

Community Residential Advocacy
for Persons with Developmental
Disabilities: Current Status
and Future Development

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I. INTRODUCTION

This paper explores an emerging advocacy concept: community residential advocacy services for persons with a developmental disability. Although the terms and concepts on this topic have been used for several years by the Advocacy and Protective Services Committee of the Governor's Planning Council on Developmental Disabilities (the primary audience of this paper), there is no common agreement about what is actually meant by the term, community residential advocacy, what a community residential advocate might do, and how such a system of services might be developed (if needed) and implemented in a uniform manner in the State of Minnesota. The purpose of this paper is to assist in clarifying terms and to suggest possible ways in which advocacy services can be provided and strengthened, particularly at the community level.

At the onset of this study, it was discovered that there was relatively little information that could be gleaned either from existing literature or from other states in the country on this specific topic. As in Minnesota, other states were providing several types of advocacy services (e.g. legal advocacy, citizen advocacy, institutional advocacy, training in self-advocacy techniques for consumers and their parents), but no one was able to contribute to the overall concept that the advocacy planners in Minnesota had in mind: a coordinated approach for assuring the acquisition and protection of individual rights for persons with developmental disabilities living in licensed, community residential facilities.

The approach proposed in this paper may not be the only one that might be used, nor, should this attempt be misconstrued as being all-encompassing or final. At most, it is only a beginning of what can be a very long process. Much like assembling a puzzle, this report tries to describe certain portions of the total advocacy picture by: (a) describing what advocacy services are already operational and affecting the lives of peo-

ple with developmental disabilities residing in licensed community-based facilities, (b) describing existing models of residential advocacy services, and (c) describing (suggesting) how other pieces of the puzzle might be assembled in the future to complete the picture.

As noted in the Glossary that is provided in Appendix A, advocacy terms are usually described according to their functions, e. g. legal advocacy, guardianship, etc. Residential advocacy, on the other hand, connotes more the location of the clientele, rather than its functions. Two types of "residential advocacy" functions are explored in depth in this paper: (a) The State Hospital Advocacy Program, which describes advocacy services in public institutions, and (b) The Long Term Care Ombudsman Program, which outlines the functions of community-based advocates serving senior citizens in nursing homes and other health care facilities.

The use of these existing models should be helpful for the eventual description about what a community residential advocate serving persons with a developmental disability might perform and how such a system of services might be implemented in Minnesota. In other words, this paper suggests the use of the eclectic approach. By selecting concepts and materials from various sources and experiences, human service planners should be enabled to then adapt and design advocacy services that will address the particular needs at the state, regional, and local levels.

II. EXECUTIVE SUMMARY

This report explores the possibilities of providing a coordinated approach for assuring the acquisition and protection of individual rights for persons with developmental disabilities living in licensed, community residential facilities in the State of Minnesota. Intended primarily for the Advocacy and Protective Services Committee of the Governor's Planning Council on Developmental Disabilities, this report should prove helpful in paving the way toward further refinement and development of the emerging concept of community residential advocacy.

Due to the past and continued thrust of the deinstitutionalization process in Minnesota, there are now more people with mental retardation living in licensed, community residential facilities (over 4,400 people) than there are numbers of people residing in state hospitals (2,780 people). Under the consent decree of *Welsch vs. Noot* (September 25, 1980), more than 900 institutionalized people will be placed in community settings during the next six years. In addition, there are an undocumented number of people with mental retardation and other handicapping conditions who have been inappropriately placed in nursing homes and other health care facilities for the elderly (latest estimate by the Department of Public Welfare, July 1980, was 370 persons) who should be placed in programs where appropriate services can be provided. Furthermore, many people will be prevented from entering state hospitals in the future as the number and quality of services (e.g. education, work training, and day programs) improve and expand in communities throughout the state.

