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THE FUTURE OF LEGAL SERVICES FOR MENTALLY RETARDED PERSONS ACHIEVING EFFECTIVE PROTECTIVE SYSTEMS

by

Melvin D. Heckt

I. Introduction:

I am not certain I understand the meaning of "Protective Systems" and have in part come to believe that the words "System", "Comprehensive Service Delivery Sytems", and "Coordination" as used in the governmental context constitute a prostitution of the English language.

Coordination has come to mean, "I will do my thing, you do your thing": if we are forced to meet, after the meeting, I will do my thing, you will do your thing and we won't interfere with each other's budget, employees, or activities.

System has come to mean, "My agency will provide a fragmented service to as few retarded people needing service as possible, your agency will do the same, and all fifty of our agencies will have different locations, budgets, applications for service and eligibility requirements in order to refer needy clients to the other 49 agencies, resulting in the client needing multiple services not receiving any or as few as possible. After all the client is poor, you understand, and our system is designed to keep him or her poor."

At least now we can all understand why we need lawyers, paralegals, professional advocates, social workers, associations for retarded citizens and their lay and professional advocates, and well trained parents, relatives and guardians if retarded persons are to secure needed services and financial assistance and have their legal rights protected.

In this paper I shall attempt to discuss advocacy by parents, relatives and friends, the Minneapolis Association for Retarded

Citizens instrumental and expressive advocacy system, the Minnesota Legal Advocacy System, guardianship and trusts as an alternative, public guardianship and conservatorship in Minnesota.

First I believe that there is a real danger that outstanding civil libertarian lawyers, law professors, courts and professionals in mental retardation have or will become so obsessed with Hitler-like horror abuses of a relatively few retarded persons that the legal and M.R. professions will overlook the serious, nitty-gritty real world legal problems of most retarded persons and will over-react to the horrible abuses and create overly-restrictive anti-normalization protection type laws which subject retarded persons to laws and court procedures which their "normal" brothers and sisters are rightly not subjected to. Examples of the latter are" over-reaction to forced sterilization of Alabama institutionalized women now effectively prevents many economically poor retarded persons from receiving desired sterilization and retarded women from securing desired abortions.

Another real danger is that professional concern about "informed consent" and "conflict of interest" between parent and/or guardian and child or ward will result in the development of laws so restrictive as to be inimicable to the best interests of many retarded persons.

II. Advocacy by Parents, Relatives and Friends.

I would like to suggest that the most effective advocates for retarded persons are the parents, during their lifetime, the brothers, sisters and other relatives upon the parents' death, long-time friends and the members of associations for retarded citizens who receive expert and competent professional training, counselling and advice. There is no substitute for the lifetime love, interest and dedication of parents, relatives, friends and members of the ARC. I do not intend to play down the importance of the professional advocate, whether he be lawyer, para-legal, social worker, or mental retardation professional; the professional's love, interest and dedication may be outstanding or impersonal, but frequently the duration of his/her relationship is relatively brief, it is rarely a lifetime or long.

Ideally, the retarded person, his parent or relative or guardian and a competent professional working as a team should be able to make most decisions which the retarded person cannot make by himself-herself without legal or court involvement.

I would strongly suggest that the parent and retarded person are more able to give "informed consent" and have far fewer conflicts of interest than have the professional or the service provider with the retarded person.

"Informed consent" too often means, I, the professional or service provider am informed and you the parent or retarded person are not and therefore only I can give consent and you can't. The legal advocacy for the developmentally disabled project in Minneapolis last year provided legal services for 453 clients and advice only to an additional 180 clients. It found that conflicts of interest between family members and the disabled person seldom occur. I would suggest that the real conflicts of interest occur between the law, the governmental agency administering the law, or the service provider and the retarded person and his parent who are seeking appropriate services or assistance or are excluded from securing any services by the professionals, the agency or the law which establish or administer the programs and the eligibility and ineligibility requirements for service or financial assistance.

For example, it is clear that the law forces almost all retarded persons to become and remain economically poor. It also prevents knowledgeable parents and relatives from leaving any but nominal valued property or assets by gift or inheritance to a retarded person or his guardian. If a retarded person, his guardian, or conservator own a sub-poverty level of assets, he or she will be either ineligible to receive SSI or medical assistance (Medicaid) or must spend down those assets to an extremely nominal amount. Likewise, he or she will have those assets subject to the claims of the State for having provided cost of care or other financial assistance, and creditors likewise may be able to reach such assets. Also, if he or she earns a sub-poverty level of income, he or she must even earn less in order to qualify for SSI or Medicaid.

