From this writer's viewpoint, direct individual advocacy is the cornerstone of all advocacy, and it is as old as the human race. The basic goal of all advocacy activity is to improve the quality of life for some person or group of persons. The purpose of this paper, however, is not to deal with personal, direct advocacy but rather to consider advocacy activity and its relationship with the human service delivery system. First, the paper presents some problems in the human service delivery system that indicate a need for advocacy mechanisms. Second, two approaches to advocacy are described: an advocacy approach that operates from inside the system and an advocacy approach that operates from outside the system. Third, an example of an internal advocacy program is described. The paper concludes with observations concerning the advocacy role and function of a DD Council.

Problems in the Human Service
Delivery System

The past twenty years have brought about unusual growth and expansion in the field of human services. In many states the human service system has resulted in the development of organizations at several geographic levels inclu-

ding local, regional within state, multi-state regions and national. To a citizen at the local level this multi-layered bureaucracy might resemble a huge onion. No matter how many layers are stripped away, there always seems to be another layer. Pressing the onion metaphor a bit farther, a person attempting to strip away the bureaucratic layers is likely to be driven to tears before an accountable agent is found. The human service network is sometimes referred to as a system or a machine. This analogy is weak since the terms "systems" or "machines" imply relationships between the parts. At or across the same bureaucratic levels, we witness a great deal of fragmentation and lack of communication. At the federal level we are confronted with the piecemeal evolution of legislation and confused agencies trying to implement this legislation and maintain coordination and communication among the many parts of the huge Washington structure. Communication and interaction between agencies is not much better at the state level. State agencies spend much of their energy in political warfare with other agencies--activity aimed at gaining support for their programs from governors and legislators. Similar inter-agency warfare and "turf-defense" takes place at the local level. Professionals disagree about theory, philosophy and intervention strategies. These conflicting viewpoints are played out in the warfare between service providers. In some instances, local agencies fight for control over the same clients whereas the majority of citizens with needs are unserved.

The tragic aspect of this waste and confusion is that the loser is the citizen who needs the service but can't access it. In the writer's opinion, our human service arrangements have become so large and complex that even competent individuals need help in picking their way through the maze of organizations that constitute our delivery system. Perhaps the best analogy for our human service system is that of a giant maze. The maze runners are not

rats but humans who are trying to access services and resources. Services and resources are the reinforcers at the end of the maze. They are dispensed by the service providers, but one gets the feeling that only a very small proportion of the total reinforcers are dispensed to the maze runners. The largest proportion of the resources are absorbed in maintaining the organizations that may exist in and for themselves. In keeping with Darwinian theory, only the fittest maze runners survive. In this system, the handicapped are always the losers. Maybe that's what advocacy is all about--trying to minimize the losing for developmentally disabled citizens.

Given the size, complexity, and unresponsive nature of the bureaucracy, it is unlikely that an individual advocate will be successful in moving the system alone. If advocacy for an individual calls for change in the human service system in order to render it responsive to an individual's needs, then advocates must have access to a source of political power. The writer proposes that advocates should create their own organization that takes on the characteristics of social movement. In this connection, perhaps advocates can learn from civil rights activity or perhaps from the women's liberation movement. Advocates resemble civil rights leaders; they represent a minority population whose basic human rights and needs are often ignored. If the voice of this minority population is to be heard in the relentless flow of the political and bureaucratic stream, then advocates and handicapped citizens must organize and present a strong and unified front. We cannot afford division among the rank and file of citizens who wish to bring about responsive governments. Two conflicting approaches to bringing about accountability in human services are described below.

Internal and External Advocacy Approaches

Advocacy activity that interacts with the service delivery system and attempts to render human service organizations more responsive to the public has resulted in two conflicting viewpoints. One viewpoint contends that the only kind of advocacy that can possibly succeed is "external advocacy," or advocacy that operates on the human service delivery system from outside and is externally supported. A second viewpoint says that "internal advocacy," or advocacy that is supported internally and works from inside the system, is a superior advocacy approach. An attempt is made below to analyze the strengths and weaknesses of the internal and external advocacy approaches.

1. Internal Advocacy

An internal advocate is an advocate who is paid by the system in which he works. It is the contention of the internal advocate that the system needs reform and renewal and that this can be accomplished most effectively by activity from inside the system. The internal advocate is committed to identifying individuals whose rights and needs are not being met by the system in which the advocate is employed. The advocate's work consists of activity aimed at changing the system to be responsive to the client and his needs.

Concerning style, internal advocates first try to negotiate with service providers and bureaucrats. Confrontation is avoided if possible. There are many critics of internal advocacy mechanism who contend that it cannot work. "Whose bread I eat, his song I sing," or, "It's hard to bite the hand that feeds you," observe the antagonists of this approach. The major concern with the internal approach is that when system maintenance or staff interests conflict with client needs, the internal advocate will compromise the interests of the client. Ideally, an advocate would always negotiate for the full interest

of his client. However, it is the author's belief that there is no person who is a "pure" advocate, that is, one who can completely and always invest himself exclusively in the welfare of another. It should therefore be pointed out that when a person fails, or chooses not to promote the best interest of a client and gives way to demands from the system, at that point a person ceases to be an advocate.

To the extent that an advocate can resist being co-opted by the system, there are some strong advantages to advocating from inside the system. For example, advocacy aimed at accessing services for a client often requires detailed knowledge of the system, its organization, and its resources. That information is much easier to acquire from within the system. Similarly, accurate data concerning program weakness and human abuse to clients can be obtained most readily from inside the system. Another advantage to internal advocacy is that financial support is likely to be relatively stable. With a stable financial base, advocates are enabled to concentrate on the work of advocacy without needing to be concerned with financial survival.

2. External Advocacy

In contrast to "internal advocates," consider "external advocates," who receive support from private sources that are outside the human service system and are not accountable to persons in the system in which they are advocating. The "external advocate" tends to be viewed (and view himself) as an adversary of the system. There is a further tendency by the external advocate to consider the system and all of its parts as evil. When insensitive system arrangements are encountered, they are inclined to promote system dismantling. External advocates are prone to think that negotiation is a waste of time and move quickly to confrontation. It is the "external advocates'" reputation for confrontation and dismantling that earns them the identity of a system ad-

versary.

The primary advantage of external advocacy is its independence from the system. The external advocate is much less likely to be "co-opted" or "cooled out" by the system. Whereas the power of the internal advocate depends upon the ability to negotiate with elements in the system, the external advocate can resort to force, intimidation and coercion. The external advocate can call upon the threat of courts, exposes through the public media, and pressure from public groups such as parent organizations to bring about change and influence the system. Internal advocates would run the risk of losing their jobs if they threatened their organizations with external coercion. Thus, if an advocate is forced to resort to confrontation, it is an advantage to be outside or have external financial support.

The great disadvantage of the external advocate is the likelihood of limited access to the environments or programs in which the clients are served. External advocates must often rely upon information that is reported to them from other sources. To the extent that an advocate is unable to collect information personally, information upon which they base their actions may be vague, misleading or even faulty. Nothing is as sure to erode the credibility of an advocate more quickly than false data. A cardinal rule for an advocate is to act only upon reliable information that can be verified. The use of unreliable data results in advocates who are reminiscent of Don Quixote of old: they know the basic issues, but they don't know the enemy. Hence they find themselves binding their lances on the wrong objects.

While a large bureaucracy has a tendency to corrupt its membership and alienate them from individual clients who need service, it is the writer's belief that there are many benevolent persons in the system whose sensibilities to client needs have not been blurred. These "good gals and guys" in

the system might be called natural advocates. External advocates with an adversary perspective tend to view the system and all of its parts as evil. Therefore they are prevented from discovering and relating to the natural advocates. With no connections or allies in the system, the advocate will be rejected as surely as a human body rejects the transplant of someone else's heart.

Another disadvantage of external advocacy is its tendency to be financially unstable. Where does an external advocate go for support? There are sufficient connections among the various parts of the human service delivery system such that it is unrealistic to expect complete freedom. For example, suppose a state advocacy organization obtained federal funds to operate its program. Let us further suppose that the advocacy organization took steps to initiate a law suit against a state agency. There are sufficient connections between the various levels of the bureaucracy so that an advocacy organization funded in this way may be prevented from exercising its freedom to pursue a lawsuit. In this sense, an organization using government resources of any kind cannot be viewed as external, because programs supported by resources from different levels of the system are clearly subject to co-option due to connections between different parts of the system.

For an advocacy organization to be truly external, its support would necessarily come from a private source. However, it has been the writer's experience that advocacy activity is often too controversial to attract funds from private organizations. Recognizing the limitations of using resources for advocacy from the system, the author recently approached a private foundation for some support. The advocacy proposal was carefully examined, need for the activity was acknowledged, but the proposal was rejected due to its potential for controversy. This particular foundation wanted an activity like

apple pie and motherhood, grits in the South, hockey in Canada, crumpets in England, or hamburgers in America. Activity that would always result in good public relations. Advocacy activity is often controversial. Thus, external advocacy designs have few sources to call upon for financial assistance and their financial support may be unstable.

In addition to unstable financial support, external advocacy programs are often faced with the problems created by temporary leadership. Persons who provide leadership for external advocacy programs tend to be highly charismatic individuals who depend largely upon part-time employees or volunteers. The internal advocate is likely to recognize that activity to bring about system renewal must be on-going. Permanent internal arrangements should be established for this purpose. In contrast to the permanent on-going nature of internal advocacy, external advocates tend to define advocacy in terms of a specific issue or problem. External mechanisms with short-term limited goals are then created to solve the problem that is often over-simplified. When the problem is solved, appears to be insoluble, when financial support runs out, or when the leader vanishes, the activity dissolves.

A final disadvantage of the external adversary approach is that an advocate is vulnerable to becoming so caught up in the process of struggling with the system and the counter forces that the interests of the clients are forgotten or ignored. In the writer's opinion, the legal advocate is particularly vulnerable at this point. In an attempt to win a decision in the courts, the welfare of an individual client may be sacrificed for months or even years. When an advocate becomes entangled in the web of system adversary, it is entirely possible to grow preoccupied with the fight. The end becomes winning against the system; perhaps system dismantling. To the extent that system adversary activity loses sight of the welfare of individual clients, one can

make the point that system adversary activity is not advocacy at all. The writer suspects that there are times when organizations deliberately set themselves up for attack in order to distract advocates from the client-oriented mission of advocacy. Courage is an admirable trait. However, system adversaries who have an inflated belief about the bureaucratic abstracts they can move remind one of a terrier chasing a locomotive. What will the terrier do with it when the locomotive is caught? Again, a system adversary or lone advocate trying to effect massive system change may be analogous to a gnat straining at a camel. Advocates need to be more than a trivial annoyance in someone's hindquarters.

In order to maintain an accurate perspective on internal-external advocacy, two points should be kept in mind. First, external advocacy was defined in this paper as activity that received its support from private sources that are outside the human service system and not accountable to persons in the system in which they are advocating. There are very few advocacy programs across the country that meet this definition of advocacy. There are, however, a growing number of advocacy programs that receive public resources from one organization in the human service system, and conduct their advocacy work in another part of the system. In reality, such an advocacy program is internal, even though it may call itself external and behave according to the external model described above. Internally funded advocacy mechanisms that adopt an external adversary style usually have a short life. This may partially account for the high mortality rate of advocacy programs. A second point that should be kept in mind concerning the description of internal and external advocacy is that in order to provide a clear description of two different approaches, the viewpoints were polarized. Most advocacy programs are a mixture of the two designs. It is the author's belief that advocacy

organizations would be in a better position to understand their strengths and weaknesses and successes and failures if they made an assessment of their programs according to the internal/external models described above.

Internal Advocacy:
An Example

Obviously, there are advantages and disadvantages to both internal and external advocacy. A specific example of an internal advocacy activity has been selected in order to consider its strength and weakness more closely.

In 1970, a statewide advocacy program known as the Child Advocacy Center was launched in North Carolina. The program was aimed at developing advocacy principles and procedures. Advocacy activity took place at the state level and in several public residential institutions across the state. The intent of the Child Advocacy Center was to train staff in the areas of institutional reform and depopulation of residents from residential institutions.

At the state level, it was recognized that very weak provisions existed to protect the rights and interests of residents in public institutions. A project was therefore designed to (1) examine existing law and policy related to the rights of institutionalized persons, (2) develop ideal legislation to protect resident rights, (3) collect data on violations of rights of residents, (4) develop steps for the passage of new and improved legislation, and (5) provide human rights training for institutional residents, parents of institutional residents and mental health staff.

Along with the state level advocacy activity described above, the Child Advocacy Center provided leadership to develop advocacy programs in four residential institutions throughout the state. Activities in the institutional settings included procedures to return residents to the social mainstream, and mechanisms in the institutions to identify human abuse and locate program

gaps and weaknesses. After three years of operation, the Child Advocacy Center as a statewide program closed its doors. Four years after the Child Advocacy Center was launched, only one of four participating institutions had an active and flourishing advocacy program. The reasons for this dismal record of failure should be examined.

The first reason that accounts for the failure of the Child Advocacy Center is that it engaged a number of highly controversial activities that called for confrontation with the system. Both the press and the courts became involved in several activities that the Child Advocacy Center initiated. While battles for clients were won, the Child Advocacy Center as a mechanism lost its war for survival with the bureaucracy. Involvement in highly controversial activity forced the Child Advocacy Center into a higher profile than it could survive. The activities and beliefs of the Child Advocacy Center resulted in many attacks. In attempting to respond to the attacks, the staff discovered that the majority of its time was utilized in justifying the existence of the Center to state bureaucrats and administrators from residential institutions. One must recognize that the phenomenon, institution, is in one aspect, an organization, facility, or program that is self-serving or exists primarily for itself and its staff. At the point of spending all of its energy justifying its own existence, the Child Advocacy Center was a self-serving institution. Another way of looking at the dilemma of the Child Advocacy Center is to examine the "fit" between its beliefs and mission and its activities. When attacks upon the advocacy program became too heavy, staff members were unable to do their work. At that point there was a breakdown of the "fit" between mission and activities. From a moral and ethical viewpoint, such programs should close their doors.

The second major problem of the Child Advocacy Center is that it was a

completely internal advocacy program. It was supported by public funds and attempted to work within the system that was supporting it. Although the Child Advocacy Center had been promised support from the chief executives in the supporting system, when controversy began to rage around the program the threatened bureaucrats withdrew their support. This undermined the only power and authority of the Center, and the staff could not do its work. An internal advocacy mechanism cannot survive without the unqualified support of the chief executive. This, in an institution, an advocacy program must have support from the superintendent, or in a Department of Mental Health, advocates working at the state level would need the unqualified support of the Commissioner of Mental Health.