Recognized as an essential component within the definition of deinstitutionalization by NASPRFMR, 1974 (i.e. "The establishment and maintenance of a responsible residential environment which protects human and civil rights."), the issue is clear that certain safeguards must be built into

any system, whether in institutions or in community programs, that purport to provide humane environments for persons with developmental disabilities. Several existing safeguarding mechanisms are already operational in Minnesota, including:

- Several "Bill of Rights" have been written into federal and state laws, (For example, The Minnesota Residents' Bill of Rights, M.S. Section 144.651 - .652),
- Standards and licensing regulations have been promulgated and are being enforced,
- Written individual habilitation and treatment plans are required that encourage the participation of many disciplines, agencies, parents/guardians and the clients being served,
- Community volunteers are actively participating in policy setting and in providing services to individuals,
- Appeal and grievance procedures have been established and complaints, (particularly about health care facilities and services) are investigated with penalties imposed, upon substantiated evidence,
- Abuse and neglect reporting laws pertaining to both children and vulnerable adults have been enacted,
- Many advocacy services, both internal to and external from governmentally administered programs, have been established, and
- Consumers of services have become increasingly more verbal in expressing their individual and collective needs and have begun to mobilize and act on their own behalf.

Indeed, there are many attributes of the human service delivery system in Minnesota that reflect sensitivity to the needs and rights of persons with developmental disabilities. However, it would be presumptuous to conclude that the quantity and quality of the safeguards listed above are adequately meeting the needs. Each provision has certain limitations.

There may be a number of "Bills of Rights" that have been written into law, but there are usually no monetary means allocated for their enforcement such as "The Patients' Bill of Rights" in Title XIX of the Social Security Act.

The provision for Protection and Advocacy Systems in each state under the Developmental Disabilities Assistance and Bill of Rights Act (P.L. 95-602) does provide money to operate such systems (a rare exception). However, the amounts are meager in comparison to the Congressionally mandated expectations. For example, Minnesota receives approximately \$123,000 per year to operate the statewide Protection and Advocacy Network.

As the deinstitutional process continues, monitoring and licensing of community programs become increasingly more difficult and inadequate. While the number of facilities increase, there are no comparable increases in the number of qualified licensing staff to meet the demand. This situation is further exacerbated by financial crises at the federal and state levels.

The Residential Study Report issued by the Department of Public Welfare in 1978 indicated a strong concern that individual program plans were not being sufficiently monitored regarding appropriate placements and services. Even though the State Guardianship and Conservatorship Program underwent a major overhaul in the 1975 legislative session, the previous problems persist, including high caseload counts among the county social workers that prevent the provision of adequate protective services.

Appeal and grievance mechanisms usually fall short of being totally effective because clients may not be fully aware of such rights and procedures. In addition, there may be strong suspicions that many people (residents, relatives, and direct-care staff) do not speak out or take action for fear of reprisals toward the resident. The Office of Health Facility Complaints stipulates that all possible attempts be made to resolve problems at the local level prior to their involvement, but there are usually few, if any, third-party advocates at the local level to intervene or to follow-through upon recommendations that are made by the state office.

It is too early to determine whether the new Vulnerable Adult Protection Act will be effective. The emphasis placed upon the prevention of abuses and neglect will demand a concerted effort by many parties for the development of the prescribed prevention plans.

Despite the development of many internal and external advocacy programs throughout the State, there are several gaps and deficiencies including:

- . Minnesota does not comply with the educational requirements under P.L. 94-142 (Education for all Handicapped Children Act), in that qualified surrogate parents should be appointed as non-biased spokespersons on behalf of children whose parents are unknown or unavailable when reviewing individualized educational plans.
- . Trained guardians ad litem could be helpful as the courts review all children with developmental disabilities in out-of-home care (after 18 months of placement), now required by Minnesota law.
- . The growth of Citizen Advocacy Programs has been relatively slow in Minnesota, as compared with other states. The competition for and recruitment of responsible volunteers is a problem that is becoming increasingly acute.
- . In addition, advocacy services are not equally available, especially in rural areas. For example, comparatively few people who live considerable distances from the Twin Cities and Duluth offices are benefiting from Developmental Disabilities Legal Advocacy Services.

