THE OHIO STATE UNIVERSITY

September 12, 1977

Mr. Miles Santamour
Presidents Committee on Mental Retardation
Washington, D.C. 20202

Dear Miles:

Enclosed please find my "paper" for the conference. It is by no means a finished article, but rather is a set of notes that can serve as an indication of my direction for other panel members and the workgroup.

I look forward to seeing you September 27.

Sincerely yours.

MK

Michael Kindred
Associate Dean

MK:sg

cc: Melvin Heckt
James Parham

September 9, 1977

NOTES ON THE PERSONAL SUPPORT SYSTEM NEEDED FOR DEVELOPMENTALLY DISABLED PERSONS: Legal Advocacy, Lay Advocacy, and Protective Services.

I. Delivery of Legal Services

Fifteen years ago the concept of wide-spread legal advocacy for developmentally disabled persons was little known and seldom discussed. Five years ago, when the President's Committee on Mental Retardation convened the first conference on the Mentally Retarded Citizen and the Law at Ohio State University, there were only a score of lawyers with a strong focus on legal advocacy for the developmentally disabled. Today, there are probably several hundred attorneys for whom such advocacy is an important part of their life. There are a good many for whom this has become a professional preoccupation. Legal advocacy stretches from the national level to local legal aid offices and private practitioners.

A. National Legal Advocacy

The National Center on Law and the Handicapped, founded five years ago, now has a budget of a half million dollars a year. The Mental Health Law Reform Project, established by Charles Halpern and now directed by Paul Friedman, has pursued major class action reform litigation on behalf of the mentally ill and the mentally retarded and has developed a guide for reforming state mental health laws. The Public Interest Law Center of Philadelphia has a unit directed by Thomas Gilhool, which has managed to stop General Motors and the Department of Transportation in their tracks and make major progress toward achievement of accessible public transportation. The American Civil Liberties Union is now proposing to establish a national center for the rights of the disabled. Substantial governmental and foundation resources have gone to support these and other highly sophisticated national and regional public interest law firms devoted to reform of the law as it affects the developmentally disabled and other handicapped persons.

B. State Legal Advocacy Units

Five years ago, only the state of New York, with the New York Mental Health Information Service, had a state unit directed to the legal rights of the handicapped, and the Service was restricted to protecting the rights of the institutionalized mentally ill. Since that time, the Mental Health Information Service has had its responsibility broadened to cover the mentally retarded. The state of Ohio, among others, has established a new governmental unit which is charged to provide legal advocacy for the developmentally disabled and other handicapped citizens. New Jersey has established a cabinet-level Department of the Public Advocate, including a unit concerned with advocacy for

the developmentally disabled. In Minnesota and other states private non-profit corporations have been established and funded to provide state-wide legal advocacy services for the developmentally disabled. These state units are of critical importance. They still do not exist in the majority of states. While the 1976 amendments to the Developmental Disabilities Act require the establishment of an advocacy system in every state, the mandate has not been interpreted or utilized to require the establishment of a state legal advocacy system in every state.

The functions and activities of these state legal advocacy units vary. The New York Mental Health Information Service has traditionally focused on individual representation in the commitment process; its forays into law reform have been few. The Ohio Legal Rights Service and the Minnesota legal advocacy system, on the other hand, have engaged in substantial class action-law reform activity. The directors of those units have apparently decided that the few resources available must be devoted to broad system-change litigation rather than individual case-by-case legal work.

Primary emphasis must be given to ensuring that aggressive legal advocacy units exist at the state level in every state. One might hope that the 1975 amendments to the Developmental Disabilities Act will further that goal substantially.

The problems of structuring such a state legal advocacy system are many. A primary focus must be placed upon ensuring that the legal advocacy unit is as free as possible from political pressures and the conflicts of interest of service providers. These and other problems are addressed in a monograph authored by Stanley Herr and published by the National Developmental Disabilities Office.

C. The Private Bar

More and more young attorneys are interested in the rights of developmentally disabled and other handicapped persons. Young lawyers increasingly provide services through the governing boards of consumer group organizations. In addition, the American Bar Association has made a major effort to mobilize the bar through grants provided by the ABA Commission on the Mentally Disabled. These grants have fostered development of local and state bar committees on the rights of the developmentally disabled and other handicapped persons. Young private attorneys, involved through their bar association, provide a valuable resource in some individual cases and in some class action litigation. Nevertheless, a word of caution is in order here. Many young attorneys have found the lure of major class action reform litigation on behalf of the handicapped inviting. Too often they have initiated such litigation, often on behalf of local consumer groups, without either the expertise or the financial backing to carry such litigation through successfully. The one thing the handicapped do not need is to be practiced upon by well-meaning neophyte attorneys.