Finally, the author contends that the Child Advocacy Center was unable to survive because it was compelled to utilize the confrontational arms of the press and the courts in some of its activities. It is the author's belief that there are few organizations that will support an internal advocacy mechanism that uses external advocacy tactics.

Advocacy That Works

It is the author's belief that an ideal advocacy program should combine internal and external forces in order to be successful. Thus, an advocacy program may look toward public resources for support. Activities may even take place in the environment from which the advocate gets paid. However, the internal advocate must seek support from the private sector. In an institution, the advocate may look toward a human rights committee for support. Such a committee would include a number of consumers and parents of consumers employed outside of the system. At the level of state government, organizations known as Councils for the Developmentally Disabled Citizens are logical ad-

vocacy mechanisms. In theory, the composition of a Council for the Developmentally Disabled has all of the ingredients of an excellent advocacy mechanism. Councils for the Developmentally Disabled include state agency staff, service providers and consumers. Internal advocacy components include agency staff and service providers. The external advocacy component is the consumer.

State agency staff, however, cannot be considered advocates if they come to the Council representing their agency, the Governor, or some political party. In many states, key administrative positions are filled due to political patronage. Political loyalties can and often do blur the advocacy mission of a Council. In some instances service providers on the Council use the Council as a forum to obtain resources for their geographic region or for their specific programs. The consumer representatives are in a unique position to prevent vested interests of state agency personnel and service providers from taking over the mission and agendas of the Councils. Furthermore, assuming that state agency staff and service providers are natural advocates in the system, consumers can provide protection for them and work toward depoliticizing the human service delivery system. The appointment of staff in the human service system should be based upon their work and experience, not upon their political alliances. It is recognized that as internal advocates, state agency staff and service providers are limited in their ability to confront the system. Adversary roles should be undertaken by the consumers on the Council rather than allowing the internal advocates to place their jobs in jeopardy. While the success of a Council as an advocacy mechanism depends upon the involvement of consumers on the Council, consumers are not immune from co-option. As members of consumer organizations, consumers may obtain grants from state or federal coffers to run their programs. In so

doing they may be selling their external birth rights. Consumer organizations should be careful to avoid this dilemma. A second problem surrounding consumers on the Council has to do with their membership in a specific consumer organization. Some consumers behave as if they are on the Council representing a specific consumer organization such as the Association for Retarded Citizens or the United Cerebral Palsy Association, etc., etc.

In the author's mind, Councils for the Developmentally Disabled have the potential of functioning as an ideal advocacy mechanism. This will happen only if there is a coalition of all the interest groups indicated above.

Finally, it is the author's belief that the struggle of advocacy programs and the struggle of Councils for the Developmentally Disabled are part of a much larger struggle. If advocacy and Developmental Disabilities Councils fill in the arena of human services to render those services accountable to our citizens, what are the implications of this failure for the principles of democracy? If administrators in local programs can't tolerate accountability, if state agencies can't be open and responsive, and if federal officials do not answer to the public, it is the author's belief that government of, for and by the people is a myth. There is too much at stake to allow the concept of advocacy and the mission of Councils for the Developmentally Disabled to fail.

A Demonstration of Three Advocacy Models
For Persons With Developmental Disabilities

Marie Moore
National Advocacy Coordinator
United Cerebral Palsy Association

United Cerebral Palsy Associations, Inc., is a federation of almost 300 affiliates across the country. Each affiliate is an autonomous organization which has membership in the national organization. As a voluntary health organization, the national organization became the grantee of the Bureau of Education for the Handicapped (BEH), National Institute for the Mentally Handicapped (NIMH), and the Developmental Disabilities Office for establishing three models of advocacy--statewide, regional (bi-county) and urban. This project started in July, 1972. It is the purpose of this presentation to share the experiences we of UCPA., Inc., have had in order that guidelines may be established for implementing PL 94-103--The Developmentally Disabled Assistance and Bill of Rights Act.

The model sites selected for the project were:

UCPA of New York State (office located in New York City)

UCPA of San Mateo County and UCPA of Santa Clara County, in California, two affiliates sharing administrative and program staff (office located in Palo Alto, California).

UCPA of Southeastern Wisconsin, located in Milwaukee. (After two years of operation, the Milwaukee program was discontinued due to administrative problems.)

Replication sites were selected for the project's fourth year to test the replicability of the model programs:

UCPA of Greater Kansas City, Inc. (urban model)

UCPA of Rhode Island (regional model)

UCPA of Illinois (statewide model)

Common characteristics in all project sites as well as at the national level have been an advocacy coordinator and an advocacy advisory council.

The responsibilities of the paid coordinators have been in the areas of:

1. Systems analysis--learning the laws; analyzing the politics, policies, practices and procedures of targeted systems that provide service or should be providing services for persons with developmental disabilities.
2. Community organization activities--bringing together those components or units within systems in order to create the environment for clearly identifying specific problems and developing specific solutions through planning and implementation mechanisms and utilization of various resources; building support systems within and without systems.
3. Dissemination of information to groups of consumers and consumer representatives.

Emphasis on the job title has been on coordinator more than advocate because the role and function of this professional staff have been catalytic more than direct intervention.

We have found that no one generic professional discipline has a corner on the market for qualifying as an advocacy coordinator although the professional background, personality and operational styles of the coordinator have influenced the program implementation of the models. Many coordinators have dual professional backgrounds--therapist/counselor, social worker/minister, psychologist/minister, social worker, public administrator, attorney-at-law, and sociologist/journalist. We have learned that previous experience in the developmental disabilities field is not necessary. Expertise needs to be in community organization, communication, administration and legal/legislative analysis.

The responsibilities of the Advocacy Advisory Council are:

1. To provide advice to the coordinator.
2. To determine priorities, target populations, target systems and issues.
3. To evaluate the impact of the advocacy program upon targeted populations.
4. To develop proposals for action by targeted groups, agencies or organizations including governmental bodies and private agencies.
5. To serve as a support group for other advocacy action groups or individuals.

Council membership must include representation from all segments of the population (ethnic, income and geographic). Members include adults with developmental disabilities, parents of children with developmental disabilities, service providers from a variety of professional disciplines and volunteer leaders of the host organization.

It must be stated at this point that the Councils are free standing bodies and are not a sub-unit of the Board of the host agencies, which are concerned with the corporate affairs of the UCP affiliate. This separation minimizes any conflict of interest--especially if UCP itself becomes a target for change (and it has). Also we have learned through our experience in Milwaukee that you cannot let corporate problems interfere with the advocacy approach; otherwise you cannot be an effective advocate.

Our experience has been that we have been able to build a number of support systems for persons who have historically had no power base from which to operate--the disabled themselves, including those disabled from ethnic minority or low income, parents of young children, and other groups. Without this type of power base, persons with developmental disabilities would be unable to cope with bureaucratic red tape, unable to interact with or become a part of the planning mechanisms, be unknowledgable about their rights and entitlements.

You have been given a two-page description that shows five case advocacy and five class advocacy systems we have identified as those systems that can support and protect the rights of the developmentally disabled (see below, pp. 120-121). Those with an asterik have been components of one or more of our project sites. Those without the asterik have been systems with which have interacted, cooperated or been in coalition.

As time permits, I would like to share some outcomes with you to illustrate what we have learned. I will start with the most exciting--Consumer Action Groups.

1. Parents for Improved Community Services (PICS) is a coalition of activist parents representing several organized parent groups that had been working with the San Mateo/Santa Clara Advocacy Advisory Council. Utilizing consultation from the Advocacy Coordinator, PICS developed and implemented a strategy to set up a fair hearing for a severely disabled child who had been expelled from a public school developmental program. Since the fair hearing was mandated by law but no procedure developed, PICS designed such a procedure, used it and won reinstatement not only for the expelled child but thirty other children. This fair hearing procedure is considered a model for the entire state of California.
2. Advocacy in Action (AIA) was founded by a group of Buffalo, New York adults with developmental disabilities in association with the New York State Advocacy Council. The first campaign launched by the group has been curb ramps to eliminate the mobility barriers of the physically disabled. The result of their efforts is a city plan for ramped curbs in the entire city by July 1, 1977.
3. Consumer Advocacy Council (CAC) of Greater Hartford was organized with cooperative efforts of UCP of Greater Hartford, Connecticut, utilizing consultation from the National Advocacy Project. Council members are elected by the adult clients of the agency. Priority areas for work have included transportation, housing, legislation and public awareness. Many people with a variety of diagnostic labels including mental retardation have been involved with CAC programs and activities.

Legislative Advocacy has been a component of both local and state advocacy programs. Advocacy Coordinators and Advocacy Councils have organized activities so that consumers, volunteers and professional staff of UCP affiliates, cooperating organizations and other concerned citizens have been able to interact with legislators, present packages for legislative action and monitor the implementation of legislative mandates. Key elements of these activities have been newsletters, organized hot lines, and planned events for direct communications with legislators. It has been observed that more disabled persons and parents are participating in legislative hearings. Examples of outcomes have been five bills passed in 1974 through the New York State legislature and use of grievance procedures in Milwaukee and Kansas City relative to education mandates.

Community Organization advocacy activities have included coalition activities for service providers of high risk infants in Kansas City and Santa Clara County, in California; Project Impact for the Chicano population in East San José, California; a seminar for professionals regarding services for abused children in Rhode Island.

Program Brokerage advocacy activities have resulted in a legal advocacy program for the developmentally disabled in Milwaukee; a community residence for people discharged from institutions or on a waiting list for institutions in Buffalo, New York; a diagnostic clinic for two rural counties in upstate New York.

Ombudsman activities centered around 106 cases during the second year of the project in Milwaukee and included problems in employment, education, and drivers' license procurement. In Kansas City cases have centered around non-compliance of education mandates.

Case Manager advocates have received on-going consultation and technical assistance from the Advocacy Coordinators. Those employed by UCP affiliates are the Home Service Directors in New York State and the Outreach staff in Illinois. The desired outcome for the project has been to assist these case managers in the expansion of their advocacy roles where clients have had difficulty in receiving services, employment discrimination, and problems in institutions and nursing homes.

I have described an advocacy approach used by a voluntary health agency which has been in operation for four years in three states, two urban areas and two suburban counties. This overview has only allowed a quick glimpse of single frames within a film of daily moving, dynamic operation.

To summarize, we have experienced that advocacy is an interaction and interlocking of many advocacy systems. Advocacy is a process

- in part reaching and teaching consumers;

• in part understanding and where necessary trying to change the service delivery system;

• in part intensifying and cementing more securely the partnership between the person who is developmentally disabled, his/her family and the agencies mandated or committed to provide services.

The goals of the UCPA Advocacy Project are helping the persons with developmental disabilities to make the systems more responsive to their needs and secure their rights, and helping disabled persons to participate and increase their fulfillment as human beings.

One final illustration of what the UCP Advocacy Project has tried to accomplish. This illustration comes from a personal experience I have had in interacting with a woman who has a developmental disability. Two years after I made a speech about the goals of the project on a day she had been in the audience, she said to me:

All my life others had said, "I will take care of you," so all of my life I had to believe them. My father took me to work until he had a stroke. After that I had to stay home Then you told me that I had a responsibility to act, represent myself and see that I was properly represented. You told me that I had a voice to speak up for my own rights. It was not easy. I had to summon up all the courage that was still within me. Each day I had to grow.

Where has she gone since summoning up her courage and finding her voice? She has organized the Consumer Advocacy Council of Greater Hartford along with others who have found their voices (one using a communication board). She has requested that the mayor change the location of a transportation hearing from city hall to a barrier free location so that she could attend. She has repre-

sented UCP of Connecticut as an educational resource for the state assembly (having to sit on the floor with the elected representatives because the gallery is inaccessible to persons in wheelchairs). She has testified before a Senate Committee of the United States Congress. She has appeared in New York Times and other newspapers demonstrating problems in using public transportation for the disabled. She organized the first Awareness Day in the state of Connecticut. She has constructively criticized UCPA. She has helped to build the foundation upon which persons with developmental disabilities can sit in full participation as first class citizens with rights, responsibilities and the power to bring about the necessary changes in our social, economic and service systems so that they may gain their lives, liberties, and pursuit of happiness.

UCPA
Advocacy Systems for the
Developmentally Disabled

System	Purpose	Governing Body
<u>Case Advocacy</u>		
A. Citizen Advocacy	A. One-to-one relationship between a capable volunteer and a person who is developmentally disabled in which the volunteer advocate defends the rights and interests of the other and provides practical or emotional reinforcement for him.	A. Citizen Advocacy Board; operated by a private association or agency.
*B. Ombudsman--private	B. One who acts as an advocate for an individual in receiving a grievance and investigating, interceding or initiating action on his behalf.	B. Advocacy Council or Committee; operated by a private organization or association.
C. Ombudsman--public	C. Same as B above	C. State Human Rights Commission; may be assigned to an institution.
D. Legal Advocate	D. One who represents a person in the litigation or legal negotiation process concerning rights, grievances or appeals.	D. None unless in an agency setting.
*E. Case Manager/ Advocate	E. One who assists the individual in information, referral, follow along services and serves as an advocate when there are barriers into the service delivery system.	E. Public or private agencies.

System	Purpose	Governing Body
<u>Class Advocacy</u>		
*A. Systems Reforms and Development (Legislative Advocacy)	A. Using the legislative process to mandate change in order to secure the rights of the developmentally disabled in areas, i.e. human services, labor, transportation, housing, education, health care, etc.	A. Consumer representative organization at local, state and national levels; consumer, volunteer and staff involvement.
*B. Community Organizational Advocacy.	B. Using the community organization process to develop better communication among agencies serving the developmentally disabled; to assist in the development of cooperative or coalition efforts on behalf of the disabled by public and private providers of service and by consumers.	B. Community planning groups; placement of consumers and consumer representatives in planning bodies; pressure groups of consumer advocates.
*C. Program Brokerage	C. Service development and program expansion by eliminating barriers and combining many resources.	C. Consumer representative organization working in cooperation with governmental and private agencies.
D. Protective Service System	D. A mandated service providing guardianship, trusteeship and other advocacy services.	D. State government board or council; e.g. Ohio program.
*E. Consumer Action Groups	E. Groups of parents or adults who are disabled that act as pressure groups or influencing groups and advocate for desired change.	E. Independent organizations; groups associated with consumer representative organizations.
* Components of Three Models of Advocacy Services for Children with Developmental Disabilities.		

The Theory and Application of Citizen Advocacy

Max R. Addison
Project Director, Advocacy Project
National Association for Retarded Citizens

The 1970's have been a period in American history when both public and private sectors have become increasingly concerned about human and legal rights for mentally retarded and other developmentally disabled persons, and how those rights relate to consumer representation and service needs. These concerns have provided impetus for the rapid development and growth of the citizen advocacy approach.