As consumers of services gain independence and assertiveness, human service practitioners and advocates alike are gradually realizing the inherent dangers of over-protectiveness ("doing for" rather than allowing to "do for oneself"). Risk-taking and the provision of training in self-advocacy remain as challenges to be met in striving toward the goals of self-actualization and normalization for each individual.

In recognition and consideration of the above unmet needs, this paper proposes that a coordinated approach be taken in order to provide an array of advocacy services to persons residing in licensed, community-based facilities. At present, community residential facility administrators and the residents have the option of acquiring the assistance of responsible, third-

party advocates who are outside of the service delivery system and who are free from conflict of interest. However, the freedom of access to private property, data privacy concerns, lack of trust, acceptance, and other barriers (e.g. lack of information and geographic distances) often prevent clients/residents to avail themselves of such services. A mandatory approach via law and/or regulation may be necessary in the future so that community residential advocacy could be made available on a more comprehensive and coordinated fashion.

As an external change agent, the role of the community residential advocate should be flexible and dynamic, an ever-changing role that adjusts to the particular needs and circumstances of the clientele over the passage of time. The community residential advocate would be considered to be a "professional" in the human service field in that a great deal of specialized knowledge and proven skills would be required. A community residential advocate cannot be all things to all people and must be able to facilitate the development or utilization of other specialized advocacy resources. Such coordination is necessary in order to avoid further duplication and fragmentation of advocacy services.

If a mandatory approach would be taken by policy makers, that is, that all community residential facilities must establish acceptable plans for the procurement of external advocacy services, several departmental rules and regulations would be affected in order to create sufficient authority, accessibility, and funding for a statewide effort. Several regulatory issues are outlined in this report in order to initiate any future discussions over these matters.

A statewide system of community residential advocacy services could be administered and organized in a variety of ways. Considerations should be

given to the provision of a central administering office, e.g. under the existing authority of the Minnesota Developmental Disabilities Protection and Advocacy Network, administered by the Central Minnesota Legal Services Corporation in Minneapolis. Based upon population and service need determinations, it would seem most feasible to provide community advocacy services in each region, with a possible combination of regions with populations of low density.

Taking a broader perspective is suggested in that other issues and populations in need of similar services could be combined into a single effort. The broader perspective would address the future placement and administration of the State Hospital Advocacy Program and combining efforts for providing advocacy services to other community-based residential facilities that serve senior citizens, people with mental illness and chemical dependency, and juveniles and adults in the correctional system. Combining efforts with the Long Term Care Ombudsman Program, which is described in detail in this report, would seem appropriate and timely as a first step in view of this broader perspective and long range goal.

In conclusion, by designing and implementing a system of community residential advocacy throughout the State Of Minnesota, several unmet needs and conditions could be realized:

1. Consumers and/or their families could become more knowledgeable about their rights and the consumers may gain the necessary skills and responsibilities that accompany such freedoms.
2. State and local agencies, as monitors and enforcement officers, could benefit from greater citizen participation as the neighborhood concept is increasingly achieved and realized.
3. Direct care staff can become more sensitive to and knowledgeable about the needs and rights of their residents and could greatly benefit from the additional supportive resources made available

to them from outside the residence.

4. Better utilization of existing advocacy services would materialize and volunteer services could be enhanced.

In short, all could benefit.

III. HISTORICAL OVERVIEW AND CURRENT NEED

As early as 1972, the Advocacy and Protective Services Committee of the Governor's Planning Council on Developmental Disabilities identified residential advocacy as an important area among their long-term goals. At that time, the Committee members were looking at the needs for protecting and advocating the rights of persons with developmental disabilities in both public institutions and in private, community-based residential facilities.

In Section VI of this report, the story about how the Minnesota State Hospital Advocacy Program came about, as administered by the Department of Public Welfare, is more thoroughly described. It is important to note that "institutional advocacy" had actually started as early as 1972 and that, today, all of the state hospitals have "in-house" advocates to address the needs and rights of persons who are mentally ill, mentally retarded, or chemically dependent.

The movement to safeguard and advocate for the rights of people, particularly those with mental retardation, in community-based residential settings has been piecemeal in comparison to the State Hospital Advocacy efforts. Many of the same questions and concerns that the Advocacy and Protective Services Committee expressed in 1972 are probably just as important today.