Suggestions:

1. Retarded persons should be entitled to earn substantially more income and own substantially more assets without losing their eligibility to receive SSI and Medicaid.

2. Parents and relatives should be encouraged to become advocates and be entitled to receive expert professional training, counsel and advice relative thereto.

3. Parents, relatives and guardians, who secure competent professional advice, should be able to give informed consent for retarded persons who are unable to do so without requiring court involvement or interference, except in those situations where the parent or guardian and retarded son, daughter or ward expressly disagree.

III. ARC advocacy systems. The Minneapolis ARC System.

I will not discuss in this paper the many effective ways the ARC at the local, State and National levels, advocates for retarded persons. Some local ARCs offer legal advicex clinics, two nights a month, a few offer direct legal services similar to the Minnesota Developmental Disability Project which will later be discussed, and some utilize the Wolfensberger type of citizen advocacy model.

The Minneapolis ARC Advocacy System is, I believe, unique in being able to offer very important day to day assistance with problems confronting retarded persons living in the community thereby both eliminating the need for legal services in many cases and referring many more clients to lawyers and legal service agencies than would otherwise be referred.

I believe that in the future many more ARCs will be providing instrumental and expressive advocacy services and would therefore like to share the Minneapolis ARC program as a possible model.

The Minneapolis ARC offers a free advocacy program which attempts to insure that people who are mentally retarded receive needed services, enjoy their legal and human rights, and experience personal support and friendship.

To meet these objectives, MARC offers two kinds of advocacy services.

Instrumental Advocacy

Instrumental advocacy is designed to provide assistance to people who are retarded and their families when their legal rights are violated or when they are denied adequate or appropriate services.

MARCs advocates become involved with people who are retarded in a variety of cases, including:

(1) discrimination on the basis of disability,
(2) obtaining appropriate special education programs,
(3) helping them gain admission to or solve problems, with community programs, such as residential facilities, day activity centers or sheltered workshops,
(4) obtaining adequate financial assistance,
(5) helping those who are involved with the criminal justice system,
(6) assisting Hennepin County residents who are having problems in State institutions.

MARCs director of advocacy services recruits and trains volunteers as instrumental advocates. After 35 hours of training and successful completion of a profeciency test, the volunteers work under the direction of the MARC office with people who are retarded and their families toward the solution of specific problems.

From September, 1975, through April, 1977, 173 cases were handled by MARC's staff and 30 volunteers who received additional class training on "The Mentally Retarded Offender", "Educational Rights", "Hennepin County Welfare System", Educational Due Process", "Sexual Rights" and "Bioethics". A committee of advocates trained a. Minneapolis Police Rookie Class on mental retardation with

assistance from the Minneapolis League of Women Voters/registered and provided voter education for 400 voters who are mentally retarded, prepared a slide-tape presentation to teach adult retarded persons about their rights, formed a task force to explore grievances concerning sheltered workshops, have five advocates on 24-hour call to assist mentally retarded persons who are brought to jail. These latter advocates assist the person in understanding what their rights are, in obtaining an attorney and in setting up a diversionary program when appropriate.

Of the 173 cases the breakdown is as follows:

Education	20%
Residential	.18%
Financial Assistance	16%
Employment	11%
Mentally Retarded Offender	8%
DAC's	6%
Committment/Gdnshp.	6%
Insurance	2%
Taxes	2%
Medical Care	2%
State Institutions	2%
Consumer Credit	2%
Child Custody Parental rights	2%
Financial exploitation	2%
Miscellaneous	8%

(Cases occurring only once, rape, physical abuse, citizenship, etc.)

Expressive Advocacy

This advocacy program addresses the social and recreational needs of people who are retarded. They are paired with volunteers who are matched on a one-to-one basis with volunteers of similar interests, needs, community location, usually of the same sex and approximately the same age. These advocates and companions carry out their relationships as equal partners. The volunteers attend several training sessions before being paired with a companion. They agree to maintain the relationship for at least one year through personal contact at least twice a month and telephone calls. Ideally, the relationship evolves into genuine friendship that no longer requires monitoring from the MARC office. A variety of free and discount activities, including plays, movies, restaurants and bowling are available to participants in the program.

The Advocacy Committee appointed by the Board of Directors is made up of 3 board members and 1 volunteer advocate. The committee oversees the activities of the advocacy program and is accountable to MARC's board of directors.

See Exhibit A attached for the 7-page Goals and Policies Statement of this program.

I believe this type of model for ARCs will be appropriate in the future as a very important part of an overall protective system which can not only **reduce** the need for legal services but increase the use of legal services by people who are retarded.