The Citizen Advocacy Concept

The model for citizen advocacy was evolved by Dr. Wolf Wolfensberger during the late 1960's while he was associated with the Nebraska Psychiatric Institute in Omaha. The concept was developed in order to assist disabled children and adults in areas in which their rights were not being appropriately safeguarded or their needs were not being adequately met by existing protective service systems or strategies. The concept was originally directed toward mentally retarded persons who had no existing or functioning parents, guardians, or close friends who could provide needed representation.

Citizen advocacy is basically a one-to-one relationship between a capable and trained volunteer who is known as an advocate and a mentally retarded, or otherwise developmentally disabled, person who is known as the protege. In this relationship, the advocate defends the rights and interests of the protege and provides practical assistance and/or emotional reinforcement. Practical assistance would include activities such as helping a protege learn to use public transportation, to properly budget money, to appropriately utilize community based programs, services and facilities. Emotional reinforcement relates to

providing friendship to a protege during periods of crisis, loneliness, or boredom and offering understanding and advice. It is important to understand that the advocate provides representation for the protege within the scope and authority of a private citizen.

The advocate and protege are brought together within the context of an organized citizen advocacy program. The citizen advocacy concept requires one or more paid professional staff for each local citizen advocacy program in order that proteges will be identified and their needs will be assessed, advocates will be recruited, selected, trained, and eventually, these two groups will be appropriately matched on an individual basis. The advocate and protege are matched on the basis of the needs of the handicapped person and the interests, availability of time, and individual strengths of the volunteer. Handicapped persons who need citizen advocacy are generally identified prior to the selection of advocates. This process enables the development of an individually tailored advocacy program for meeting the specific needs of a protege.

As each advocate and protege are paired, the program's staff begins offering on-going backup and support in order to help the advocate become effective in his or her efforts on behalf of a protege. Additional support for the advocate's activities is provided by a citizen advocacy advisory committee which generally consists of professionals from a variety of disciplines (e.g., law, law enforcement, social work and psychology), parents and other consumer representatives, and consumers. The expertise represented by the advisory committee's members is available on an individual or collective basis when needed by the program's staff, advocates, and/or proteges.

Ideally, the same advocate will provide emotional support and/or practical assistance for the period of time a protege needs one or both types of advocacy.

When this continuity is not possible for reasons beyond the control of the advocate (e.g., relocation to another city), another advocate is located and trained to assist the protege. Regardless of whether one or more advocates are involved over a period of time, the long-range objective for each relationship is to help the protege develop self-advocacy skills and become as independent as adaptive behavior and intellectual level will permit. Over a period of time, there should be a decreasing need for assistance from the citizen advocate.

The effectiveness of the citizen advocacy approach is largely a result of the citizen advocacy program's independence from service delivery systems and agencies which provide direct services for proteges. By ensuring that the citizen advocacy program is not related to or a part of the delivery of direct services in terms of operating funds, administrative control, or physical location, the advocate can provide representation for a protege without conflict of interests, which are oftentimes experienced by direct service providers who attempt to advocate for a client within the structure, procedures, and policies of agencies and service delivery systems.

The citizen advocacy concept appropriately focuses on the volunteer as the provider of advocacy services. In practice, however, the local program's staff are also involved in very important advocacy roles.

A program's coordinator is frequently called upon to provide crisis assistance to potential proteges and/or their families. For example, emergency intervention may be required with regard to medical problems, infractions of the law, financial assistance, or emotional stress which necessitate immediate and decisive action. The program coordinator is oftentimes in the position to render emergency help in a situation which may be the only necessary occasion for advocacy intervention for a handicapped person or the family.

Parents and professionals also depend upon the program coordinator for information and referral services. The coordinator is frequently very knowledgeable about a community's programs, services, and facilities for handicapped people, and is accessible to people who are requesting information and advice.

An on-going advocacy function of the program coordinator is community education. The coordinator utilizes all available means (e.g., public media, speaking engagements, and individual contacts with professional and lay community members) for disseminating information about the nature of a handicapping condition and problems encountered by the handicapped group which is being served by the citizen advocacy program, the rights and needs of handicapped persons, the community's obligations for providing services, and the intent of the citizen advocacy approach.

NARC's Sponsorship Role

The citizen advocacy concept was first applied in Lincoln, Nebraska in January, 1970. The Lincoln Association for Retarded Children (now Citizens) was the sponsor for this first-time effort. This Association was assisted by Dr. Wolfensberger in implementing the program, and he continued to be involved during its first year of operation. This program became very successful during its initial period of operation and was awarded a Presidential Commendation by President Nixon in January of 1971. The second citizen advocacy project was implemented in Omaha, Nebraska immediately after the Lincoln program was established.

The merits of the citizen advocacy approach were demonstrated by the local projects in Nebraska, and NARC enthusiastically endorsed the concept. By July of 1972, NARC had received a federal grant from the Bureau of Education for the Handicapped, the National Institute of Mental Health, the Rehabilitation Services Administration of the U.S. Department of Health, Education, and Welfare in

order to establish a national Child Advocacy Program and promote the citizen advocacy concept.

The immediate task of the NARC Project was to develop materials which presented standardized information and guidelines for establishing and operating citizen advocacy programs. At that time, the citizen advocacy concept was being communicated primarily on a verbal and personal basis and the printed information which was available was sketchy and frequently presented inconsistent views of the concept and program. NARC developed a package of core training materials which consisted of:

1. a set of four books, Avenues To Change, which contains information on all facets of the citizen advocacy concept and approach, including specific information for advocates;
2. a 14½-minute film, "Something Shared," which presents general information on the concept; and
3. a slide presentation, "Citizen Advocacy: An Answer For Thursday's Child," which depicts and discusses the variety of advocacy roles which are possible within the citizen advocacy scheme.

The core training materials were developed in an effort to provide basic information to all persons who are generally involved in sponsoring, planning, operating, or evaluating a citizen advocacy program. Once training materials were completed for helping people establish local programs, the Project began developing specific information and materials for adequately preparing volunteers to provide advocacy services for mentally retarded people. An advocate training package was developed which included:

1. a manual, A Coordinator's Guide For Training Citizen Advocates, which provides specific instructions and information for training

advocates in a group setting; and

2. two slide presentations, "A History of Mental Retardation," which deals with the development of attitudes and practices toward mentally retarded people, and "Normalization," which acquaints volunteers with a philosophy upon which programs and services should be based.

In order to achieve rapid dissemination of the core training materials to state and local levels of NARC, the Project developed a national training program on citizen advocacy and selected sites for model citizen advocacy programs in each of NARC's six regions.

The national training program. The Project staff developed a curriculum for an eight-hour "Citizen Advocacy Training Workshop," which supplemented the core audio-visual and printed training materials. The workshop was conducted in conjunction with each of NARC's six Regional Conferences, which occurred between February and June of 1974. The participants of these workshops, Regional NARC Officers and key volunteers and staff of state ARCs, were trained to conduct similar workshops at the state and local level. This training strategy did result in a rapid dissemination of the core training materials to the local level. Training activities were assisted by staff of NARC's Regional Offices.

Model citizen advocacy programs. The Project staff provided direct technical assistance to selected ARCs in order to establish a model citizen advocacy program in each NARC Region. The model programs were established for the purposes of: (1) evaluating the Project's printed and audio-visual training materials; (2) demonstrating and documenting the benefits of citizen advocacy for mentally retarded proteges; and (3) serving as training and resource centers for other agencies and organizations which were establishing citizen advocacy pro-

grams within the respective regions. After providing extensive consultation for establishing the model programs, the Project staff began conducting extensive evaluations of the citizen advocacy approach.

The Project's evaluations of the model programs represent the first systematic assessment of the conceptual and programmatic aspects of citizen advocacy. The collection of the following types of data and information began in July, 1975 and will continue through June, 1976:

1. statistical information on advocates and proteges, relationship classification, and staff's program related activities;
2. proteges' progress;
3. program impact on local service agencies for mentally retarded people; and
4. effects of advocate training.

The Current Status of Citizen Advocacy

Since the initial application of citizen advocacy in Nebraska in 1970, the approach has been implemented in 30 other states. There are currently 129 local programs and nine state citizen advocacy offices.

Sponsors for citizen advocacy programs are primarily Associations for Retarded Citizens (ARCs). Approximately 75% of current citizen advocacy programs are controlled and operated by state and local ARCs. Of the remainder, a small number are independently incorporated, some are sponsored by other voluntary organizations (e.g., affiliated of United Cerebral Palsy Associations, Inc.), and others are controlled by service providers (e.g., public institutions). The ARCs are natural mechanisms for providing citizen advocacy for mentally retarded people, since these organizations have functioned as corporate advocacy agencies since the early 1950's.

NARC recently conducted a national survey of local citizen advocacy programs in order to obtain information on their progress and characteristics. A 15-item questionnaire was sent to the coordinators of the 117 programs which were operating at the time of the survey. Sixty-three of the 117 coordinators completed and returned the survey. The descriptive information resulting from this survey is summarized below.

Program growth patterns. The results of the survey indicated that the average growth of a local citizen advocacy program, based on the number of advocate protege relationships, was approximately 25, 50, 80, 86, and 117 pairs for the first, second, third, fourth, and fifth years respectively. These statistics do not necessarily represent potential growth, since the vast majority of programs were staffed by one professional person. For example, in contrast to the first year average of 25 relationships, one program (Dade County, Florida), which was just beginning at the time of the survey, was staffed with three professionals. At the end of the first year of operation this program had recruited and trained 93 advocates and matched them with proteges.

Funding mechanisms. One of the greatest problems faced by citizen advocacy programs' staff is long-range funding. The majority of local programs are funded under the authorization of either the Developmental Disabilities Services Act (DDSA), which is a short-term funding source, or Title XX of the Social Securities Act. Funding from the latter source is extremely difficult to obtain for this type of program in most states even though advocacy is an allowable service under the "protective services" section of the federal regulations for Title XX. Only a small number of local programs are receiving operating monies from private sources (e.g., United Ways, ARCs, and civic organizations).

Population of geographic areas served. Citizen advocacy programs are located in communities and cities with general populations which range from 25,000 to over one million. The majority of programs are serving cities with general populations of 100,000 to 300,000. There appears to be no relationship between the number of advocate-protege pairs in a program and the size of the general population in the area served.

Advocate characteristics. The results of the survey indicated that more than one-half of the advocates are twenty to twenty-nine years of age, female, and employed in white collar and professional positions. The paucity of male volunteers suggests the need for reassessing recruitment techniques and the manner in which the concept is communicated to the public.

Protege characteristics. Citizen advocacy activities are being directed primarily toward mentally retarded children and adults who live in community settings as opposed to large multi-purpose institutions. There are strong indications, however, that there is a trend toward serving greater numbers of mentally retarded adults, persons with other developmental disabilities, and institutional populations.

Types of advocacy activities. The survey indicated that the type of advocacy intervention which is being provided by a majority of advocates is emotional reinforcement for proteges. A little less than one-half of the advocates are providing a combination of emotional support and practical assistance. An extremely small number of advocates are providing only practical assistance. Separate research efforts by the Project revealed that the majority of proteges require practical assistance. Thus, there is a need for stressing to a greater degree the practical types of advocacy during the training of advocates.

In summary, the survey found that the citizen advocacy approach is popular

and wide-spread. There were several specific problems identified (i.e., short term funds, need for male volunteers, and the tendency for advocates to provide emotional support as opposed to practical assistance for proteges) which suggest the need for further refinement of some programmatic aspects of the concept. With the amelioration of these problems, the citizen advocacy approach should offer even greater potential for effectively safeguarding the rights and interests of proteges and insuring that they receive appropriate and needed services.

Misconceptions About the Concept

Several serious misconceptions about citizen advocacy have been voiced by those who do not understand the concept and, as a result, react to the connotations of the term "advocacy," which can stimulate a variety of unrelated or inappropriate ideas about the approach.

A major misconception is the belief by some that citizen advocates' major concern is being an adversary to professionals. In this context the advocate is viewed as a rabble-rouser-type individual who is overly eager to condemn and criticize the efforts of professionals. This image of advocates is inconsistent with the fact that the majority of proteges are being provided emotional support by advocates. Secondly, the intensive screening process which is used for selecting advocates minimizes the possibility of volunteers entering the program for self-serving or destructive purposes as opposed to having a sincere interest in promoting the rights and welfare of proteges.

Another major misconception is that parents' and professionals' roles and responsibilities will be diminished by citizen advocates. The intent of the concept is the opposite of this concern. The existence of advocates should serve to increase the accountability of professionals who provide programs and services for proteges. A major function of advocates should be to interact constructively

with professionals in regard to the proteges' needs and insure that professionals are responsive to these needs. In regard to advocates displacing parents, an advocate should not be assigned to a protege against the wishes of the parents. When advocates are matched with proteges who have parents, the advocate should respect the interests and concerns of the family and be supportive of the family's efforts. Under no circumstances should an advocate interfere with the legal and moral obligations of a family or between family members.

The citizen advocacy approach has been perceived by some as a duplication of efforts by service providers. Actually, the citizen advocacy concept specifically requires that professionals not provide direct services and function as a citizen advocate for the same person (client). The rationale for this requirement has been alluded to earlier--the professional who is employed by an agency or service delivery system must respond to the needs of the client and the policies, procedures, and structure of the agency or system, and there is thus a potential conflict of interest when the needs of the client are opposed to the needs of agencies or systems. From the basic standpoint of job security, even the most dedicated and concerned professionals are not likely to advocate for the client and against the policies, procedure, or structure of a system or agency.

A final misconception is that the citizen advocacy model does not provide for advocates being accountable once paired with a protege. This concern is without basis, since the concept stresses on-going communication between the programs' staff and citizen advocates.

Consumer Perspectives of Advocacy: A Panel Discussion

David Sloane, Moderator
Executive Director
Texas Association for Retarded Citizens

We are pleased to have an opportunity finally to let you hear from consumers. I have a comment or two about that and our place on the program, and what we will be doing here, which I would like to share with you before I introduce the panel. It is of some note that having spent two days talking about how and what we might do to protect and advocate for the interests of the developmentally disabled, we have now come into session to listen to the consumers themselves talk about their own interests and rights, and what they perceive to be needed from an advocacy and protective service system. The people you are going to be talking to today are consumers of services: they are cerebral palsied, or epileptic, or parents of handicapped individuals who are autistic or mentally retarded. They are consumers themselves, and they are in many instances perfectly capable of, and desirous of, advocating and protecting their own rights. They want a heavy and thorough voice in protecting those rights and in determining what kind of system is going to be developed to protect those rights. As a professional person in the field of mental retardation, I think I can say, with a good deal of self-criticism that we as professionals in this field tend to get somewhat blinded and side-tracked in our enthusiastic endeavors to advocate for and protect the rights of "our clients" without having first talked to those persons. The people you are going to be talking to today are people who quite frequently are not consulted about the services and programs they would like to have, about the activities in which they would like to engage, about their own rights, and how they would like to have those rights protected.