In the following sections of this paper, highlights of major events of the 1970's will be explored in order to illustrate the need for community residential advocacy programs.

- A. Deinstitutionalization and the Protection of Rights
- B. The Development of Internal and External Advocacy Services
- C. Data that Supports the Need for Advocacy Services in Community Settings.

1. Services and Data Provided by Legal Services for Persons with Developmental Disabilities in Minnesota.
2. Findings from the Office of Health Facility Complaints.
3. Physical and Sexual Assault of Disabled People/Creation of the Vulnerable Adult Protection Act of 1980.
4. Consumers Speak Out.

A. Deinstitutionalization and the Protection of Rights

In the past few years, Minnesota has experienced a dramatic change in providing services to persons with a developmental disability. This change is most acutely observed and experienced among the population with mental retardation. The population shifts from large, public institutions to community settings became a national goal in 1963, since then referred to as the process of deinstitutionalization.

The populations of the Minnesota State Hospitals for people with mental retardation reached their peak in 1967, when the count was approximately 6,500. In 1979, the existing 10 state hospitals reported a total of 2,700 residents with mental retardation, a decline of almost 4,000 people over 19 years.

There has been a comparable shift to providing the needed services in the community. In 1962, there were only five community facilities in Minnesota that had a bed capacity of 100. As of March 1981, there were 267 community residential facilities licensed under DPW Rule 34 that had a bed capacity of 4,491, with a utilization rate of 96%.

Some of the most important events affecting the development of community residential care for persons with mental retardation occurred between 1972 and 1974 when:

- there were court affirmations regarding the constitutional right to treatment,

- DPW Rule 34 was promulgated that prescribed and enforced program standards for community-based facilities,
- the National Life Safety Code was implemented and there was monitoring of such facilities, and
- federal funds became available to assure a stable funding base under Medicaid (for Intermediate Care Facilities serving people with mental retardation).

In the Residential Care Study (Department of Public Welfare, March, 1979) several interesting characteristics about community-based residential programs for persons with mental retardation were revealed as a result of a survey:

- . As of August, 1978, there were 206 community-based Rule 34 facilities with a bed capacity of 3,827 (p. 15).
- . The facilities were almost equally divided into for profit and non-profit facilities (p. 15).
- . 73% of the facilities were licensed for 15 or fewer residents. Facilities licensed for 16 or more residents were more likely to be for profit facilities (p. 15).
- . Facilities opened in the last three years tended to serve more of the lower functioning physically disabled individuals with mental retardation (p. 15).
- . The facilities surveyed with a licensed capacity of 15 or fewer residents were more likely to accept individuals with psychiatric and behavior problems (p. 15).
- . Approximately 40% of the residents in all the surveyed facilities had their last formal treatment at a state hospital (p. 15).
- . Non-profit homes licensed for 16 or more residents had the smallest percentage (13%) of former state hospital residents (p. 15).
- . The majority of residents (65%) in the surveyed facilities were severely and moderately retarded (p. 16).
- . The larger non-profit facilities with 16 or more residents had a much higher staff to resident ratio than other types of facilities, or 86.4 staff per 100 residents compared to approximately 55 staff per 100 residents (p. 16).

- . The metropolitan area generally contains the counties with the lowest admission rate to state hospitals per 10,000 population while the northeastern counties of the state generally rank second lowest in admission rates. This was probably due to the high number of community residential facilities in both of these areas of the state (p. 26).

Infrequent monitoring of the individual treatment plan in order to assess compliance and to protect clients' rights in community-based residential facilities was a cause for concern of the Residential Care Study Advisory Council, especially in the context of policy options that call for increased community-based programs (p. 29).