IV. Legal Advocacy for the Developmentally Disabled in Minnesota— a Model For Your Consideration.

This project commenced in 1973 and currently has a project staff of four attorneys and one para-legal advocate, operates in the offices of the Legal Aid Society in Minneapolis, and is in the process of establishing a branch office in Duluth, Minnesota.

In 1978 the project will consist of a managing attorney, three attorneys, two para-legals, one secretary, plus assorted miscellaneous office costs, travel, printing funds. The regional office in Duluth will have one attorney, one para-legal and the 1978 fiscal year budget will be approximately $134,000.

The project provides comprehensive legal services throughout the State of Minnesota to citizens with mental retardation, autism, epilepsy and cerebral palsy. The majority of the staff's time is devoted to representation of clients in Courts and administrative hearings. Many of the cases are of a law reform nature. The project also drafts legislation and regulations, engages in public education and training in the legal rights of the handicapped, prepares training materials for parents and consumer organizations, develops and evaluate systems of legal advocacy, serves in a clinical setting for law students, and operates as a back-up center and clearing house for legal matters affecting the developmentally disabled.

During the year July 1, 1976 to June 30, 1977, the project provided representation to clients in 453 cases and advice only to an additional 180 clients.

A breakdown of cases is as follows:

25%	Social Security and Welfare
15%	Special Education
8%	Release from Institutions
8%	Institutional Conditions
6%	Guardianship and Restoration to Capacity
5%	Minimum wage claims
5%	Discrimination
3%	Zoning of community residential facilities
3%	Custody disputes (dependency and/or neglect actions against disabled persons).

In addition the project has disseminated three types of products; (1) an outstanding advocacy manual (I hope you will all see it); (2) 99 training sessions and speaking assignments during the past 18 months for advocates and those interested in the rights of retarded citizens; (3) the third product consists of comments on laws, regulations and legislation. Project staff wrote comments for others as requested and testified before appropriate groups studying legislation.

The project operates on a strict advocacy principle; it answers only the client; if a legal method exists for achieving what the client wants, the staff will use that method; it will tell the client if there is no legal resolution for his or her complaint and will inform the client of alternative remedies. The staff will not counsel a client to seek different goals; it may suggest counseling services if necessary and if the client desires same. If the client is an adult and able to communicate the project will usually directly represent the individual; clients who are severely handicapped and non-communicative typically have a parent, social worker, an ARC member or other interested person who speaks on their behalf. In almost all cases, the objective is so obvious (.e.g, obtaining financial assistance for the client) that there is no question that the spokesman is in fact promoting the client's interests and objectives.

Usually the clients legal problems must arise out of the disability, but the project will represent those persons whose difficulty does not give rise to the legal problem if the individual would otherwise be unable to obtain legal services, or if the lawyer's knowledge about the disability is important in providing adequate service to the client.

The project also represents organizations serving developmental disabled people, such as group homes, associations for retarded citizens, or other associations, when such groups clearly seek to advance the interests of disabled individuals. The project has never been asked to, nor would it agree to, provide legal assistance to any organization for internal corporate matters.

Legal services are provided without charge. Clients are expected to pay costs, such as Xeroxing, filing fees, travel expense, if they have funds to do so. The project will represent any developmentally disabled client who meets federal poverty standards and any other client whose case has significance for other handicapped persons or require the specialized expertise of the project staff. The client able to retain private counsel are asked to do so unless they require special resources of the project.

Clients are referred to the Project from State and local chapters of Consumer organizations, individuals and agencies who provide advocacy services, such as state hospital patient advocates, agency ombudsmen and para-legal advocates trained by the project . Special education teachers, social workers and other professionals also make referrals. Often family members request services. Although the project will not represent family members if there may be a conflict of interest, in practice this seldom occurs. Many clients also seek services as a result of information from other consumers or from the project's own outreach activities.

In addition to the case of Welch v. Likens with which most of you are familiar, the project handled many other cases, for example:

(1) In December several out-of-state insurance companies brought an action in Federal Court to have Minnesota's new comprehensive health insurance act enjoined and declared unconstitutional. The project intervened on behalf of Minnesota ARC, Epilepsy League, United Cerebral Palsy and two named individuals. The litigation is extremely important to all developmentally disabled persons who are otherwise unable to purchase health insurance or are only able to purchase limited coverage because of pre-existing disabilities. The insurance companies' motion for a preliminary injunction was denied,sthe Project's motion to intervene was granted, and as a result the law became effective January 1, 1977.

(2) The Project also was involved in two cases of segregation of handicapped students in separate educational facilities.