The only point that I really want to make today is that if we sincerely believe in a service delivery system, be it direct professional services in the

programmatic aspect or advocacy and protective services, if we are truly interested in a high quality first class system, we must, it seems to me, always remember that it is the persons who are being served who have the most right to speak on their own behalf and that the adequacy of any advocacy and protective service system will first and foremost adopt the principle of the least restrictive alternative. The least restrictive alternative in advocacy and protective services is to develop a system which will help developmentally disabled persons speak on their own behalf. I think we sometimes forget that.

I'm glad to have an opportunity as an employee of a consumer organization to chair a panel and introduce people who I know to be very fine consumers and consumer representatives who are competent and vocal spokesmen. They are members of the four organizations serving the developmentally disabled in Texas. These organizations are in the process of forming a coalition in Texas with the intent to be declared the Title II agency in the state to work with all the other agencies in the development of the advocacy and protective services systems. We have received a small developmental disabilities grant to help us put the coalition together and do some of the initial planning. I am glad that after two days these people finally have a right to tell you what they would really like to see in protective services and advocacy systems.

Marilyn Kristovich

Moderator: Marilyn Kristovich is a very active volunteer with the Dallas Association for Retarded Citizens and is currently serving as the president of that organization. She is the mother of a retarded son.

Ms. Kristovich: I would like to ask a question before I begin and you can answer it by a show of hands. I don't want to be facetious with the question, but how many here are mentally retarded? I know we all are, so don't everybody raise your hand, but I am very curious: are there any mentally retarded persons sitting out there? No. I have been in this unique position before. For some

reason, people have the misconception that a retarded person cannot sit here in this seat and in this case tell you what their needs are with regard to advocacy.

Now I also have another advantage today. For one thing, not being a professional I have made terrible notes: I scratched them out while standing up. Another thing, I can sit here and talk about my son and, as any parent knows, there is not anything nicer than talking about your own family. But in this case I am in a very unique position in that in the last few months I have probably become more aware than at any other period of my son's life just what an advocate would mean not only to him but to other people on his same level of mental retardation. For one thing the retarded can speak out for themselves, and I think with this whole program of advocacy, one of the greatest mistakes that can and will be made is for a group of professionals or even volunteers to decide policy for the mentally retarded, to make all the decisions for these people without talking to them or allowing them to express what they are learning, what they need, and what type of representation they need.

I want to touch just very briefly, and I mean very briefly, on the topic of legal and protective rights. I feel that there are many far better versed in this area than I am, but I will tell you the needs that have come to my attention. We have a lot of mildly retarded persons in the community and of course we are advocating community living. But parents and guardians are going to pass away some day. My son is now working and he is going to be wanting to live on his own. As a matter of fact, come this August, he is going to make his first attempt at apartment living. Well, one of the questions he asked me just recently was, "What if I want to buy a house some day and you are no longer here?" He is going to need legal advice some day. He is working at Sears in the stock room, and he will probably end up richer than any of us in this room, because of their profit sharing program. The way we have it figured out, at the age of 65 he is

going to have a minimum of \$250,000 retirement money. That's a lot of money for a retarded person. He is going to need legal advice; advice on how to invest that money--whether he should take those stocks and cash them in all at once. He is not capable of deciding this on his own; he will need an advocate to advise him, hopefully a legal advocate. I'm not going to go into other areas because I think you are all aware of these. As a parent I hope that when legal advocacy is mentioned, we do not get so bogged down in thinking of legal advocacy only as court cases that we forget the other legal needs of the retarded or handicapped.

Another need that I have become aware of, and this may seem very frivolous, is for a cookbook the retarded can use. I've seen "easy to cook" cookbooks, "I hate to cook" cookbooks, and children's cookbooks. But how about all these kids that are going to be living on their own? My son doesn't really know what a third of a cup is. Cannot some advocate agency come up with a picture cookbook for the mentally retarded?

Many of these young people are going to be driving automobiles. I know they have a verbal test for those that do not read but cannot some better means be devised for a retarded person to take the written portion of a driving test? They do not like to be labeled, and we don't like to label them as retarded. So I was confronted with the problem, do I go into the Drivers Bureau, tell them my son is retarded, and ask that they give him this test in some special way, when my retarded son sat on the other side of the car and said, "Mom, I don't want you to go in there and tell them I'm retarded. I'll do it my own way." Well, we spent a year going back and forth taking written tests. We took one every three weeks until finally we came upon the idea of taping it for him. We read it the way it was in the book, we paused, we broke it down into understandable English for him, another pause, we gave the answer. He played the tape every

single night and in time he was able to associate the way it sounded with what he would be seeing at the Drivers Bureau, and then connect with the simplified version that we gave him with the answer. It took a year but these people can drive and I think of all my children he is the best driver in the family and certainly the safest driver. Again, though, an advocate will be needed in a case where a parent does not fully understand what's needed to teach his child either how to read, take these tests or how to simplify it for him.

Another area for advocacy is banking and money management. This is very obvious to most of us, particularly to those who have any contact with a retarded person. They do not have a really good sense of money. Maybe the parents never gave them more money than what they needed to buy something at a given time. As a result, these children, if they do go out and work, suddenly have the idea, my gosh I've got all this money, and I've been wanting to buy this radio. Well they can go radio happy, and blow all their money. Retarded persons need advice when it comes to purchasing things. They are very impulsive. Quite often they won't wait for sales. An advocate can teach them by taking them out, pointing out sale items and explaining that you purchase items on sale if you have the opportunity. You don't just impulsively buy. They need to be taught how to bank, how to manage. And again there is a problem with what to do if they do bank. Based upon my personal experiences, I recently decided that since Stephen is going to be living alone, he will start another bank account. We have a joint account in his name and mine, but I felt if he feels that he can cope on the outside alone, then he has got to cope alone when it comes to opening a new bank account. Well he got into the bank and the lady behind the cage there started asking him whether he had another bank account anywhere and Steve said, "Yes." "Where do you have it?" "Well, I don't know." "Well, I mean the name of the bank." "I don't know." We have been going there for years but it had never occurred to me that I had always

gone with him and he really hadn't paid attention. Well, he was embarrassed. I think the girl was thinking he was here to hold them up if he didn't know where he had his money. Now again if he had an advocate, it would have been very simple to write down, on a card that he could put in his wallet, the bank account number and the name of the bank.

Maybe one of the most important things an advocate can provide is friendship. I don't think there is a parent of any handicapped child who wouldn't buy a friend for his child if it could be done for money. And I think that is what advocacy is all about. An advocate is a friend, someone there who is not going to over-protect you as a parent will do, someone to share your feelings with. I think that an advocate should be practically the same age as the retarded person. Obviously this is not possible when you are dealing with a small, very young mentally retarded person, but I think a retarded person or any other handicapped person in his or her teens should have an advocate who is very close to his age. They are far more open with someone whom they sense is their age. They will learn such things as dressing from a person closer to their age. The instinct for them to imitate one of their age group is far better in learning experiences than it is to have someone older trying to teach them the same thing. They want to learn, they want to imitate. And this can be the greatest teaching experience there is, an advocate working with a handicapped person, where both can learn. The advocate is going to learn just from being exposed to the problems of being handicapped, and the handicapped person will learn from that advocate.

Another thing that an advocate can do is to teach the handicapped person how to use public transportation, how to use community services, and make available to them phone numbers such as that of the Dallas Association. I doubt that many retarded persons know that they can call DARC if they have a problem. The parents know it, but they don't tell their children this. And someday those children

are going to grow up and be alone. They need to know that there is a home in the community where they can go to for help. And hopefully we will have the advocates there to lend a hand to them. We have been fighting tooth and nail to get funding for an advocacy program, which I think is the most visible program that the DARC has ever had an opportunity to begin.

Mary Brock

Moderator: Mary Brock is with the Society for Autistic Children. Mary is a parent and speaks from that vantage point as a consumer representative for the autistic.

Ms. Brock: Autism has been called the cruellest handicap possible because its victims have so much potential and so little help. These children are often beautiful, sometimes highly intelligent, but they cannot understand the world around them and they can't express their own thoughts and feelings. After years of being blamed for causing autism in our children, parents have won a tremendous victory in 1975 by having autism accepted as a developmental disability. For years and years psychologists and psychiatrists have said that autism was caused by parents rejecting their children. Well, autistic children had been rejected but not by the parents. They had been rejected by almost everyone else. Institutions, schools, and sometimes doctors would not serve them. Parents are actually the only ones who have not rejected them. You sometimes talk about poor institutions as being such bad places, but sometimes even these won't accept our children. Some parents would be grateful for even that.

I would guess that there are very few people in this audience who are not familiar with mental retardation, epilepsy, cerebral palsy. How many of you are familiar with autism? A few. This is a much better audience than most would be. We are going to have to begin at step one: at the beginning. We are going to have to educate the people about autism. Those who serve and those who will be advocates for autistic persons are going to have to be taught about the problems

of autism and the methods of treating autism. My opinion of the medical profession changed very drastically when I became the parent of an autistic child. My daughter was diagnosed because of a newspaper article and not because of the medical profession. In fact, it took us quite a long time to convince the doctors that she had autism. We are just years behind other developmentally disability groups. Things that others have had for years we are going to have to try to get for our children now.

Autism is a syndrome, there is no known cause or likely causes, and no known cure as yet. Autistic children have problems of communication and problems of processing sensory information. They have problems in relating to other people, and problems in modality, such as hand flapping and spinning, and movements. With a world that is so confusing to them you can see that they have emotional disturbances. Their behavior is very disruptive and to say the least it is socially unacceptable.

We have found that most places don't want this kind of children in their programs. We want places that will accept our children as they have other disabled children. Parents want the same kind of services for autistic children that other people want for their children. We want professionals who can accurately diagnose and treat autism, professionals who know what it is all about. We want professionals and advocates who are open-minded about autism. With these multiple handicaps they cannot be approached in the same way that others can. Sometimes it takes drastic means just to reach these children. We want professionals who will at least be willing to try something different. There is talk about the mega vitamin theory. I don't know if this will work with autistic children or not but we will never know until someone tries it. But generally we have found that people are just closed-minded about many of the things that we would like to try. We want infant stimulation, nursery programs, educational

programs and respite care. Autistic children are some of the most difficult to live with. Parents desperately need respite care. We need short- and long-term residential programs. Some of the children will need good residential or institutional services. A few of our children will be able to function in the mainstream, in the big world. Most of them will fit somewhere in between. There seems to be very little provision for this middle ground. Most of our children will probably need a protected environment. We need pre-vocational, vocational programs, social and recreational programs. Like normal children, autistic children need the services that will help them grow into productive citizens.

Most of the other developmentally disabled groups have those within their group who can represent their group as consumers. As Marilyn was saying there are mildly retarded persons who can talk and who can say what they want. Unfortunately because of the nature of the disability of autism, rarely will you find an autistic child who will be able to do this. It would be very difficult for the autistic citizens to speak for themselves. We need someone who will represent them, and who will this be? We need those who will really understand the situation of the autistic. Speaking for parents of the autistic, I'm glad that we are here...at last.

Carol Cervenka

Moderator: *Carol Cervanka is with the Dallas Epilepsy Association and serves on the State DD Council. She also has epilepsy.*

Ms. Cervanka: I suddenly realized sitting here why the home football team has the advantage. This is one of the few times I've ever been at a national conference that I haven't been assailed by just a whole host of butterflies rumbling around in my stomach. This is home, and you're our guests; I hope you are having a good time.

One of the difficulties in advocacy is understanding what the problems are.

And nothing was brought home more clearly to me than when David said I was a consumer on the DD Council. I came on the Council as a consumer, but somebody up there, and I don't know who, says you can't be a consumer and an agency representative. And so now I am an agency representative and I'm no longer classified as a consumer spokesman. So I guess that for at least one portion of my life I got rid of that label. I don't know that it is preferable one way or the other. For me epilepsy has been pills to take and a blamed nuisance to interpret to the rest of the world. It hit when I was 22 years old and I knew the day after the seizure that I was the same flakey character I was the day before. It wasn't as much hassle as it could have been. If you are a teenager, and identity is a real problem if you have just one zit, you've got a real problem when you are having seizures and you are not there to know what they are like and everybody else is telling you that you did something that you would never do if you had any control over it.

I hear the plea from Marilyn and Ms. Brock for services. When we formed the Dallas Epilepsy Association, I guess because we didn't know where to start we started with human need. What do people need to function appropriately and correctly in life? Because we have already talked about autistic children and adults, and the retarded, I will talk about persons with epilepsy who have a normal or above normal IQ. What are the problems of the epileptic with the normal IQ who is just going to go out and try to function in today's world, and what kind of things does he need? He needs first of all the education to enable him to become his own self-advocate. The battles that I fought more years ago than I like to tell you about when epilepsy first hit me, are no longer the battles that face people today. Part of this is because they were won one by one, small victories, on an individual basis. The victories were won not because the system was changed by a knight on a white horse, but because individual change ultimately brought about the group change

that we all seek. That viable difference in whether you can drive a car or not is now reduced to waiting a year, and when you have been seizure free that year and have demonstrated levels of maturity and responsibility to operate a motor vehicle, you may drive. Now that makes much more sense.

In advocating for ourselves or for others, some of us have gone overboard. That all important word keeps cropping up--credibility. Don't ask for the extra advantage. I don't think any of us at this table seek or want the extra advantage. We just want the same advantage and the protection from being denied an opportunity. Often times we need more protection from all of the blessings of society than we need from all of its curses.

When you have educated the individual to the limits of the potential that he or she has to be his or her own self-advocate, the professional advocate must confront the system and make it do what it should do. If it says, I will do this for you, then the professional sees to it that the system does it. And then and only then do you begin to bend the system and make it change. But you cannot know how to make the system more amenable to the needs of the developmentally disabled if you do not speak to the consumer.

Tom Morrison

Moderator: *Tom Morrison is Executive Director of the United Cerebral Palsy Association of Dallas. He has cerebral palsy.*

Mr. Morrison: Would all you men in the audience raise your hand? OK. Now all the ladies in the audience raise your hands. Now all you others raise your hand. Nobody? Come on, in a group this size there are bound to be one or two. You see what I just demonstrated? Graphically, that no one likes to be labeled. Believe me, if there were one of you in the audience you damn sure wouldn't raise your hand. Right? And I think that this is what many of the people that you have been hearing for the last few days have been saying to you.