In addition to the population of people with mental retardation who reside in DPW Rule 34 facilities, there are a considerable number who reside in non-MR facilities, such as in Skilled Nursing Facilities (SNFS) and in Intermediate Care Facilities -- General (ICF-Gs). A report issued by the Quality Assurance and Review Section of the Department of Health (July 30, 1980) indicated that there were 599 people with a primary diagnosis of mental retardation in SNFs and 922 in ICF-Gs, a total of 1,521 in non-MR facilities. According to Mary Kudla, Technical Assistance Specialist in the Mental Retardation Program Office (DPW, March 14, 1981) an estimated 370 of those in non-MR facilities could be considered as being inappropriately placed. This estimate was based upon available data provided by the Minnesota Developmental Programming System for the period ending July, 1980.

An earlier study (Krantz, December 1975) indicated that there were 667 in non-MR facilities who could be identified as being mentally retarded and were in "technically inappropriate placements." It appears that the major problems in getting an accurate count of the number of people who might be inappropriately placed is due primarily to inaccurate diagnostic data. At any rate, this segment of the community-based population should

be taken into account by human service providers and advocates alike. The creation of more appropriate alternatives and conscientious individual planning should remedy such inappropriate placements in the future.

The trend to deinstitutionalize is very likely to continue. The recent consent decree of the Welsch vs. Noot class action suit stipulates that at least 30% of the population with mental retardation in state hospitals must be moved to more suitable settings in the community between 1981-1987. This will affect the lives of over 800 additional state hospital residents.

The above information is provided in order to point out that the process of desinstitutionalization has occurred quite rapidly over a relatively short duration and that during such times of rapid transition, there may be great dangers and frustrations experienced by the individuals involved, particularly in terms of human dignity, rights and freedoms. As a reminder to human service planners and providers, the latter part of the definition of deinstitutionalization (NASPRFMR, 1974) should be noted:

Deinstitutionalization encompasses three inter-related processes:

1. Prevention of admission to institutions by funding and developing community methods of care and training;
2. Return to the community of all residents who have been prepared through programs of habilitation and training to function adequately in appropriate local settings; and
3. Establishment and maintenance of a responsible residential environment which protects human and civil rights. (pp. 4-5)

B. The Development of Internal and External Advocacy Services

As noted previously, there has been a tremendous shift of populations and services during the last two decades, from large public institutions to small community residential facilities. As a major element within the deinstitutionalization process, there must be adequate attention given to establishing and maintaining responsible residential environments which protect human and civil rights. This section will describe what has been accom-

plished in Minnesota regarding the provision of advocacy services for persons with a developmental disability and will provide some documentation on the kinds of advocacy problems experienced and the overall need for better coordination.

There were significant events that occurred in the 1970s that delineated the rights of people with developmental disabilities and provided for the acquisition and protection of those rights. Regarding the specific population of people that reside in community residential facilities, there were many public and private mechanisms put into place that addressed advocacy and protective service needs. These advocacy services can best be described by means of two categories: (1) internal advocacy provided within a public service agency, and (2) external advocacy provided by private organizations or agencies outside of government control.

1. Internal Advocacy. The Minnesota Department of Public Welfare has been recognized by law and in practice as the central coordinating unit among the public human services in serving people with mental retardation and other developmental disabilities. This department's primary function is that of monitoring, evaluating, and enforcing public law and policy related to the provision of services under its jurisdiction.

Some of the more salient developments by DPW during the last decade included:

- . Advocacy Policy: The Department of Public Welfare issued a policy statement on advocacy on May 18, 1972. (DPW Manual, Chapter 7, as revised August 20, 1978). See Appendix D. In this policy, DPW authorized the development and implementation of advocacy procedures for all units in human services under its jurisdiction "that would ensure that legal, civil and human rights would be up-

held in a way that is recognizable and immediately responsive to grievances of individuals and families and would, at the same time, provide an approach for modifying the decision-making process."

Both "internal" and "external" forms of advocacy were recognized as being essential and that service providers would be protected from harassment if they called attention to suspected violations of rights.

As a direct result of this policy, advocacy positions were established in each state hospital and the Client Protection Office was created in DPW.