(3) In one case 50 EMR and TMR students had their speech therapy services terminated without notification in violation of the due process statute. The Project successfully secured resumption of service to previous levels, individualized program plans for the parents of the

students were obtained, and make-up sessions fir lost services were scheduled.

(4) The Project's involvement in the EPSDT lawsuit has resulted in far-reaching improvement in the implementation of the EPSDT's program in our own State which affects some 100,000 children.

It is suggested that substantially increased Federal DD funding for this type of legal service agency is greatly needed in our nation.

V. Guardianship.

I should like to add just a few comments to what Mike Kindred has covered.

For a mildly mentally retarded person and for some moderately retarded persons, the loss of rights resulting from guardianship may be unthinkable unless there was a demonstrated pressing need for protection which was substantially more important for the welfare of the retarded person than the loss of such rights. On the other hand, the loss of such rights for most profoundly and very severely retarded persons may be meaningless and the need for protection and supervision much more important for his or her welfare.

Therefore, it is important to ask, "Why Guardianship?" "Is it really necessary?" "Is there an alternative?" Before instituting guardianship procedures it would seem to be important to ask the following questions: Is there a real danger that the person who is
be
retarded will: (1) run away and be incompetent to provide himself or herself with food, clothing and shelter? (2) inflict injury or death upon himself or herself? (3) be physically abused if he or she stays in his present residence, (4) become involved in serious criminal activity, (5) be subject to frequent civil litigation for buying things he or she can't possibly pay for, (6) be forced into prostitution against her will, (7) be exploited by marriage or by others, (8) be denied the right to be sterilized in the absence of

a court order, (9) be denied medical or surgical treatment in the absence of guardianship.

Suggestions;

1. Guardianship is not the single solution to the problem of what will happen after the parents' death. Before seeking guardianship one should be satisfied that there is a compelling reason which is in the best interest and welfare of the retarded person and that the advantages clearly outweigh the disadvantages of guardianship.

2. Guardianship for many retarded persons when used properly may be of real assistance.

3. Guardianship for many retarded persons when used improperly may result in a total denial of their rights, impede their ability to make decisions for themselves which they can and should make and greatly dehumanize them.

4. Most parents are naturally concerned about protection for their children but this form of security and protectorship can be secured in a number of ways without necessarily using the court supervised formal guardianship.

5. Sometimes an effectively drawn estate plan can eliminate the need for a legal guardian, yet secure the concept of guardianship for the person who is retarded.

6. Real security for people who are retarded lies in appropriate quality education, vocational and rehabilitation training, financial assistance through SSI, Medicaid, Social Security and other governmental benefits, appropriate quality residential living arrangements, employment opportunity, state and Federal legislation protecting the rights of people who are retarded, advocacy programs which reach out to monitor and secure services to provide for retarded citizens the quality of life that all citizens deserve.

VI. Trusts as an alternative to Guardianship or Limited Guardianship.

This discussion assumes the person who is retarded cannot manage money or property, or cannot manage more than his or her own income, or is vulnerable to having his/her income or assets taken by the unscrupulous, or will at some time probably require governmental financial assistance to pay for all or part of his/her basic costs of care.

Unfortunately, if a person who is retarded needs Supplemental Security Income or Medicaid or some other form of governmental financial assistance, he/**she** cannot earn a sub-poverty level of income or own a sub-poverty level of assets without having his or her governmental benefits terminated until the income becomes lower and the assets are spent down to a very nominal amount. Also his or her assets are subject to reimbursement claims made for his/her cost of care. Thus the law not only forces many retarded persons to maintain a sub-poverty level existence but forces parents to not make distributions of property by gift or inheritance to their retarded sons or daughters and to not permit them to become beneficiaries of any life insurance benefits.

In some states, however, a carefully drawn testamentary trust or living trust agreement can serve two very important functions:

A. The Trust can protect assets and income from the claims of creditors including the State or County and protect the retarded person from becoming ineligible to receive SSI and Medicaid, etc. The trust, however, must be carefully drafted and include the following provisions:

1. All income shall be accumulated and added to principal
2. Trustees shall have sole or absolute discretion to expend or not expend principal for the beneficiary who is retarded.
3. A strong spendthrift trust clause must be **included.**

4. Provisions must be made for distribution to others upon the death of the retarded person.

5. The trustees must not commingle with the relarded person's earnings or assets with the trust assets.
6. The trustees should be prohibited from using principal or income for reimbursing the State or County for having furnished cost of care to the retarded person.
7. The Trustees should be directed or given absolute discretion to terminate the trust and make distribution to persons other than the retarded person if a Court of competent jurisdiction should in the future determine that the retarded person may be ineligible to receive SSI or medicaid, or similar government financial benefits or if a creditor should in the future be able to reach the income or principal of the trust.