You know, they pick this marvelous hotel here in which to have a consumer conference, but some of the consumers are having a hard time getting around. They should put a sign up here that says uprights' restrooms that way--handicapped people's restroom this way, because if you don't know that some johns are down the hall, you've either got to go up a flight of stairs down yonder or find a convenient tree outside. This morning I really got worried for a while because I knew that at 1:30 yours truly was going to have to figure out some way to pole vault up on this damn stage. You know I kept seeing these guys jump on and off that thing over there, and I thought, me and my walker are going to have a problem come 1:30. Thank God some good soul did put a step over there, so if I can make it back down I got it made.

Now I want to speak just briefly about something that I spoke on in Washington not too long ago. Ladies and gentlemen, you can legislate all you want, the government can legislate all it wants, the city can legislate all it wants, but there is a vast difference between legislative mandate and attitude toward implementation of those mandates. The black population found this out a long time ago--you know they have had their rights since 1964. The law said you can not discriminate against Blacks as far as jobs are concerned. But let's be honest ladies and gentlemen, and right today, there are employers who, if they really and truly do not wish to employ a Black, are going to figure out some way to get around all the laws on the book.

I know legislation is important, because it gives attorneys the legal groundwork by which to pursue attitudinal changes. But in the hard core reality of it you and I as advocates have a selling job to do. I am not sure at all that we need to sit here listening to a group of professional politicians educated in the law. I am not sure at all that at the next conference you should not get a marketing expert from General Motors or some other

very successful corporation to come up here and teach you how to market a product. It is just that simple, that's just what we are doing. We are literally trying to convince people that it's good business to employ a disabled person, that it's good business and just as easy to make buildings free of architectural barriers as it is to build a whole bunch of stairs.

And that brings to mind another little thing. We often get hung up on thinking about you can only eliminate architectural barriers by building ramps. I visited a place down in Houston with a ramp on which you've got to roll 14 miles just to get up one flight of steps. It looks like a damn rat maze--you know it goes this way, that way, this way, that way, and if you are successful in making it to the top you may have enough energy to go to work. I told my good friend down there Frank Berecka that he should allow some rest time at the top before you have to punch a time clock. That's my own opinion. Hell, I didn't like that ramp; you know I'd rather go and take my chances of falling down the steps. It's just too much trouble to use that stupid ramp. Some countries in Europe, for example West Germany, have realized that it would be physically impossible to build a ramp long enough to get to their subway train systems. They would have to build a ramp four blocks long to get down there. And if you are going to walk that far, why ride the damn train? The Germans saw there are other alternatives to this problem and they simply built a wheel chair lift, right along side the steps. You know, it doesn't bother the steps at all. People who can maneuver the steps go right on about their business. The other people who are in wheel chairs, or aged, or having any other disabilities, get on that lift which takes them to the bottom, no problem. It takes up very little room and it works very successfully.

There are many many alternative ways to eliminate architectural barriers. It is your job and my job as spokespeople for the mobility-impaired to show people,

show drawing engineers, show architects, show school principals and motel and hotel operators that there are alternatives. They don't have to build a ramp 14 blocks long. There are other mechanisms to use without totally disrupting the entire building. So in reality, you and I have a massive selling job to do. And I'm not sure that anybody in governmental institutes, whether it be federal or state, is a good enough salesman to do that. I'm concerned about that, to be honest with you. We have had physically crippled people on this earth since time began. And yet we still build facilities that a certain section of our population can't get in. How many years do you want to wait? That's the key. The black population in about 1968 or so finally got tired. They said to heck with it, we're not going to wait another hundred years for bureaucracy to turn its very slow cogs and things to filter down from up there some where. Nobody quite understands where up there is. When you want to say up there you are really talking about right here. Right here in Dallas, ladies and gentlemen, there is a man running for mayor of this city, who, if he is elected, will set back the causes for disabled people at least 10 years. So when we say up there, I don't think we really mean it. We had better start saying right here. Right in your own home community. And it is my responsibility and yours to sell people on the idea that, by golly, if you put a lift on those stairways out there more physically disabled people might stay at this hotel; therefore you are improving your business prospects. We actually have several motel chains in this country now advertising that they cater to the physically disabled. You and I, their advocates, need to give those places our business. It's simply a job of selling and if you are a good enough salesman you can convince a person to change his attitude about the problems of the mobility-impaired.

Human Rights Advocacy Committees
and
Citizen Advocacy in Florida

Roberta Malavenda
Citizen Advocacy Director
Florida Association for Retarded Citizens

Introduction

Florida has recently passed landmark legislation for the mentally retarded. The Bill of Rights for Mentally Retarded Persons was signed by Governor Askew in 1975 with a total of 5.2 million additional dollars for its partial implementation. The Florida Association for Retarded Citizens (FARC), its local affiliates, and its advocacy mechanisms played an instrumental role in securing the passage of that legislation, which guarantees the right to unrestricted communication; the right to own property; the right to receive education and training; the right to recreation and good physical fitness; the right to receive prompt and appropriate medical treatment; and the right to be free from physical restraint.

Florida has every reason to be proud of the Bill of Rights, but as we know legislation in and of itself is not enough. Its success and ultimate benefit to retarded citizens is dependent on the continued efforts of citizens to monitor its implementation, to speak out on issues, and to continuously insure that human and civil rights are being upheld.

The FARC had initiated two advocacy mechanisms prior to the passage of the Bill of Rights. Both mechanisms, the Human Rights Advocacy Committees and the Citizen Advocacy program, are in operation today to expand and protect the human, civil, and legal rights of retarded persons in the State of Florida. The purpose of this paper will be to briefly review their history and current activities.

Human Rights Advocacy Committees

Background

In April 1972, Florida's attention was focused on the Sunland Training Center, a state institution, at Miami. Repeated incidents of abuse and denial of human rights concerned and outraged Miami citizens. Through the efforts of the Acting Superintendent and the Dade County ARC President, Mr. Leo Plotkin, the first Human Rights Advocacy Committee (HRAC) was established in July 1972.

The concept embodied in the Miami HRAC was found to be an answer to the need for citizen input and citizen monitoring to assure that the rights of the mentally retarded citizens residing in a state institution were not violated. Mr. Plotkin, who became chairman of the Miami HRAC, presented a proposal to the FARC Board of Directors, extending the concept to all programs and services funded by the Division of Retardation and asking for Committees to be developed in the eleven client service regions of the Florida Department of Health and Rehabilitative Services (HRS). The Division of Retardation and the FARC reached an agreement¹ and by November 1, 1973, the first six Human Rights Advocacy Committees were established in those regions which had major residential facilities. By July 1974, Committees in the remaining regions were constituted. FARC Citizen Advocacy Director, Ms. Carol Horvath, and Division of Retardation lawyer, Mr. Frank Johns, provided staff assistance to the Committees.

The following statement from the initial agreement summarizes the original

¹The original agreement between the FARC and the Division of Retardation outlines Committee operation and structure as well as the appeal procedure. It is available from the FARC office.

purpose of the HRACs:

- A. The purpose of Human Rights Advocacy Committees is to serve as a third-party mechanism for protecting the health, safety, welfare, civil and human rights of retarded individuals. Specifically, it shall discover, investigate and determine the existence of abuse within any program or facility operated, funded and/or regulated by the Division of Retardation, Department of Health and Rehabilitative Services. This abuse may consist of physical or mental punishment, unfair discrimination, withholding legal rights, the denial of social or community participation, the failure to recognize a retarded person as a human being, entitled to all the rights of humans.
- B. To review and react with respect to any research program directly or indirectly affecting the lives of retarded persons insofar as their Human Rights may be concerned. Upon approval of the research, the proposal would then be forwarded to the appropriate authority for further consideration.
- C. Any existing program or service is subject to review by the Human Rights Advocacy Committees. Any new or revised program may be reviewed by the committee or designated sub-committee prior to its implementation.

The HRAC's, composed of parents, retarded citizens, Retardation staff, professionals, and interested community persons, met monthly. Under the agreement between the Division of Retardation and FARC, the Committees had the right to appeal when a problem could not be resolved. Through this procedure, Committee concerns and recommendations could be brought directly to the Governor.

The HRACs were responsible for helping to realize many positive changes in institutional and community life for retarded citizens. Parents, clients, staff, and members of the community were encouraged to bring their concerns before Committee members.

Several Committees reviewed the use of restraints in the institutions, and their efforts contributed to a gradual reduction of the use of restraints and the substitution of programs. Committees reviewed drug administration, diets, new programs, as well as suspected cases of abuse. Because of their interest in and concern for adequate medical treatment, the Committees were responsible for the creation of pilot Medical Program Review Committees in three Sunlands; because of their documentation of the lack of adequate programs and services in the institutions and in the community and due to their exposure of abuse, there was a renewed public interest in the needs of mentally retarded citizens. A series of legislative investigations and hearings were held around the state, all of which culminated in the passage of the Florida Bill of Rights.

The creation and operation of the HRACs were not without problems. It was sometimes difficult for the volunteer members to separate administrative decisions from the scope of the Committee's legitimate concerns. The support and cooperation of the Division of Retardation administration and staff was essential, and in a few cases this was not easily attained. The monthly meetings were long, and the job of the Committee sometimes appeared overwhelming to the volunteer members who had no staff to assist them in their investigations and research. However, most committee members were extremely conscientious and gave generously of their time and expertise.

The Reorganization Act of 1975

The HRACs were considered to be an effective, independent, third-party

advocacy mechanism. The FARC was successful in securing legal status for the Committees and for extending the concept to include all programs and services under HRS.

The Reorganization Act of 1975 created a statewide Human Rights Advocacy Committee, composed of eight citizens to be appointed by the Governor.² Under the Act, the new HRS Districts were mandated to establish at least one district HRAC to provide for the protection of rights of all clients of HRS. The Mental Retardation Human Rights Advocacy Committees were "grandfathered" to continue their specific task of monitoring retardation services and programs and investigating abuse.

The State Human Rights Advocacy Committee's responsibilities include:

- (1) Serving as a third-party mechanism for protecting the constitutional and human rights of any client within a program or facility operated, funded, or regulated by the department (HRS);
- (2) Receiving, investigating and resolving reports of abuse or deprivation of constitutional and human rights referred to the Human Rights Advocacy Committee by a district (or mental retardation) Human Rights Advocacy Committee;
- (3) Prior to implementation, reviewing and making recommendations with respect to the involvement of departmental clients as subjects for research projects insofar as their human rights may be affected;
- (4) Submitting an annual report to the legislature concerning activities, recommendations, and complaints reviewed or developed by the committee during the year;

²The Reorganization Act of 1975 would provide the reader with a description of the current composition, duties, and appeal procedures of the HRAC. The Act, and guidelines developed by the State HRAC, are available from the FARC office.

(5) Developing policies and procedures to carry out the purposes of the law, including procedures for appeal. An appeal to the state Committee is made by a district (or mental retardation) Human Rights Advocacy Committee when a valid complaint is not resolved at the district level. The statewide Committee may appeal an unresolved complaint to the Secretary of HRS. If after exhausting all remedies, the statewide Committee is not satisfied that the complaint can be resolved within the department, the appeal may be referred to the Governor.

The Mental Retardation HRACs had to reconstitute themselves to satisfy the requirements of the Reorganization Act. The committees had to conform to the new geographic districts as well as to a change in committee composition (Division of Retardation staff no longer serve as members of the Committee, and the Committee was reduced in size to 11 members). Each district and MR Committee could establish its own operating procedures.

The Role of the Florida Association for Retarded Citizens

While the effect of the new legislation was to abrogate the agreement between the FARC and Division of Retardation (now the Retardation Program Office), the FARC still considers the growth and efficiency of the MR/HRACs as a high priority. FARC has pledged to "monitor the monitors"³ to insure that the committees adequately protect the rights of retarded citizens and remain independent, third party advocacy mechanisms, free from government domination.

The Florida ARC President is a Governor-appointed member of the State Human Rights Advocacy Committee, which is currently establishing guidelines for the operation of all Committees and will serve as an appeal body under the 1975 legislation. FARC has specifically urged the Committee to monitor the

³ FARC Position Paper with Respect to Human Rights Advocacy Committees, available from the FARC office.

Bill of Rights and the reorganization of HRS as it affects retarded citizens.

It should be noted that both the Secretary of HRS and the Retardation Program Director have been very supportive of independent, non-governmental advocacy mechanisms. According to a statement by the Retardation Program Director, Fran Kelley, "The positive action of our HRACs and our Citizen Advocates have led to many improvements of care for the retarded in discovering weaknesses in our programs for clients, individual attention, improved treatment, institutional reform, and more open communication."

Citizen Advocacy

Background

A second component of Florida's current advocacy system is Citizen Advocacy, a state-wide program which seeks to recruit volunteer participants in citizen advocacy roles. The Florida program is based on Wolf Wolfensberger's Citizen Advocacy scheme, and the Citizen Advocacy materials prepared by the NARC Child Advocacy staff have been used in implementing the concept.

The Citizen Advocacy Project officially began on April 2, 1973, with the hiring of the FARC Project Director, Ms. Carol Horvath. Funding for the program is through a five-year Developmental Disabilities Service Act grant to FARC. The purposes of the project as stated in the initial grant proposal were: (1) public information; (2) state-wide development, including material design and development; (3) implementation of the advocacy concept and overall supervision of and consultation with regions of the state in setting up advocacy programs.

A demonstration project, whose purpose was to develop and test materials and procedures and to serve as a training site for new coordinators, was part of the initial grant proposal. The demonstration project was established in

July 1973 in Gainesville, Florida, a university community. Citizen Advocacy was enthusiastically received in Gainesville, and in two and a half years of operation, over 200 volunteers have been involved in advocacy roles, ranging from short-term to long-term, expressive and instrumental. Recruiting, screening, matching, and follow-along procedures and forms were developed and are currently in use in Florida's Citizen Advocacy programs.

In September 1975, Ms. Horvath resigned as FARC Citizen Advocacy Director to accept a position with the Georgia ARC. Ms. Roberta Malavenda, the Gainesville Coordinator for two years, became State Director, and Mr. Frank Leclerc was hired as the Demonstration Project Coordinator.

Role of FARC Citizen Advocacy Office

Four additional Citizen Advocacy programs have been organized by FARC based on the materials and procedures developed by the Demonstration Project and the FARC Citizen Advocacy office.⁴ The FARC Citizen Advocacy Director provides technical assistance to each program through frequent on-site visits, the preparation of a Coordinator's newsletter, and periodic meetings of the Coordinators. A FARC Citizen Advocacy Steering Council, composed of proteges, advocates, representatives from United Cerebral Palsy, the Epilepsy Foundation, ARCs, and other citizens, provides the state program with important input and advice.