- . DPW Rule 34: Standard for the Operation of Residential Facilities and Services for Persons who are Mentally Retarded, November 17, 1972. Under Minnesota Statute 252.28, the Commissioner of Public Welfare is charged with the responsibility for licensing of residential facilities and services for persons with mental retardation. "The purpose of the licensing law and regulations is to establish and protect the human right of mentally retarded persons to a normal living situation, through the development and enforcement of minimum requirements for the operation of residential facilities and services." Besides specifying individual rights, these regulations provide for another person, other than a parent, to represent the rights and interests of the person with mental retardation as if they were their own, e.g. an advocate or guardian. The standards also specify that there be "meaningful and extensive consumer representation and public participation in its operation" e.g., on its governing board and/or advisory committee (s). These standards and policies were later enhanced and enforced by federal standards (June, 1976) relating to the certification of ICF/MR, Intermediate Care Facilities that were funded under Title XIX of the Social Security Act, known as Medicaid.

The Intermediate Care Facility standards included requirements for the recognition and maintenance of the rights of residents with mental retardation in ICF/MR certified facilities, which are summarized below:

1. Reasonable advance notice of transfer or discharge of a resident is at least 5 days.
2. Only a physician and a Qualified Mental Retardation Professional may authorize chemical or physical restraints except in emergencies when facility policies must identify the personnel who may authorize.
3. Residents may participate in planning their total care and medical treatment. They may refuse treatment and take part in research projects only with their written consent.
4. Facilities must have an internal grievance mechanism with appropriate follow-up.
5. Consent of the resident and informed consent of the parent or guardian is required before the use of aversive behavior modification programs and not before the use of all behavior modification programs.
6. Enactment and enforcement of facility policies are required regarding confidentiality of resident's personal, health, and medical records.
7. Facility services and charges are to be provided to recipients in writing.

8. A physician or Qualified Mental Retardation Professional may determine if a resident is capable of understanding his rights. The specific impairment must be documented in his records.
 9. The residents are not required to perform services for the facility unless they agree and such services are part of their care and treatment plan.
- DPW Rule 80: Standards for Residential Facilities and Services for the Physically Handicapped. Under Minnesota Statute, Sections 245.78 through 245.82, the Commissioner of Public Welfare is given the authority to set rules and license residential facilities and services for the physically handicapped. As of December, 1979, there were ten facilities licensed under this rule with a capacity for serving 472 children and adults with physical handicaps. One of the major objectives under this rule is, "to provide a home-like atmosphere to the greatest possible extent where the resident is recognized as an individual whose personal interests are maintained and developed and whose personal dignity is respected and safeguarded."
 - The Mental Retardation Protection Act (M.S. 252A): This law became effective on July 1, 1975 and established that, "It is the policy of the State of Minnesota to provide a coordinated approach to the supervision, protection and habilitation of its mentally retarded citizens." Furthermore, this law provides for public guardianship and for a more limited form of guardianship, called "conservatorship." This law authorizes the Commissioner of Public Welfare "to supervise those mentally retarded citizens who are unable to fully provide for their own needs and to protect

such mentally retarded persons from violation of their human and civil rights by assuring that such individuals receive the full range of needed social, financial, residential and habilitative services to which they are lawfully entitled."

- DPW Rule 185: Community Mental Health Board and County Welfare or Human Service Board Responsibilities to Individuals Who are Mentally Retarded (1976). This rule provides for the coordination of individual service plans. A revision in 1977 included a section on volunteer services, which recognized the importance of activities of individuals, service organizations and advocacy groups "that provide a variety of services on a group or one-to-one basis that supplements and augments services provided to mentally retarded persons."
- Protective Services: DPW is also responsible for providing protective services for children and adults. DPW Rule 207 governs the administration and provision of protective services to children through local social service agencies. DPW Rule 221 is being developed which relates to the protection of vulnerable adults under M.S. 626.557, The Vulnerable Adult Protection Act, 1980, as described more fully below.

In summary, the Department of Public Welfare developed many internal advocacy functions for assuring individual rights and protections for persons with a developmental disability. These functions are carried out by performing the following types of activities:

- monitoring county plans;
- inspecting and licensing facilities;
- evaluating programs;
- providing training and technical assistance to service providers; and
- supervising and conducting appeals and complaint procedures.