D. Local legal aid and public defender systems

Many developmentally disabled persons are also poor persons. Historically, legal resources have not been readily available to poor persons. Since the early 1960's, such services have become increasingly available through the development of local legal aid and public defender organizations. These organizations, often began by local bar associations, expanded services greatly when 0E0 provided a substantial influx of federal funds. They are presently funded by a combination of local, state, and national Legal Services Corporation funding. It is to generalized public legal services that we must look for the delivery of most legal advocacy services for the developmentally disabled. Developmentally disabled and other handicapped persons have great numbers of legal problems; within any group of such size a multitude of legal problems are bound to exist. There are scrapes with the criminal justice system; there are problems of consumer fraud and overreaching; there are disputes within a family and disputes between a family and public officials; there may be workmen's compensation concerns; there may be auto accidents and the need for recovery of damages. While legal services for a few of these problems may be available from the private bar on a contingency fee basis, most of the legal services will have to be provided by public funds. It is essential that we look to the generic legal service agancies for these services for the developmentally disabled. Two problems, however, present themselves.

First, legal aid and public defender organizations have traditionally been and still are plagued by exceedingly large case loads and a consequent inability to focus substantial time on any one individual's problems. There is a tendency for legal services to be provided in such settings on a mass production basis. This is likely to operate to the disadvantage of a client who is less capable of expressing his legal needs clearly and clients whose legal problems may be less clear-cut than those of other persons. This often describes the developmentally disabled potential client. While public legal services for the developmentally disabled will never be adequate until adequate public legal services are available for everyone, special interest efforts may be of some avail. Special, earmarked funds can be provided to legal aid organizations to establish a division to deal with legal problems of the developmentally disabled.

A second problem is one of training of attorneys. Most attorneys, in legal aid and public defender clinics, as elsewhere, have little experience with special aspects of the law that relate to the rights of the developmentally disabled. They, therefore, are likely to be substantially handicapped in delivering services to developmentally disabled clients, A second and related problem may be a lack of sensitivity to identification of developmentally disabled clients. A legal aid attorney, like any other attorney, without previous exposure to the developmentally disabled may give short shrift to the legal problem of a person who is inarticulate in describing his problem to him, or "who seems a little funny."

II. Problems in the Development of Legal Services for the Developmentally Disabled

There are a number of problems, some of which are alluded to above, which need to be kept in mind as legal services to serve the developmentally disabled are developed.

A. Law Reform Glamour

Class action law reform advocacy is of great importance to the developmentally disabled, Successful class actions have already established many legal principles that are of great benefit to developmentally disabled citizens. Nevertheless, this is no substitute for individual representation in individual problems and controversies. Because class action advocacy carries with it the glamour of doing something "socially important" and is also relatively cheap, in terms of numbers of clients served per dollar, there is a great tendency for legal services to focus on this aspect of the law. It has its place. Nonetheless, the time has arrived when resources must be applied to the development of individual case legal advocacy services.

B. Tendency to Cooption or Absorption

A legal advocacy unit that has a clear identity in terms of serving the developmentally disabled runs a severe risk of becoming a part of the social service system against which its advocacy ought to be directed. The process of constant negotiation contact, the experience of repeated frustration in finding solutions to difficult problems, and the pressure to maintain public acceptance and adequate funding, all create tensions in the direction of cooption. The strength of a legal advocacy system is in its independence and objectivity, in its constantly critical posture in terms of the inadequacy of services delivered. If it becomes part of the service system, it no longer serves that function. Every effort must be made in structuring such systems to guard against cooption. Nevertheless, cooption is a danger. As it occurs, new centers of advocacy will be needed.

The opposite danger is the danger of absorption. A unit may be initiated to focus on the rights of the developmentally disabled and then be expanded to include the rights of the mentally ill and then of other handicapped persons. It may be merged within a general public advocacy system for all persons needing advocacy services. In this process, there is a severe danger of loss of focus. We can be only too aware of the neglect of the developmentally disabled through history. As the glamour of the cause wears off and the frustration of daily problem solving arises, there can be a tendency for legal advocacy programs increasingly to ignore the special problems of the developmentally disabled.

C. Case Loads

The constant problem of large case loads has been mentioned above.