⁴Materials developed by the Florida ARC Citizen Advocacy office include: (1) brochure, "What It Means to be a Citizen Advocate"; (2) Citizen Advocacy handbook (for new advocates); (3) Citizen Advocacy manual (for groups interested in starting a program); (4) Organizing a CA Community Workshop; (5) Citizen Advocacy in Florida (history of Citizen Advocacy in Florida; description of current programs; examples of all forms, procedures, and guidelines, including institutional advocacy); (6) A Coordinator's Manual (in progress). Available from the FARC office.

Structure and Operation of Florida Citizen Advocacy Programs

The Florida Citizen Advocacy programs closely follow the model outlined in the NARC "Avenues to Change" series. All of the programs have a full-time coordinator, advisory committee, required training for all advocates, and emphasize instrumental advocacy. A Citizen Advocacy "flow chart" developed by Shirley Schekman, Citizen Advocacy Director, Dade County ARC, describes the operation of a local Citizen Advocacy program (see page 158). A more detailed explanation of procedures and forms can be obtained by contacting the FARC.

Summary of Existing Citizen Advocacy Programs

The Gainesville Citizen Advocacy program, funded through a Developmental Disabilities Service Act grant, has a full-time coordinator and a part-time secretary. The program serves all developmentally disabled citizens. Two advisory committees--one for the institution and one for the community--have been organized to provide input and assistance.

Instrumental advocacy was stressed from the outset, and the Gainesville program gained a nation wide reputation for its involvement in securing and monitoring services for proteges residing in a large state institution (Sunland). Citizens from all walks of life and of all ages were in fact reporting alleged abuse, pressuring for individual tooth brushes, securing hearing aids and speech programs, participating in protege's staffing and giving a "third party" opinion, and obtaining foster parents for their proteges. Advocates also served as liaisons to Sunland parents who live outside of Gainesville; many helped in their protege's transition from the institution into community facilities by providing new community experiences.

Advocate activities in the institution were not without their problems and repercussions. Because the institution was large and the program was new,

there were initial misunderstandings and misconceptions. Because advocate training stressed normalization, the right to privacy, etc., advocates' questions and demands were bound to cause concern on the part of institution staff not used to "outside" involvement. With time, however, the Citizen Advocacy program was accepted by staff who in many cases saw Citizen Advocacy as a needed and welcome service to clients. A periodic review of advocate guidelines and procedures by advocates, proteges, and staff, as well as frequent in-service training for staff, played an important role in the acceptance and success of the program.

The Gainesville program currently has 75 advocate-protege relationships, with approximately half of the proteges residing in the institution and half in the community. Expansion of the program will be dependent on the securing of additional staff, which is not likely in the foreseeable future.

Citizen Advocacy programs have also been organized in Miami, Orlando, Jacksonville, and Tallahassee. The Orlando Citizen Advocacy Coordinator, a CETA employee, has done an excellent job in involving representatives--professionals, parents, and consumers--of all of the developmental disabilities in every aspect of her program. The Miami program, sponsored by the Dade ARC, is the largest Florida Citizen Advocacy effort and has been in operation one and a half years. The Miami program perhaps leads the nation in the number of advocates recruited and trained in one year. Over 120 matches are currently active; the program is still expanding with the possibility of a fourth staff person being added in the very near future.

Relationship Between Citizen Advocacy and the HRACs

Citizen Advocacy Coordinators are urged to work closely with the MR/HRACs in their district. When a protege problem cannot be resolved through normal administrative channels, or when an abuse is suspected, the Citizen

Advocacy Coordinator and/or the advocate brings the matter to the attention of the HRAC. When a Citizen Advocacy Coordinator becomes aware of collective denial of services or abuse, he or she has a responsibility to report it to the HRAC. HRAC members are also urged to refer proteges to the Citizen Advocacy office for possible monitoring of services and follow-up.

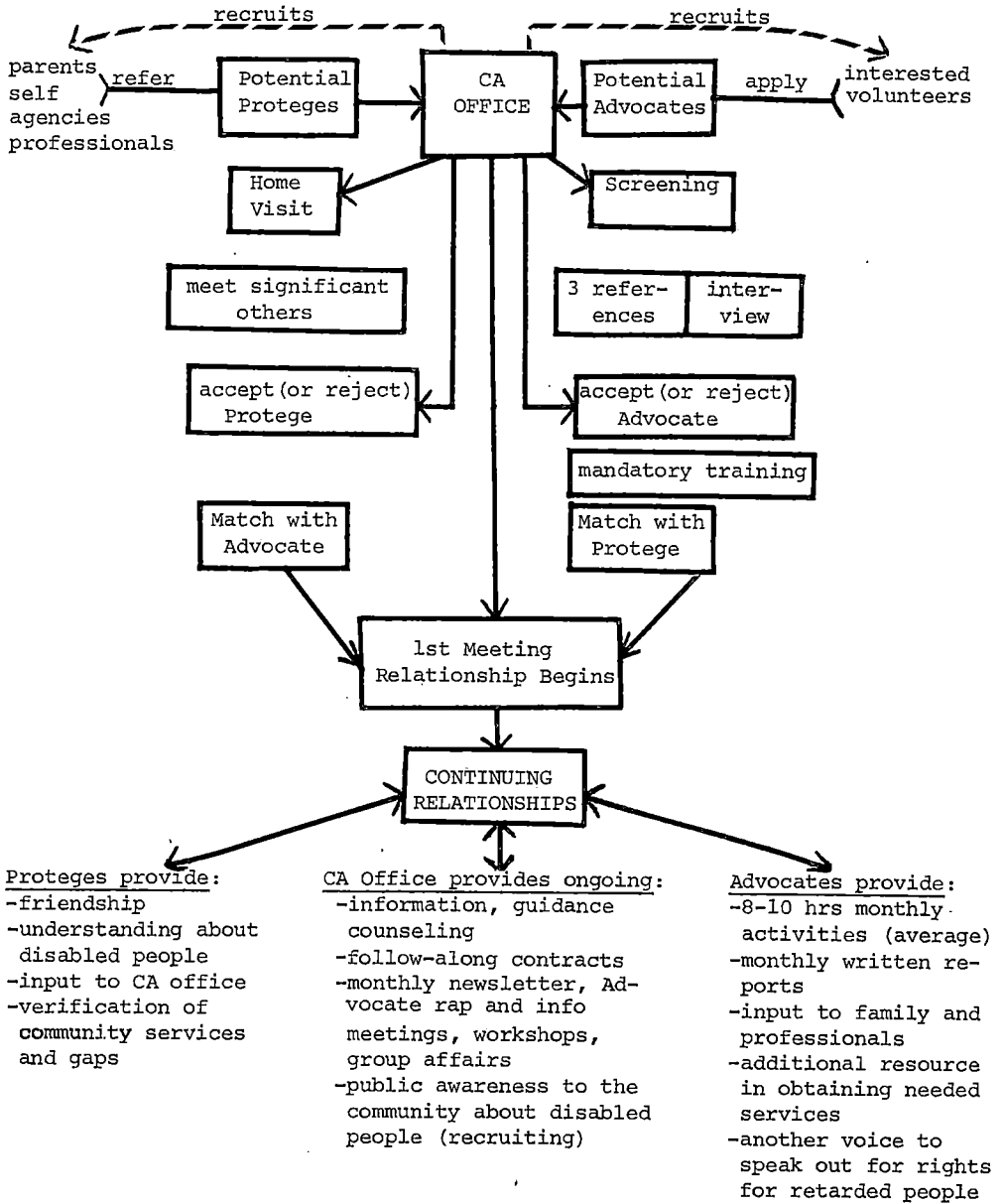
Future Goals of Citizen Advocacy

The expansion of Citizen Advocacy into as many counties as possible is one of the goals established by the Steering Council. An advocacy program in a rural county is currently being explored. The increase in the number of programs is of course largely dependent on the availability of funds. More instrumental and formal types of advocacy roles are also being investigated, such as limited guardianship and advocacy for the mentally retarded offender.

Title II

Two components of an advocacy system for developmentally disabled citizens--Citizen Advocacy and Human Rights Advocacy Committees--are in operation in Florida. It is my belief that three additional components--legal advocacy, guardianship advocacy, and self-advocacy--are needed to complete the system. These components should be interrelated in such a way that they will complement each other and provide a full continuum of advocacy services for the developmentally disabled. Fragmentation and competition for funding and power must be avoided at all costs. Perhaps this can be avoided if all the components are administered by one agency, but whatever the structure, the relationship between the various components must be clearly defined. In addition, I would like to strongly urge that consumers themselves be involved in all aspects of the planning and implementation of each state advocacy system.

Citizen Advocacy Flow Chart



Ohio's Personal Advocacy System

Carolyn Knight
Personal Advocacy Director
Ohio Developmental Disabilities

Ohio is unique in its effort to establish the advocacy system mandated by the new Developmental Disabilities legislation in that our state has three "pieces" or components already in operation. The system is centrally administered by Ohio Developmental Disabilities, Inc., and has a private nonprofit Board representing all four of the disabilities, a Legal Rights Office, a legal advocacy system attached to office of the Chief Justice of the Supreme Court, and a Protective Service and Guardianship program presently under the administration of the Division of Mental Retardation and Developmental Disabilities, which must be made to a non-provider agency before it can qualify as a part of the mandated system. Ohio's problem is one of deciding how these components best "fit together" to maintain a continuum of service and yet also maintain some degree of independence to serve as a check and balance on each other.

On February 5, 1973, the State Office of Personal Advocacy was established by a resource development grant from the Developmental Disabilities Planning and Advisory Council. The Office is staffed and administered by the consortium board, Ohio Developmental Disabilities, Inc., and staffed with a Personal Advocacy Director and a secretary. An Advisory Committee composed of representatives from the areas of mental retardation, cerebral palsy and epilepsy (autism to be added) has been established to provide guidance and direction to this State Office.

During the past three years, seventeen local Advocacy programs serving the developmentally disabled have been established and maintained by the State Advocacy Office with the help of additional funding awards from the Council which were used as Advocacy program seed money grants. Requests for Proposals

(RFP's) were sent to all organizations which might be considered appropriate vehicles to operate Advocacy programs--ARC's, UCP groups, etc. The Personal Advocacy Advisory Committee had the responsibility for screening the seed money proposals and then submitting their funding recommendations to the Ohio Developmental Disabilities, Inc. Board for final approval.

Local Advocacy programs have been established with an eye to geographic location as well as to specialized programmatic thrusts to meet special problems. Advocacy programs are currently in operation in every service district in the state. Appalachian southern Ohio has a high priority need for all services for the developmentally disabled and three programs service this area. About half of Ohio's existing programs are operated by ARC groups, traditionally considered one of the most appropriate vehicles for this volunteer based service. However, since there was such an overwhelming response on the part of other private voluntary agencies, such as Big Brothers, which have heretofore had little experience or interest in the developmentally disabled, the Personal Advocacy Advisory Committee felt that it might be worthwhile to fund some of these groups on an experimental basis. This new involvement gives the whole concept of Personal Advocacy a much broader base as well as affording other community agencies an opportunity to gain some much needed expertise in working with the developmentally disabled.

A special problem became apparent in the first year of operation and special programs had to be established to solve it. Advocacy programs, mandated in Ohio to serve the developmentally disabled, experienced much difficulty in serving the individual with the primary diagnosis of epilepsy. Thus, two local Advocacy programs under the auspices of Easter Seal Societies have been established with a major thrust of serving this segment of the developmentally disabled population.

The Advocacy system is also interested in becoming actively involved with

institutional residents. To this end an Advocacy program has been established within Applecreek State Institute, but is administered by the public institution's aggressive Parent Volunteer Association, an independent organization which has no ties to the state service delivery system. This all important independent administrative structure eliminates the possibility of a conflict of interest on the part of Advocacy staff, a factor which can easily negate the whole concept of advocacy.

During the past three years, the Nisonger Center, one of Ohio's UAF's, has received a grant from the Developmental Disabilities Planning and Advisory Council to provide training workshops for coordinators of local Advocacy programs. The state office has acted as a consultant in these workshops with authority to review and comment. The State Office has been extraordinarily pleased with the training which the Advocacy staff have received. Nisonger is responsible for 14 days of training, and the sessions are scheduled on a two-day basis once a month. The training provides broad-based information useful in serving the developmentally disabled rather than specific Advocacy program philosophy or guidelines for training objectives.

Thus, Ohio has what is probably one of the most diverse systems of advocacy in existence. We are very pleased with our system, which is to our knowledge, the largest program network in the country today. We hope that our system will not only be maintained but expanded as interest and awareness of the merits of the program grow throughout the country.

Ohio Legal Rights Service

Douglas Rogers
Director
Ohio Legal Rights Service

The Ohio Legal Rights Service was established on July 1, 1975, pursuant to a state statute (S.5123.94 of the Ohio Revised Code) passed in 1974. This statute was part of a larger bill commonly called in Ohio the Bill of Rights for Mentally Retarded Individuals (Senate Bill 336). Pursuant to this bill, the Legal Rights Service was created to protect the rights of individuals in institutions for the mentally retarded, individuals who have been in such institutions, and individuals threatened with such institutionalization.

The Director of the Legal Rights Service is appointed by the Chief Justice of the Ohio Supreme Court for a five-year term, and the remainder of the staff is hired by the Director. The Legal Rights Service is independent of the Office of the Attorney General and the Department of Mental Health and Mental Retardation. After attempting to achieve administrative resolution of disputes, the Legal Rights Service has the statutory authority to initiate litigation.

I would now like to describe the range of activities in which the Legal Rights Service participates. I want to do this to show that not only can legal advocacy help clients, but the (1) legal advocacy entails much more than just litigation, and (2) a legal advocacy system for mentally retarded individuals can actually prevent litigation.

The most frequent activity of the Legal Rights Service is individual client representation. For instance, we are now representing about 50 different clients with a range of concerns, the most common of which is the desire to be discharged from an institution to an appropriate community setting. Since July 1, 1975, we have helped around 80 clients obtain discharges from

state mental retardation institutions. These clients, as of July 1, 1975, due to the passage of aforementioned "Bill of rights," had the legal right to be discharged. We did not have to file suit to obtain the release of any of these clients, however, because we always first approached the institution administrators and advised them that the clients had the legal right to be discharged. If residents who have a right to be discharged are not released for long periods of time, the chances are increased that they will be harmed by their periods of detention and that they or their guardians will bring damage suits against the state or its officers for violating the rights of these residents. The intervention of lawyers at a relatively early stage to point out to administrators that certain residents do have a right to be discharged both helps the residents and prevents litigation.