Unfortunately, the laws of some States do not permit the use of such a discretionary spendthrift trust and parents then have two options: (a) exclude the retarded son or daughter from the Will or Trust, or (b) establish a trust in another State which does protect the corpus and income thereof.

The Trust

B. Enables the Trustees to provide guardianship and advocacy services and provide the retarded person with those things which governmental financial assistance programs do not now provide. For example, the Will or Trust can direct or authorize the Trustees or their agents to:

(1) Visit the person who is retarded weekly, monthly or quarterly to act as a friend and to see to it that the residential facility is providing adequate food, clothing, spending money, health services, etc.

(2) Have an annual evaluation of his/her medical and dental condition, educational program, vocational education, employment

opportunity, appropriateness of his residence, his social program. The Trustees should also be instructed to check at least annually concerning the governmental financial and other benefits to which he is entitled, and should be directed to assist the retarded person in securing same. Also the person's legal rights should be checked and reviewed annually to see if any are being violated.

(3) The Trustees can be directed to check with the local ARC or other advocacy agency on a regular basis to become updated on what services and benefits the retarded person may be entitled to and the appropriateness of same.

(4) A provision can also be inserted that if a guardian of the person may become necessary, such individual trustees or their successors shall be so nominated.

(5) The Trustees can also be informed that if they should in their absolute discretion decide to expend any principal for the retarded person, the Trustees might consider the provision of spending money, additional food and clothing which he or she likes, movies, TV sets, radios, record players, vacation trips, camping, picnics, meals out of the residence, etc.

The use of the above types of trusts should be encouraged for the reason that not even a millionaire parent can be certain that the money he would like to leave would be sufficient to pay for all of the person's cost of care and medical and hospital costs for a lifetime. For 99 per cent of the parents it is totally out of the question. For example, $1500 to $2000 per month for group home services today may be multiplied by a factor of 3, 4 or 5, 10, 20 or 30 years from now; hospital bills of $100,000 or more are not unheard of today and may be commonplace 25 years from now.

Therefore, it is suggested that State laws which now effectively prohibit the use of such discretionary spendthrift trusts should be changed. Also it is suggested that Federal laws relating to SSI, Medicaid, Title XX, HUD etc. should be clarified to clearly exclude the principal and income of such trusts from being counted or included as assets or income for eligibility purposes.

VII Public Guardianship and Public Conservatorship in Minnesota.—

An important part of an effective protective and advocacy system for some people who are retarded. Public guardianship and public conservatorship (limited guardianship) have been part of Minnesota's laws. Under this plan the probate court determines whether guardianship or conservatorship is needed and if needed the type of supervision which is appropirate. The State Commissioner of Public Welfare assumes such guardianship or conservatorship functions and delegates the responsibility to the appropriate county welfare department social workers. The probate court receives a comprehensive social, medical and psychological evaluation before the hearing. The proposed ward or conservatee/must be represented by counsel; the person cannot be unduly medicated before the hearing which may be held in the person's home.

Under this plan the retarded person has the right to (a) have the commissioner prepare an individualized program plan to insure that his or her therapeutic, habilitative, social, medical and dental needs are met, (b) receive an annual review of his or her physical, mental, social adjustment and progress, (c) receive an annual review of his or her legal status and have that status modified if necessary to reflect the person's progress, (d) have the Commissioner exercise the supervisory powers in a manner which is least restrictive of the ward, conserving as many of his personal freedoms consistent with the need for supervision, (e) obtain judicial review of decisions by the state guardian or state conservator when the retarded person or interested person acting in his behalf disagrees with that decision, (f) be free of sterilization unless he gives informed consent or if unable to legally give such consent, to have the court review whether it is in the person's best interest, (g) to receive a full due process hearing prior to placement in a State hospital (institution).

Under this plan parents have the right to (a) participate in planning and decision making for the retarded child even if he or she is over age eighteen, (b) consent or refuse consent to sterilization or other surgical operations for their minor child, (c) petition the Court to modify the guardianship or conservatorship or to restore their child to legal capacity or to review the decisions by the state guardian or the state conservator.

Under public guardianship, it is very important for those persons who have no parents, relatives or friends or advocates to protect them if they need protection,and to provide a continuing personal interest for their entire lifetime.

Under public guardianship or conservatorship, it is clear that the state has a legal duty which can be enforced to provide education, medical, dental and hospital care, maintenance, support and humane living arrangements for the lifetime of its ward or conservatee who is retarded.

There are of course advantages and disadvantages and potential or real conflicts of interest in any form of guardianship, advocacy, legal advocacy, welfare, or other system which includes only friends or relatives.