D. General Laxity in Enforcing Ethical Standards

Developmentally disabled clients, perhaps particularly in the criminal justice system, have often been inadequately represented. In public legal service entities, there is always a danger of inadequate representation because of case loads and inexperience. Young private attorneys may find themselves under pressure to make a living and therefore pressured to cut corners in the representation of an indigent developmentally disabled person. The bar of most states has not been notorious in its rigorous enforcement of the standard of adequate representation with respect to any client. On this issue, advocates for the developmentally disabled have common ground with other consumer groups. The bar associations must be expected and required to enforce professional standards on their members.

E. Failure to Allocate Adequate Resources

Legal services are not inexpensive. Many of the problems alluded to above are problems that are exacerbated if inadequate funding is available.

F. Identifying the Client

One of the most difficult issues that attorneys face in representing the developmentally disabled is the question of who is the client. If the developmentally disabled individual is articulate, the problem is unlikely to be severe; most attorneys will listen to their clients' expression of interests and desires if the client is articulate. Where the client is inarticulate, however, a sharper dilemma is posed. If the attorney can get little guidance from the developmentally disabled individual and will not look to others for guidance, there is a severe danger that the attorney, in fact, ends up representing himself, or his view of what is right for the client. On the other hand, if he blindly follows the wishes of a parent or guardian, he may seriously disserve the interests of the developmentally disabled individual where those interests conflict with the interests of the parent or guardian.

III. Guardianship

Guardianship is an ancient institution. Detailed rules on guardianship were developed in the Roman legal system. Guardianship was also utilized in feudal England and has been a concept known in American legal jurisdictions since their establishment.

The tension in the use of guardianship between protection of the interests of the ward and the utilization of guardianship as a means to promote someone else's interests is a tension that

existed in feudal England and continues today.

A. Conflict of Interest and Institutional Guardians

With the development of large custodial institutions in the United States came the concept that the superintendents of such institutions could also serve as guardian for the individual institutionalized. In fact, one of the earliest cases of involuntary institutionalization was based on procedures and concepts of guardianship. The individual being institutionalized was placed under the care of the superintendent of the institution, as guardian. While this legal mechanism no doubt served one purpose in providing a theoretical basis for the development of processes of involuntary institutionalization, it is probably also true that providing the powers of guardian to the institutional superintendent served other needs as well. Because a guardian stands in the position of a substitute decision-maker for his ward, combining the function of guardian and superintendent provided the superintendent the legal authority to make all decisions necessary to the care and control of the individual.

This frequent joinder of the role of guardian with the role of institutional superintendent continued for many years without challenge. Only quite recently has attention been focused on the conflict of interest created by that joint appointment. Statutes in several states now prohibit an institutional superintendent from also serving as guardian. The reason for this is clear. A primary function of the guardian is to act as a fiduciary, loyal only to the needs of his ward. It is the responsibility of the guardian to make decisions which are in the best interest of the ward. His fiduciary responsibility prohibits him from allowing any other considerations to jeopardize his unbiased decision making. The theoretic, and often practical impossibility of an institutional superintendent putting aside all conflicting considerations should be obvious. The institutional superintendent is often in the position of primary service provider. He is working with limited resources and must balance the interests of all residents of an institution, as well as sometimes conflicting interests of personnel policy and budgetary constraints.

The conflict of interest was more than theoretical. Numerous instances are known where an institutional superintendent consented to the use of experimental medical procedures on wards in institutions. The justification for such procedures was very often to be found, if anywhere, in the importance of medical experimentation rather than in the interests of the ward himself.

Some state statutes have gone even further. They have prevented any employee of the governmental department which operates institutions from serving as guardian, at least for certain purposes.

Prohibition against joining the roles of institutional superintendent and guardian has, however, created new problems as it solved old ones. Because large state institutions have been society's primary means of dealing with the indigent disabled, this population is now often left without a guardian. The institutional superintendent did provide a public mechanism for guardianship services. Eliminating this resource poses a new problem of finding a new guardianship resource.

Disabled individuals in the community, if they lacked both family and funds, never have had a guardian available to them.

B. Finding Guardians for the Poor

Being a guardian for another individual takes time. It also creates risks of liability upon the guardian. He may make a decision for the ward which may later be found to have been an improper decision. Liability for that improper decision may be placed on the guardian, with potentially severe financial consequences.