The Legal Rights Service also approaches problems through system-wide negotiations and/or investigations. For instance, in September of 1975, it appeared that the Department of Mental Health and Mental Retardation was going to fire all 1400 resident employees of state institutions for the mentally retarded, but not fire any non-resident employees. I suggested to the Department that such action would constitute discrimination against the handicapped, and would be illegal under both federal and state law. The resident employees were not fired in October, nor have they been fired so far, and for the last six months the Legal Rights Service has been negotiating with various employees of the Department on what might be an appropriate resolution of the resident labor question. Without a legal advocacy system in existence in September of 1975, all of the resident employees would have been fired in October, and damage actions brought by private attorneys very possibly would have resulted. Although the matter has not been resolved yet, at least for six months over 1,000 residents have been allowed to keep their jobs (they would have had nothing to do if they had been fired), and litigation has been avoided.

Another area of Legal Rights Service activity has been investigation. A number of months ago, the Director of the Department of Mental Health and Mental Retardation asked the Legal Rights Service to participate in an investigation of the health care services provided for residents at one of the state mental retardation institutions. One of the attorneys of the Service spent months working on a report which has been submitted to the Director and which makes thoughtful and significant recommendations for the improvement of health care services at the institute. Some of these recommendations have already been accepted, and it is hoped that the Department will react positively to the full report so that conditions at the institution will be improved. It should be noted that litigation has also been avoided here.

The Legal Rights Service also participates to a certain extent in the legislative process. It has, for instance, worked on proposed statewide zoning legislation concerning the establishment of group homes in the community, and it has presented testimony before a legislative committee which subsequently drafted legislation requiring all the state institutions to be brought up to J C A H program standards by 1979. The activity of the Legal Rights Service in the legislative area has been somewhat limited, however, because the Law Reform Project of Ohio State University Law School has spent a great amount of time on state legislation for developmentally disabled citizens, and we have not wished to duplicate its efforts.

Finally, the Legal Rights Service does pursue litigation where necessary. However, so far it has filed only one complaint, a class action in federal court challenging conditions at Apple Creek State Institute, a state mental retardation facility. In response to a motion for preliminary injunction filed by the plaintiffs, the defendants agreed to hire 200 additional direct care staff within four months and submit within two months a detailed plan to the court setting forth what additional staff, programs, equipment, and

changes in physical structures are needed at Apple Creek to bring it up to JCAH standards. A supplemental complaint has also been filed in this case asking, among other things, that no resident be transferred to community residential facilities until individual habilitation plans are prepared for them. It should be emphasized that this suit is not asking for damages, just injunctive relief. Indeed, improvement in conditions at Apple Creek will probably prevent many damage suits in the future. Hopefully, therefore, the suit will help both the residents and the administration.

It would be misleading to talk about the activities of the Legal Rights Service without also talking about its main structural weakness, its budget. Its first-year budget of \$83,300 can support three attorneys and one administrative assistant. The budget of the Legal Rights Service next year will be approximately \$115,000, enough to support four attorneys, a social services worker, and an administrative assistant. In Ohio there is one attorney for every 700 citizens. However, these attorneys rarely represent individuals who are on the rolls of state mental retardation institutions, a total of about 10,000. Therefore, even next year there will only be one attorney for about every 2,500 individuals on the rolls of institutions for the mentally retarded. Since these individuals have even more legal problems than other citizens of Ohio, the staff of the Legal Rights Service cannot even protect the rights of present residents of state mental retardation institutions, let alone individuals who have in the past been residents of such institutions.

Even though its budget is too small, I think there are at least three aspects of the Legal Rights Service which should be considered in the development of other advocacy systems. I do not suggest that other states adopt a legal rights service in the same form as Ohio's, but I do believe that the three factors are important to keep in mind. First of all, it is necessary to establish an independent legal advocacy unit with the specific respon-

sibility of representing developmentally disabled citizens. The private bar associations and legal aid societies generally do not have the resources to provide adequate representation for all developmentally disabled citizens. Second, any legal advocacy unit must have the authority to bring suit against the state when the state is violating the rights of developmentally disabled citizens. Such authority will probably be used very sparingly, but it is necessary for the legal advocacy unit to negotiate more effectively. Third, it is necessary for the legal advocacy unit to be independent of any service providers and the executive branch of government. Without this independence, the legal advocacy unit will be dissolved or severely shackled when it starts advocating in an aggressive manner the rights of developmentally disabled citizens.

Government and Advocacy

Gareth Thorne
Commissioner
Connecticut Department of
Mental Retardation

Governmental systems are public systems and thus are systems accountable to the public and to the heterogeneity of the public's expectations and demands. Governmental systems, therefore, must be responsive to, and relate in their functions in a general sense to, the will of the people.

Bureaucracies are action systems within the governmental structure which form the power base or energizing force to enable the function and practice of government. They operate according to the prevailing political philosophy which deems itself the most appropriate for social action and need.

The bureaucrat is an individual who has power and is action oriented as a leading member of the bureaucracy. The direct service provider (professional et al.) is a member of the bureaucratic system and may or may not accept its philosophical base, but most often generally operates from the perspective of his or her own ethical or personal frame of reference.

Advocacy is an essential element in each of the processes noted above. Governmental systems, because they are public systems, have a multitude of advocates, many in complete disagreement, but each essentially right within his own perception of public need and accountability. Bureaucracies as action systems based on political and philosophical commitments are replete with advocates who wish to bring to the general public the ultimate benefit of their beliefs, which they do not regard in any way contrary to the public good.

Bureaucrats as individuals are advocates of the bureaucratic system and often of the political philosophy which supports that system.

Service providers as professionals and lay persons apply their beliefs and systems of morality as the basis for their advocacy in treatment and/or

direct care programs for the developmentally disabled.

Thus, within the governmental structure there is a plethora of advocates and a variety of political, ethical, and personal advocacy systems, which is in its way a true reflection of the democratic process in action.

Now the problem arises when these systems seem to be, or function as though, they are unresponsive to the needs of a particular individual or group. The assumption is quickly made that the system is insensitive, unaware, and/or lacks the capability, much less the desire, to be responsive to the needs of a particular individual or group. This constitutes an indictment leading to a mistrust of the government in general--the bureaucracy as a system, the bureaucrat in particular--and, of course, riding on the coattails of the bureaucrat is the governmental service provider and professional who is painted with the same broad brush.

The solution is to interject another system, the advocacy system, whose function is to truly represent the individual or group to which government has not effectively responded. Now if the advocacy system is to be effective, it must be highly sophisticated not only in matters of government, philosophy, and politics, but in the ethical persuasions of the professional community and the motivating forces of the general service provider. Because of the variety of problems and types of people to which the advocate must relate intellectually, and emotionally etc., a complexity of knowledges (research, administrative, financial and legal) must be organized to form the matrix of an action oriented advocacy system. In other words, another bureaucracy is needed, created as the most appropriate resource for social action, with a philosophical base, and run by the bureaucrats who have power to make the advocacy system work in the image of its creators, with a professional staff working according to its ethics, and advocates operating within the framework of their own ethical or personal frame of reference.

Thus, we truly have a dual system of advocacy at every level. But who is to say which one is right? At what point in time and place, over what issue, and why?

With competing forms of advocacy we may see emerge as a natural outgrowth of the ego survival struggle of individuals a battle for power which would completely utilize the energy of those involved. The defensive posture of government under attack by the system of advocates will provide the battle ground to establish the issue of power once and for all, from which will emerge no victors, and the developmentally disabled will wander as displaced persons in a society disillusioned by the failure of advocacy to support either its systems or its people.

In an address given at Carnegie Hall in New York City in 1952 entitled, "Hope for this Hour," Martin Buber pointed out that since World War I, "genuine dialogue between men of different kinds and convictions" has become increasingly difficult. Buber insisted that the future of man depends upon a rebirth of dialogue. He quoted approvingly the words of Robert Hutchins on the "Civilization of the Dialogue," the essence of which is communication, mutual respect, and understanding even if there is no agreement. But in order to attain this civilization of dialogue, Buber said, there is an essential pre-supposition.

It is necessary to overcome the massive distrust in others and also that in ourselves. . . . What does it avail to induce the other to speak if basically one puts no faith in what he says? The meeting with him already takes place under the perspective of his untrustworthiness. And this perspective is not incorrect, for his meeting with me takes place under a corresponding perspective.

The basic mistrust, coming to light, produces ground for mistrust, and so forth and so forth. . . .

He expresses a thought about a problem of life that concerns me, but I do not ask myself about the truth of what he says. I only pay attention to the question of which interest of his group has clothed itself in this apparently so objective judgment. Since it is the idea of the other, it is for me only an "ideology." My main task in my intercourse with my fellow-man becomes more and more, whether in terms of individual psychology or of sociology, to see through and unmask him. . . .

It is. . . no longer only the uprightness, the honesty of the other which is in question, but the inner integrity of his existence itself. . . This mistrust not only destroys trustworthy talk between opponents, but also the immediacy of togetherness of man and man generally. Seeing-through and unmasking is now becoming the great sport between men, and those who practice it do not know whether it entices them. . . . For this game naturally only becomes complete as it becomes reciprocal, in the same measure as the unmasker himself becomes the object of unmasking. Hence one may foresee in the future a degree of reciprocity in existential mistrust where speech will turn into dumbness and sense into madness. . . .

That we can no longer carry on a genuine dialogue from one camp to the other is the severest symptom of the sickness of present day man. Existential mistrust is this sickness itself. But the destruction of trust in human existence is the inner poisoning of the total human organism

from which this sickness stems.

In this context the awesome burden of advocacy becomes evident. The course of action it must take is to build a future for the one advocated. To do so means that the advocate must look beyond what has transpired today in terms of his client, but more perceptively, must determine what foundation for a secure and relevant structure of services and life styles has been laid in the future by his present action.

Government and its bureaucracy have not done all things wrong. The accomplishments that have been achieved for the handicapped have emerged in this country from its democratic process as a product of two forces, the will of the people and the bureaucratic system, which translates this will into action.

The accountability systems of government are external as measured by public reaction but importantly accountability is internal as well, generated by the bureaucracy and its employee members who also have sensitivity and concerns for those they serve. We need only to look at innovation of programs and the mountains of research over the past 20 years, which bear witness to the creative mind of the public employee and to the bureaucratic system that encouraged, enabled, and yes, even demanded, a more adequate service and new life style for the developmentally disabled.

The advocate must approach his role mindful that someone came before him. The advocacy of the developmentally disabled long precedes his interest and involvement. Yet the new advocate has an important opportunity--an opportunity to establish a new attitude, an attitude of partnership, a complete dialogue based on trust. At what point in time do we advocate the good things?

Of course, the advocate may be a service provider! Who is to say that this cannot be! Any system that denies him the right and opportunity indicts itself by the limitations it places on others. The very essence of advocacy is that it serves to protect the right to intervene in the best interests of one who

is physically or mentally disabled. This is a continuous function of the service provider, who at any given moment in time must act to protect through intervention.

If what we demand is an immediate remedy to the injustices dealt to the developmentally disabled, then we shall not succeed. The complete resolution of their problem lies far beyond even the complexity of advocacy. Traditions and whole systems of thinking must change. New priorities of social responsibility must be established. Laws and court orders alone will not suffice if they do not have strong public support. This process will take time but the time it will take can be substantially reduced if the total complement of people, governmental and non-governmental, will work together. The concept of "watch-dogging" only brings real progress when it is regarded as an accountability system which is utilized with the consent of all concerned. It then becomes a productive system and the information it produces in a system of mutual trust can be an accepted incentive to change.

Advocacy systems established within the government itself to review the action or inaction of government have merit only if the intent of such systems is to improve government, not to indict it. The reality of the political structure of government mitigates against (to put it mildly) a self-destructive system. Formidable defense systems can be established, and certainly would be established, against an internal advocacy system which had less positive motivation than to improve government.

In the final analysis we must look at systems which can produce change. In government these systems are primarily political.

The advocate, whether within government or outside, must work to turn the good intentions of any political system towards the goal of meeting that system's primary objective of being politically most relevant to the needs of the general public. The reward for that system is political survival and an

assurance of having a key role in forging the future of the nation and its people. The trump card of the developmentally disabled is found in understanding the political forces of government and utilizing this understanding as the basic ingredient upon which to build an advocacy system.

The puristic notion that the advocacy system must lie outside the agency which is the provider of services reduces the advocacy potential proportionate to the number of service providers within the agency. This loss of potential may seriously impede the innovation of needed services, but more seriously, divides the issue of advocacy into two factions--advocacy by the service provider, and advocacy by the person outside the system. The seeds of mistrust grow quickly in such soil, and communication becomes limited to specific issues, rather than focusing on a partnership of resources.

The developmentally disabled can ill afford to have anything less than a consortium of forces directed to their advocacy. The strength of this consortium depends not entirely upon the number of its members, but more importantly upon the communication and education process that occurs internally. The greatest danger to the effectiveness of advocacy is failure to understand the rules of the game in the social process of responding to the needs of society's minority members. There is always a time and place for action, a time when change can be effected. Strategy is a key element in the advocacy process and forced response to an emotionally charged approach comes at a price which often exceeds the value received.

And now, a few questions must be answered:

1. Should the advocacy program be part of the system of service providers?

Most certainly it should. As has been noted previously, service providers are intrinsically advocates of what they provide, and by and large, for the individuals they provide the service to; to exclude or ignore their role of advocacy is to deny both reality and, very importantly, the impact of people who

through service delivery constantly produce change.

2. Should an advocacy program lie outside the system of service providers?

Most certainly it should. The objectivity of those who have no immediate interest in the survival of the service system per se is an essential component of a complete advocacy approach. It is a counter balance to lethargy, standardization, status quo, and the halo effect upon service delivery methods. It provides incentive to change through activating the bureaucracy, the bureaucrat, and his staff of service providers. It is a sensitizing force which concentrates on the individuality of needs, and the rights of people to have such needs resolved.

3. Is there room for both systems to be in place as an effective model for advocacy?

Most assuredly, provided there is a balance of trust, and acknowledgment of existence by both groups. Each has a unique contribution to make to the whole of advocacy, but they must first understand one another, and they must deal with the motivations which set them into motion as action forces. If, however, they concentrate on their differences, they will indeed sacrifice the issue of advocacy in the struggle for survival. The status of the developmentally disabled as a minority group places them in a precarious position when viewed from the totality of society's problems and needs. History has taught us that society is not beyond sacrificing even good causes if the price seems to be too high. The resultant tragedy is a proliferation of rejection and callousness, which becomes the new base of social judgment.

Reference

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Appendix A

Excerpts from Public Law 94-103

An Act

To amend the Developmental Disabilities Services and Facilities Construction Act to revise and extend the programs authorized by that Act.