Melvin D. Heckt

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Final Draft

EXHIBIT A
MARC's ADVOCACY PROGRAM

GOAL OF INSTRUMENTAL ADVOCACY

To serve the client to the best of one's ability.

A. Client may be a person who is mentally retarded (18-adult) or a parent or guardian of someone who is mentally retarded. The client has an expressed need and has requested assistance of an advocate.

The expressed need may be anything that is a problem from without the person as opposed to a problem within the person which would be a counseling need. Thus, the need would be service or community related as opposed to interpersonal relations.

Serving a client means that an advocate is not to judge, impose values, or dictate the needs of the client. The client's needs and wishes are what directs the course of action. The advocate is to discuss all relevant information, outline options, and let the client decide the strategy and tactics to follow which Will best fulfill the client's needs.

C. Service to the Best of One's Ability means that it's an advocates duty to keep informed and knowledgeable about laws, regulations, and resources. The person best able to serve a client is one who is most knowledgeable about these areas. Advocates have an obligation to seek outside help when they have exhausted their "best ability" and it is agreed to by the client.

D. Intake. The Director of Advocacy Services will act as the intake source for all cases. He/she will do background information gathering and will make the decision as to whether there is a client who has a problem that is service or community related and has a chance of being resolved.

If the problem is a counseling one, it should be referred to a counselor. There are times when problems are intertwined and the advocate and counselor should coordinate their efforts.

If a regulation clearly does not allow for a resolution which the client desires, the client should be so informed, and at this time other methods should be explored.

This guideline does not mean to imply there is any decision on the part of the advocate as to whether the client-has a "good" or "reasonable" request or claim. Requests for an advocate will be reviewed by the advocacy committee if the client has been turned down or referred to another source and is unhappy with that decision.

The Director of Advocacy Services may refer a case to a volunteer advocate who has particular interest or skills which would benefit the client's particular goal. If there is no volunteer advocate who has time and is qualified in a particular area, the Director of Advocacy Services will take the case.

If an advocate, for reasons of conscience, does not think he/she could wholeheartedly support their client's wishes, the case should be referred to another advocate.

Advocates' Responsibilities An advocate will not attempt to solve conflicting attitudes within a family. This means that if the parents disagree with each other or with the feelings of an adult who is mentally retarded, they should be informed that there are other advocates that could represent the other person if they so desired. The advocate may also suggest counseling, but all attempts should be made to make clear to family members that the advocate is there not to counsel, but to help the client resolve a service or community related problem.

The Advocate Will:

1. Be prompt in followup on requests for assistance or referral.
2. Through interviewing the client, find out what the problem is and which laws, regulations, agencies, services, and outside parties are related to the problem.
3. Explain possible alternatives to solving the problem.
4. Consult with the client when there is new information which is relevant to the cllent's case.
5. If compromises are offered by the other side or if alternatives exist along the way, the advocate should inform the client and ask for his/her opinion and decision.
6. Keep the client informed of the advocates action and results.
7. Resolve a case as quickly and satisfactorily as possible.
8. Seek to resolve the case at the lowest level of an organization.

Developmental Disabilities Basic Principles of Advocacy Manual

1. Investigative, including assistance in Obtaining information from agency personnel;
2. Research;
3. Referral - with followup to make sure client is being helped;
4. Representation in certain limited cases (e.g., hospital review boards, welfare appeals, local level appeals, negotiations);
5. Qualified and limited advice with referral to attorney;
6. Gather and provide legal information to association members or general clientele when not acting in a representative capacity;
7. Organize clients to protect their own legalrights;
8. Act as an advocate on certain boards and oommittees (e.g., Humane Practices Committee).

Prohibited Activities

1. Representing oneself as an attorney;
2. Drafting legal documents;
3. Giving legal advice for client to act upon in a specific case except when acting In a legitimate representative capacity.

Agency Advocacy. "A vast majority of cases will involve either a failure or refusal of some agency to provide a service to a client or some affirmative act which in some way injures the client."

informal Agency advocacy is not governed by established or written procedures. It includes personal contact by phone, letter, or in person with officials in an agency.

Thus, the advocate should become familiar with the structure, operation, and personalities involved in an agency.

Formal Agency Advocacy. Many agencies have an established or written procedure for appeal. This formal means of reviewing decisions is provided through a channel, such as an administrative hearing or "fair hearing."

External Advocacy. Many disagreements can be settled without ever calling upon persons who work outside an agency. But in certain cases, the agency will refuse to change its' position even after informal and formal means within the agency have been exhausted. Then the advocate will need to go outside the agency for assistance. Some external advocacy resources include the courts, government office, or other government agencies and officials, such as the Human Rights Department of Licensing Division of the Department of Public Welfare.