Where a disabled individual has a substantial estate, there is no difficulty in providing a guardian. Our communities are full of individuals who are willing to provide this service for a fee. The courts have traditionally appointed guardians in situations where a disabled individual had an estate that could support those services. There are also cases in which volunteer resources may be called upon to provide a guardian. This most often occurs where a family member is willing to assume the responsibility of being a guardian without compensation where no funds are available to support the guardianship. Nevertheless, there are many situations where no volunteer resource appears to be available and where there are no funds to provide for a paid guardian. It is these cases that create a pressing problem in today's society.

The issue that must be faced is where the resources are to be found and where the responsibility is to be housed for providing guardianship services when they are needed. Two problems present themselves, a problem of financing and a problem of organization.

The financing problem is a relatively simple one. Whatever guardianship needs exist must be paid for. This requires an allocation from federal, state, or local treasuries. To date inadequate resources have been provided.

The more vexing problem is one of organization. Having rejected the institutional superintendent as a guardian, because of his conflict of interest, where do we now turn? A variety of options exists.

Guardianship services (particularly financial or property guardianship) often have been provided by members of the bar for a fee. One could look to the bar for this service. If adequate funds were provided through governmental sources, there is little reason to fear that adequate services could not be purchased.

Courts, in fact, could probably appoint members of the bar as guardians without payment of fees as part of their responsibility to the court, although one must doubt the quality of guardianship services one would then receive and ask why the bar should be taxed uniquely to provide this social service.

Another model that could be used is the provision of funding to local private non-profit organizations (perhaps including consumer groups) who could be appointed by the probate court to provide guardianship services. One problem that must not be ignored if this solution is used is the nature of the contract provided between government and the non-profit corporation. In particular, the same kinds of conflict that are sought to be avoided by removing the function from government can exist if the contract is so controlling that the guardian fears retribution and termination of the contract if the ward's interests are aggressively asserted.

Another option is the establishment of a new governmental entity or the designation of an existing governmental entity as a public guardian. This solution collides with increasing objections to the creation of new government entities and services. Unless such an entity is clearly independent from the service-providing bodies of government, there is also reason for concern about its independence and objectivity. Perhaps most importantly, one must be concerned about the enormous potential power that a new governmental unit would have if that governmental unit were to be appointed guardian over a substantial portion of the population. The advantages of a new governmental unit in the guardianship area are primarily in the direction of regulation; such a unit could establish standards for the delivery of guardianship services and could itself be policed by advocacy units. The disadvantage comes in centralization of control implied in the creation of a single state unit and the potential atrophy of any bureaucratic entity.

C. Limited Guardianship

There are situations where a guardian is needed. Nevertheless, it is important to recognize that the essential function of a guardian is quite limited. Most people can survive in their day to day life without a guardian. Even persons who are significantly mentally disabled can usually have most of their needs met without the intervention of a guardian. Services, of course, must be provided, but service provision is separate from guardianship. It is also important that there be persons to watch over service providers and to advocate for the provision of decent services. But again, advocacy and guardianship are not one and the same. It is possible to have advocacy structures which do not also have controlling authority that a guardian has over his ward. Trust mechanisms can often be used for the control of funds without the imposition of a general guardianship. Where guardianship is required, it is often possible to provide it on a very limited, topical basis rather than as a general substitution of one person's decision-making power for another's.

These considerations relate to two notions of limited guardianship. Most simply, the use of guardianship services ought not to be used unless essential to the well-being of the ward. Secondly, the term "limited guardianship" has become increasingly utilized to refer to the potential for designating a guardian as having authority over some aspect of an individual's life without having control over all decisions in his life. Social science research has now established that individuals, whether disabled or not, have a wide variety of competencies. The fact that an individual is incapable of making certain kinds of decisions for themselves, does not preclude their capability of making other kinds of decisions. Thus, an individual may be perfectly capable of entering into an apartment lease, making rent payments, buying food on a daily basis, collecting his check and depositing it in the bank, but still be incapable of managing large investments. In such a case, it is important that guardianship relate only to those areas where the individual, indeed, needs assistance. Similarly, in the medical area, many disabled individuals are perfectly capable of making decisions with respect to their ordinary medical needs. When more complex, or experimental, medical services are called for, it may be that a guardian is necessary to provide an intelligent and informed decision.

D. The General Guardian, an Instrument of Limited Use

One caution must be provided against the current popularity of the limited guardianship concept. While the general guardian, with total power over the life of another individual, is a concept that does not square well with our knowledge of variable individual competencies, it is also an instrument that has been utilized in fairly limited cases. Because it was essential to demonstrate a general incompetence in order to have a guardian appointed, guardians have not been utilized in many situations. If, instead of showing general incompetence, one must only show incompetence in a particular area, it is possible to fear a much more widespread use of guardianship albeit on a limited basis.