TITLE I -- EXTENSION AND REVISION OF THE DEVELOPMENTAL DISABILITIES SERVICES AND FACILITIES CONSTRUCTION ACT

"Definitions

"Sec. 102. For purposes of this title:

"The term 'developmental disability' means a disability of a person which--

"(A) (i) is attributable to mental retardation, cerebral palsy, epilepsy, or autism;

"(ii) is attributable to any other condition or a person found to be closely related to mental retardation because such condition results in similar impairment of general intellectual functioning or adaptive behavior to that of mentally retarded persons or requires treatment and services similar to those required for such persons; or

"(iii) is attributable to dyslexia resulting from a disability described in clause (i) or (ii) of this subparagraph;

"(B) originates before such person attains age eighteen;

"(C) has continued or can be expected to continue indefinitely; and

"(D) constitutes a substantial handicap to such person's ability to function normally in society.

TITLE II -- ESTABLISHMENT AND PROTECTION OF THE RIGHTS OF PERSONS WITH DEVELOPMENTAL DISABILITIES

"Protection and Advocacy of Individual Rights

"Sec. 113. (a) The Secretary shall require as a condition to a State receiving an allotment under part C for a fiscal year ending before October 1, 1977, that the State provide the Secretary satisfactory assurances that not later than such date (1) the State will have in effect a system to protect and advocate the rights of persons with developmental disabilities, and (2) such systems will (A) have the authority to pursue legal, administrative, and other appropriate remedies to insure the protection of the rights of such persons who are receiving treatment, services, or habilitation within the State, and (B) be independent of any State agency which provides treatment, services, or habilitation to persons with developmental disabilities. The Secretary may not make an allotment under part C to a State for a fiscal year beginning after September 30, 1977, unless the State has in effect a system

described in the preceding sentence.

"(b) (1) To assist States in meeting the requirements of subsection (a), the Secretary shall allot to the States the sums appropriated under paragraph (2). Such allotments shall be made in accordance with subsections (a)(1)(A) and (d) of section 132.

"(2) For allotments under paragraph (1), there are authorized to be appropriated \$3,000,000 for fiscal year 1976, \$3,000,000 for fiscal year 1977, and \$3,000,000 for fiscal year 1978."

Complete copies of this Act may be obtained from:

Developmental Disabilities Office
Office of Human Development
Washington, D.C. 20201

Appendix B

Summaries of Small Group Discussions

Group I Group Leaders: Ronald Attkisson
Iverson Riddle

Group Reporter: Jan Chapman

Several questions and concerns were expressed by the group:

What does Section 113 of the DD Act require and what is the advocates role in relation to that legislation? Why is the law needed?

What agencies and people are involved in advocacy now?

How do you handle the risk of an advocate "assuming" what is best for a developmentally disabled person rather than determining what he really wants or needs?

Some participants report conflicts between citizen advocacy and legal advocacy. Most agreed that the advocate serves a facilitator role. It was generally agreed that each state would handle advocacy in different ways and some would no doubt fail. Also, many believed that with all of the concern regarding regulations and which agency would be responsible for various components, we would get hung up on procedures rather than the needs of the individuals. How do you provide the freedom and authority necessary for an effective system and yet have it funded, and therefore controlled, by the state?

It was felt that those concerned with advocacy systems should be constantly reminded that they were there to serve the developmentally disabled. This being the case, shouldn't consumers have a major role in deciding how funds are expended? The advocacy program should have some clearly stated objectives. Its operation should be monitored and evaluated just like any system. The advocacy system should be closely related to the DD Council since the Council's function is to serve as an advocate. One needs to remember that although advocacy includes legal advocacy, it is much broader than that and litigation should not be its major activity. Without wide support from many agencies and groups, the advocacy

program cannot be effective. The University Affiliated Centers (UAF's) should be a good resource to train advocates.

Two additional concerns were expressed. First, we have not discussed how an advocacy system meets the disabled person's needs. Secondly, it appears that the governor, rather than the DD Council, is deciding where and how the program will operate. This could create many difficult problems for the future.

Group II Group Leader: Charles Acuff

Group Reporter: Pam Bernanke

Considerable time was spent in discussing the meanings of the terms "advocacy" and "protective services." The group did realize that a comprehensive advocacy program would be very complex and difficult to implement and coordinate. It was decided that protective services might best be viewed as a system to insure that the DD retain the rights they now have. An advocate's primary purpose would be to help them gain the rights they do not now possess.

Financial support for an advocacy system would have to be considerably more than is currently planned. If the advocacy agency is detached enough from state government to be free of control, how can it be held accountable from a fiscal point of view?

Advocacy should consist of several equally important layers that must inter-face to insure the effectiveness of the system. It should include volunteers to carry on both continuing and crisis advocacy on a one-to-one basis, as well as a legal component. It should also have access to sufficient power to challenge state-wide policies. By having legal authority to enter into litigation, much can be accomplished by merely threatening to initiate court action. Litigation should be used, however, only as a last resort.

One should not lean on litigation as a way of meeting individual needs of the developmentally disabled. It may take several years to decide a particular case if it goes the full appeal route.

The problem of conflict of interest continued to be a concern. If the agency were funded through the governor's office or through another state agency, it would be difficult not to become compromised at some point. Several "watch dogs" were suggested, such as law schools, civil rights groups and parent groups. However, the idea of channeling funds through the State Supreme Court seemed to be preferred.

Group III Group Leader: Fred Girardeau

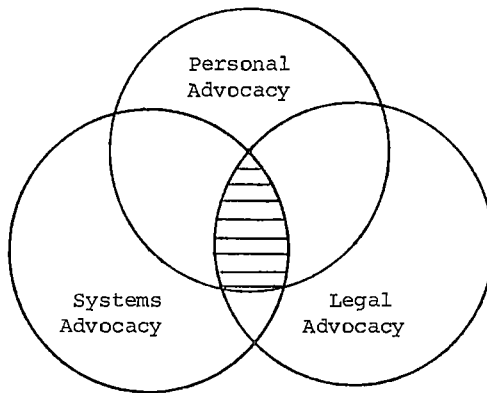
Group Reporter: Carolyn Rude

A primary concern expressed was that consumer representatives should actively participate in placement, design, and implementation and evaluation of an advocacy system. The regulations should be flexible enough so that states can use the consumer representation principle and yet be able to adapt the system to fit their own needs.

Since many developmentally disabled persons and their advocates lack knowledge of how to use the legal system, a training program to help them understand how to access the system would be helpful.

Some state governments and agencies are opposed to an advocacy system. Thus the interest and support of a variety of sources, such as the state bar and other organizations, would help assure the success of the system.

It was recommended that the planning money which becomes available this year could also be used to access existing advocacy programs. One component of planning should be to identify the needs of the developmentally disabled. It was also recommended that the DDO guidelines should define the minimum components of a broad based system. These should include legal advocacy, personal advocacy and systems advocacy as three interlocking components:



It was generally agreed that the \$10,000 available to small states was an unrealistically small amount for developing an advocacy system.

Group IV Group Leader: Michelle Morrison

Group Recorder: Carol Sigelman

How to define advocacy so that all of its components are considered is difficult. We have experienced problems in understanding and implementing other legislation, such as Title XX. Questions of interpretation regarding eligibility, for example, are common. There are many types of advocacy and one should always consider the elements of protective services as being included.

It was recommended that public education, persuasion and influence rather than litigation be used to get policies and procedures changed within a state.

It was felt that the DD Council should have been given the opportunity of orienting the governor to the legislation and making recommendations to him as to where an advocacy system should be housed and how it is to work.

There is considerable confusion regarding the planning phase and what is to be considered in the planning effort. It isn't feasible to cover all types and aspects of advocacy within the money and time constraints available. One should be aware of funds other than those from the DDO which can be used for advocacy.

If a state contracts with a private firm to conduct its planning, a representative of the state council should be appointed as coordinator to maintain contact with the governor's office, the DD Council and the planning office.

Achieving cooperation among different agencies and groups is a type of advocacy. Most states indicated that they now have an advocacy system which might be embryonic or fairly substantial. One state indicated that it is separating legal advocacy from other advocacy programs. A mental retardation center indicated that it was having its staff become advocates for retarded persons. They realized that this did not represent a total program.

It was recommended that the nine agencies already mandated in the law should be involved in support of the advocacy program. Not only are they already involved in advocacy, but they also have financial resources which might be used. The advocacy system should be closely integrated with the DD program. Many questions remain as to the specific nature of the relationship.

Sources of present and continued funding remains one of the key issues. If DD formula grant money is used, a state might overlook the potential resources of other agencies.

A step-by-step grievance procedure should be developed in order that a complaint or request might be handled at the lowest and most readily available level. The phrase "administrative remedies" is mentioned in the legislation and needs to be clarified. Perhaps an overall statement should be mentioned in the guidelines that advocacy is just one of the programs of the total DD program and it should be considered in terms of all the programs. Everyone is involved in advocacy and one cohesive line should run through the fiscal and program aspects of advocacy and the overall DD philosophy.

Group V Group Leader: Marjorie Kirkland

Group Reporter: David Chapman

This group was also concerned about the definition of advocacy and whether it should be defined in the federal regulations or defined at the state level. Related to this was the question of priorities or emphasis. Should advocacy include protective services (preventing and correcting abuses) or be restricted to only acquisition of needed special services? Who has the right to intervene? The problem of whether advocacy services should be centralized at the state level or be focused at the local or regional level was raised. It was generally agreed that the initial organization would be at a state level but could be decentralized after the program became operational.

The problem of funding and its relationship to agency operation was raised. If the advocacy system became a lobbyist for the DD, the state government might refuse to fund the operation. It will be necessary to establish the advocacy system by means of state statutes if it is to have legal authority to enter into litigation. It would be unfortunate if precedents were set early in the program which polarized agencies against one another or which established poor programs.

A discussion of the strengths and weaknesses of an internal and external advocacy system indicated positive aspects of each. If the advocacy agency is to be independent to act, can it be influential in any way other than litigation? If funds go to a private agency, how does a state demonstrate that it is rendering advocacy services?

It was generally agreed that a legal component was necessary to the system but that the system should use free legal services, such as the public defender or legal aid society, where available. Perhaps the state should be given a go-no-go responsibility for funding the advocacy agency but have no authority in its operation. It was generally agreed that the best monitors of the advocacy system were the developmentally disabled themselves.

Appendix C.

Recommendations

A majority of conference participants endorsed the following recommendations related to PL 94-103.

1. Consumer Participation

Consumers or consumer representatives should actively participate in the placement, design, implementation, and evaluation of an advocacy system. These consumers should represent all the developmental disabilities as well as all economic, ethnic, and geographic segments of a state. States should insure consumer participation with a mechanism appropriate to their own situations. Such mechanisms might be the DD Council, a coalition of representatives from agencies serving the developmentally disabled, or existing consumer groups.

2. Planning the Advocacy System

The planning body should be broad-based, composed of persons with a variety of backgrounds-- for example, consumers, service providers representing the various disabilities, attorneys, and the DD Council. The DD Council might be in the best position to designate the planning body. In order to insure an advocacy system applicable to all service delivery systems that affect the developmentally disabled, the planning must not be done by any single group. Planning the advocacy system should include a needs assessment to determine the needs of the consumers and the sources of financial support for the system.

3. Immediate Implementation of Advocacy and Protective Services

States should be able to use present allocations immediately for advocacy services rather than only for research and planning. Some needs for advocacy and protective services of the developmentally disabled are already

identified, and models of advocacy systems are already available. The regulations involving the implementation of PL 94-103 should not require elaborate and time-consuming planning of an advocacy system.

4. Structure of the Advocacy System

The Developmental Disabilities Office (DDO) should define in its regulations or guidelines the minimum components of a comprehensive advocacy system. Such a system should consist of at least three interrelated areas of advocacy, each with a number of components. These three areas are personal advocacy, systems advocacy, and legal advocacy. States should be granted the flexibility to weigh the components according to their own resources and needs. One element of the advocacy system should be a plan for public relations and public education. The DDO should outline the general steps of a grievance procedure consistent with existing grievance mechanisms and ranging from initial negotiation steps to litigation as a last resort. States should fill in the details of the procedures including time frames. The system must also be comprehensive in that it operates in both continuing and crisis situations, and in that it provides everyday services for consumers as well as solving problems. DDO, in order to help states structure their own systems, should provide for the states information on currently existing advocacy systems. The DDO guidelines should address the problem of advocacy in rural areas.

5. Independence of the Advocacy System

At least some components of the advocacy system must be independent of public and private service providers. Furthermore, these should not be under direct control of the executive branch of government. States should adopt statutes to prevent political interference or the manipulation of the system by one special interest group. The role of the DD Council as it relates to the advocacy agency should be defined.

6. Accountability

Throughout the planning, implementation, and evaluation processes the advocacy system must insure programmatic and fiscal accountability. A mechanism for self-evaluation should be built into the system. The system should further be accountable to an external monitor, such as a Board of Directors, the Governor, law school, civil rights group, non-profit corporation with board representation, or the State Supreme Court.

7. Funding

The DDO should estimate the minimum resources necessary to put its minimal broad-based advocacy system into effect. The Office must also specify what financial assistance, in addition to present funding, the federal government will provide, as well as the responsibility of the states to continue funding advocacy. The DDO should publish for the states a list of potential sources of funding.

8. Existing Resources

States should use existing resources (for example, existing advocacy systems, legal aid groups, consumer groups, Medical Services Administration, Head Start, the Committee on Human Rights, the Welfare Department, and the Bar Association) as both funding and people power sources.

9. Legal Advocacy

Dr. Michael Kindred, a Professor of Law and Staff member of the Nisonger Center at Ohio State University, moved that the Conference adopt a resolution which had been passed by the United Cerebral Palsy Association at its annual meeting on March 25, 1976. This motion was seconded and passed by a majority vote. The resolution was as follows:

Be it hereby resolved, in the interests of effective, vigorous, and comprehensive systems advocating and protecting the rights of developmentally disabled persons

pursuant to the 1975 Act, that the Secretary require in the general regulations applicable uniformly to all the states under Section 109 that an adequately funded statewide legal advocacy resource having the capability to bring lawsuits and administrative appeals, be included as an essential part of every state's Section 113 advocacy and protection system.

Although it was not put to a vote, several participants were in favor of the resolution but preferred to substitute the word component in place of resource in line seven of the resolution. One group felt that small states should be encouraged, though not required, to have a legal component in their advocacy systems. Financial limitations and scarcities of trained and experienced lawyers may make it unfeasible for these states to establish a fully operative legal component.

Appendix D

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* This roster includes those who mailed in a prior reservation as well as those who completed a reservation form at the time of the meeting. Due to some confusion at the reservation desk, this list may have omitted a few persons who didn't register as well as including a few who had to cancel attending the meeting.

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