The fact that there are both formal and informal approaches for resolving problems Joes not prevent the advocate from employing both at the same time. Nor should he/she Feel he/she cannot employ more than a single channel of informal advocacy at any one time.

A general rule might be that the advocate should start out by approaching the lowest official in the agency who has jurisdiction over an issue and should first attempt to learn the agency's side of the problem.

Tactics must also be geared to getting the best results for the clients. In doing so, it would hot be good to unnecessarily upset anyone in the process. Therefore, if one is going to appeal to a number of different persons, it is a good idea to let the others know before or as one is doing so, unless tactics dictate otherwise.

Recruitment of Instrumental Advocates. The Director of Advocacy Services shall determine the number of volunteer advocates reeded to help handle cases. Volunteer adyoeates wi11 agree to help the director find a replacement when they terminate-their committment. The director will informally screen all applicants who wish to become advocates. The volunteers will agree to:

A. Participate in the MARC training sessions in instrumental advocacy;

B. Participate in periodic update sessions throughout the year;

C. Make at least a one-year committment to being an advocate (2-4 hrs. per week);

D. Adhere to the concept and goal of advocacy as they are outlined in the guidelines;

E. Keep written record concerning each advocate activity;

F. Consult with and update MARC advocacy director about the progress of cases

Training will consist of five to ten training sessions that will cover the following topics:

A. Philosophy and goal of MARC.

B. Philisophy and goal of advocacy, techniques of advocacy, communication, lines of authority, etc.

C. Education infant stimulation, education regulations (e.g., due process, pupil fair dismissal act, etc.).

D. Hennepin County Welfare Department - foster care, protective services, homemaker services, MR unit.

E. Financial Assistance (SSI, MSAP, MA, FOODSTAMP, GENERAL ASSISTANCE).

F. Human Rights (medical rights, conservatorship, guardianship).

G. Residential Facilities, Institutions and community facilities.

H. Community programs (DAC,sheltered work, work activity-—DVR, rehabilitative programs).

1. The mentally retarded offender - diversions to community programs.

Proficiency. Upon completion of the training sessions, each of the advocates will be required to pass a proficiency test to be given by the Director of Advocacy Services. Secondly, each advocate will determine, with the director, the area or areas in which the advocate would like to specialize. Thirdly, the advocate will then be expected to accompany the Director of Advocacy Services or other experienced. advocates through the development of at least one case. Such inservice training should be available to advocates at their request when they would like background in a new area or to refresh or update their general techniques. Likewise, the director may at any time suggest such inservice training to an advocate.

Supervision and Evaluation of Volunteer Advocates.The Director Services should make the determination after the proficiency test and inservice training as to whether the advocate is able to handle a certain type of case by him or herself. If the advocate needs more training, the advocate should work on cases with another advocate until he or she is able to handle cases on their own.

When a case is assigned to an advocate, the Director of Advocacy Services will make contact with that person periodically to make sure the case is proceeding smoothly and to remind the advocate that the director is there at any time to answer questions, discuss the development of the case, and directly assist, if requested.

The Director of Advocacy Services may at any time terminate the involvement of an advocate due to inappropriate performance or representation or in the event the advocate does not uphold the goal and objective of advocacy. Such a termination can be appealed to the Advocacy Committee and the MARC Board.

Supportive Services for the Advocate. The Director of Advocacy Services will agree to offer appropriate training workshops and updated information to all the advocates.

The Director of Advocacy Services will, at all times, be available to offer **rifner** suggestions or to help advocates with their cases.

Mailing and typing services of the MARC office will be available to the advocate for work on their cases.

Upon the request of the advocate and approval of the Director of Advocacy Services, MARC will reimburse expenses related to cases on which the advocates are working, subject to approval of budgetary restrictions and the Executive Director.

The committies in MARC (e.g., Advocacy, Education, Governmental Affairs, etc.) may be appealed to for help by any advocate who feels that external agency help is needed to resolve a case. For example, the Governmental Affairs Committee may be able to help lobby for additional funds or services.

Case Records. Each advocate will observe the privacy and confidentiality laws of the state. Each advocate must obtain written permission from their client to obtain any information that other agencies may have. Likewise, the advocate, prior to releasing any information from the case file, will obtain written permission from their client after informing them of the purpose that the information will be used for.

The advocate will keep a specific record of all contacts made, meetings attended, and developments in a particular case. After the case has been closed, the file will be returned to the MARC office. Such files will be destroyed after a reasonable amount of time,and only general data on cases will be kept (e.g., types of cases referred to MARC, agencies dealt with). in

The Director of Advocacy Services has responsibility to make sure files are returned and kept in a locked file, and destroyed after being inactive for three years.