IV. Concepts of Protective Services

A new concept, amid a significant amount of confusion, has recently been introduced to the whole area of guardianship and advocacy. This is the concept of protective services.

There is now a body of literature on protective services. It is generally viewed as a "positive" concept. It has a good press. The most fundamental idea behind it is that there are helpless persons who need to be protected from overreaching persons. Thus, the protective service worker is seen as an individual who keeps a disabled or helpless individual from being exploited by others.

Protective service is primarily a social work concept. It is a concept that suggests an aggressive outreach approach

to social work services. Other terms often associated with protective services are "active intervention" and "initiative." My purpose here is not to address developing notions of good social work practice. Rather, it is to address the question of whether the concept of "protective services" should become a legal concept as well as a social work concept. If it is to be a legal concept, it is essential that we analyze specifically what its legal impact is.

The clearest legal manifestation of a legal concept of protective services is found in the child welfare area. Through statutes to prevent child abuse and extreme child neglect, social agencies are now often given the power to actively intervene in a family situation, without court order, to protect a child from abuse or extreme neglect. Specifically designated social agencies, or the police, are given express statutory authorization to enter a home and remove a child where they have probable cause (or some other standard) to believe that a child's life or safety is imminently threatened. Usually their authority to intervene is strictly limited.

Even in the child welfare area, however, the term protective services is often used much more broadly than that referred to above. It is often used almost simultaneously with preventive services, although with a strong overtone of potential coercive intervention. In some cases the intervention may take place on a long-term basis and may be based on a court order. In this case the term "protective services" is used to describe regular social work family services backed up by the coercive threat of a court to remove the child from the home if necessary.

I have referred to these uses of the term "protective services" in the child welfare area because this is the area in which the concept is best developed. The issues to be addressed here are the question of the extent to which similar, or other, notions should be utilized in the area of the disabled adult.

The same kinds of coercive intervention power associated with social agencies in the **child welfare** area have not generally been extended to the area of services to the disabled or the aged. There is discussion as to whether that should be the case. Meanwhile, the concept of "protective services" has found its way into much broader and more general kinds of legislation.

Ohio, in the late 1960's, enacted a protective services statute for the developmentally disabled. This statute sets up a special office within the service provider state agency, the Division of Mental Retardation, and allows that office to be appointed as "protector" or "trustee." While the statute is generally phrased in consensual or voluntary terms, it also contains serveral coercive elements. A parent or guardian of a developmentally disabled person may apply for protective services for the developmentally disabled person. This does not require the initial consent of the developmentally disabled person hemself. Once the relationship is established, it can be

terminated by the developmentally disabled person, although the statute ironically requires that the request for termination be provided in writing. Beyond this, the coercive element appears in a provision that allows the Office of Protective Services to request probate court appointment as an involuntary protector where termination of protectorship is requested and the Office feels that the protectorship is still needed. This statute, in my opinion, presents several very serious problems.

First, the powers of the protector are not at all well defined. While there is no specific authorization to enter another's home in an emergency situation, nor any specific grant of authority to remove an individual from an unsafe environment, the broad language of the statute is unclear on what power does and does not exist.

Second, the statute states no basis upon which a court is to make a judgment concerning whether the involuntary protectorship is to be established or not. The test articulated in the statute is "whether the person is in need of protective services." No more guidance than that is provided.

Third, the placement of the Office of Protective Services in the service-provider agency creates potentially severe conflicts of interest. Assuming that the primary role of the protective service worker is to assert the rights and interests of the developmentally disabled person, one must ask how aggressively those rights and interests can be asserted against the very agency which is providing the salary and the opportunity for promotion of the protective service worker.

The Developmental Disabilities Amendment Act of 1975 also incorporates in very general language the concept of "protection." It states that each state is to have in place a system to advocate and protect the interests of developmentally disabled persons. The concept of protection is not specifically defined, although one can expect that persons developing systems to comply with this act would look to the social service history of protective services in the child welfare area.

In summary, protected services is one of those intersection points in present society between two disciplines, social work and law. The development of aggressive social work practices and of the concept of social workers as advocates for their clients are no doubt positive. On the other hand, critical analytical attention must be focused on the question of whether new legal authority should be created in social work agencies that relate to the disabled, what such powers should be, how they relate to guardianship services, and what protection must be provided against their abuse.