If another person wishes to enter the case and give assistance (i.e., Director of Advocacy Services or Executive Director of MARC), permission must be obtained from the client. Such persons will be expected to follow the objectives of instrumental advocacy as outlined in these guidelines.

Complaints

From Clients - If a client is unhappy with an advocate, they should be aware that they can ask for the assistance of another advocate or take their concerns to the Director of Advocacy Services and the Advocacy Committee for review.

The Advocacy Committee, with the advocate present, will then discuss the problem and resolve the matter.

From Agencies - The Executive Director shall meet with the Director of Advocacy

Program, the client (or have the informed consent of the client), and the advocate involved in the case to determine the facts of the situation. The Executive Director, Director of Advocacy, and Chairman of the Advocacy Committee shall agree on a way to deal with the complaint.

Either a client or agency shall have the option of meeting with the MARC President or Executive Director to discuss a complaint that pertains to procedures, attitudes, or demeanor of the advocate.

Advocacy Program Relationship to MARC

1. The Director of Advocacy Services is to be employed and supervised by the Executive Director.
2. It shall be the responsibility of the Director of Advocacy Services, together with the Executive Director, and other MARC staff to inform agencies and providers of the role of the advocacy program, including the fact that MARC expects the agencies to deal directly with the advocate and their client.
3. It is recognized that an instrumental advocate must represent the client and his needs, and that sometimes the feelings and desires not be compatible with the broad goals, objectives, and concerns of MARC, except the goal to provide instrumental advocacy services.

The advocate is one who assists in the process of obtaining or changing services for an individual. MARC must be willing to risk occasional misunderstandingsand periodic strained relationships, if it is to provide individual advocacy services. MARC, as an agency, has community confidence and funding,and anyting which jeopardizes MARC, also jeopardizes the advocacy project.

If, in the judgment of the Director of Advocacy Services, he is embarking in a project which could affect MARC relationships with other agencies, the Advocacy Director shall inform the Executive Director of the situation, or if after undertaking a case, the Advocacy Director sees a strained situation developing, he shall inform the Executive Director of MARC.

Endeavors which are not undertaken in the name of .individual clients shall be within the goals and objectives of MARC and have board approval. This includes actions to change government regulations, laws, funding, etc. to affect groups of retarded people.

Any person has the right to attend an Advocacy Committee meeting where there is general review of the cases handled through MARC. Furthermore, anyone can ask that the Advocacy Committee review a particular case, as long as the advocate is present and such a review is agreed upon by the client.

Addendum

Because a client seeks out an advocate to solve problems, it can often mean that the client has not received satisfactory help from an agency or a provider of services. Naturally, when an advocate becomes involved in a case, the agency or service provider may be uncomfortable. This occurs for a number of. reasons.

One reason may be that often agencies and particular individuals feel they are advocates for the client and they are unhappy to have a client secure another advocate.

In addition, some people in an agency may be hampered by the nature of their agency from providing a service. They may feel that the advocate is spending useless time trying to solve an unsolvable problem.

Another annoyance to some is.the concept of advocacy which does not involve a counseling role. The people in the agency may think that the advocate should judge the position of the client and support only those actions which seem "reasonable." They cannot understand why an advocate could support a position the agency people think has no validity. They do not see the person as an advocate, but rather as one who should guide and counsel the person who is their client.

These are only some of the reasons advocacy and advocates may not be viewed favorably. Even though advocates and clients will generally try to resolve a problem at the lowest level, using a method which will bring the quickest resolution, the situation can often be viewed as a confrontation by the agency or individual approached.

Because the advocate is not always appreciated by those his/her client seeks services from, it is very important that the advocate has a supportive agency which upholds the actions of the advocate. Positive feedback should be given to help the advocate maintain the confidence needed to carry on the advocacy function.

At all times, it should be assumed by the MARC Board, staff, and membership that the advocate has the best capability'to handle a case. Not only should the advocate know most about how the services and regulations relate to his/her specific client, but the advocate is also the one who knows the wishes of his/her client. Therefore, the advocate generally will have the greatest capability to carry out those wishes through a strategy which has been decided upon by his/hep client

MARC's Instrumental Advocacy Program adds a different dimension to the organization. Although MARC supports particular positions with which not all members may agree, it also offers every member and person who is mentally retarded an advocate who will serve them to the best of their ability. The advocate will support their client's position even if it is not the position of MARC, and they will use their knowledge to help the clients get what they want.