The above paragraphs describe only the Department of Public Welfare and some of its internal advocacy functions. There are other forms of "internal advocacy" in other governmental agencies which are also pertinent and available to persons with a developmental disability who reside in community-based facilities. Such programs are geared to serve individuals and groups of people with a variety of handicaps.

- The Division of Vocational Rehabilitation Ombudsman Program
- The Minnesota Council for the Handicapped (particularly "Access Minnesota")
- The Office of Health Facility Complaints (Described in detail below)
- The Long Term Care Ombudsman Project in the Board on Aging (Described in detail below)
- The Minnesota Human Rights Department
- Office of Consumer Services in the Department of Commerce
- Equal Education Opportunities Section of the State Department of Education
- Ombudsman for Corrections
- The Governor's Planning Council on Developmental Disabilities and Developmental Disabilities Planning Office of the State Planning Agency
- Office of Client and Employee Advocacy in the Department of Economic Security

2. External Advocacy. During the 1970's, many advocacy mechanisms were developed outside of the service delivery system. Such programs were developed primarily by consumer groups who were either not satisfied with the quantity or quality of services being provided or who saw that additional needs were not being met by the delivery system.

There are literally hundreds of private organizations or agencies that specialize in one form of advocacy service or another. Many of these agencies were identified in the Minnesota Advocacy Resource Directory, 1978 and its

1981 revision. (Available through the Developmental Disabilities Planning Office of the State Planning Agency).

Historically speaking, the most significant development in the last decade was the establishment of the Minnesota Developmental Disabilities Protection and Advocacy Network under the Developmental Disabilities Assistance and Bill of Rights Act of 1975 as amended in 1978 (P.L. 95-602). As of October 1, 1980, the Governor of Minnesota has designated the Central Minnesota Legal Services Corporation for the administration of the Protection and Advocacy Network. This agency has the authority to pursue legal, administrative and other appropriate remedies to insure the protection and advocacy of the rights of persons with developmental disabilities. As administrator of the Minnesota Protection and Advocacy Network, this agency via its State Plan, is to coordinate efforts and resources with other internal and external advocacy agencies or groups in order to strengthen and make accessible advocacy services for people with developmental disabilities who are in need of such services. In order to be a part of the Protection and Advocacy Network, advocates are encouraged to enter into an informal inter-agency agreement called, "Statement of Mutual Obligation." As of this writing, 75 advocacy agencies and 25 individuals have signed this agreement.

Rather than list all the external advocacy organizations, the following listing offers a sample of what kinds of outside resources that people residing in community-based facilities might have at their disposal:

- Legal Advocacy for Developmentally Disabled Persons in Minnesota (Statewide services provided out of offices in Minneapolis and Duluth).
- P.A.C.E.R., Inc. (Parent Advocacy Coalition for Educational Rights).
- Regional Developmental Disabilities Coordination Programs (in most of the Economic Development Regions in the State).
- Minnesota Citizen Advocacy Coalition (Citizen Advocacy programs have been developed in Duluth, St. Paul, Minneapolis, Two Harbors, Cloquet, and Mankato).

- ACT, Inc. (Advocating Change Together), Minneapolis
- Project CADRE (which addresses citizen advocacy needs of persons who are either offenders or victims in the criminal justice system).
- Advocate for the Blind, United Blind of Minnesota, Inc.
- Foster Grandparent Programs
- Senior Companion Programs
- Nursing Home Residents' Advocates (Minneapolis)
- The Mental Health Advocacy Coalition
- Information and Referral Services
- Crises Intervention Centers
- Community Action Councils
- CENTS; Inc. (Center for Education for Non-Traditional Students).
- Big Brother and Big Sisters
- Human Rights Commissions
- Consumer Organizations, e.g.:
 - Associations for Retarded Citizens
 - United Cerebral Palsy
 - Epilepsy League
 - Society for Autistic Adults and Children
 - Spina Bifida Association
 - Association for Children and Adults with Learning Disabilities
 - United Handicapped Federation

In summary, it is important to realize that there are many existing advocacy services available to a person who resides in a community-based facility, avenues that are available both within and outside of the service delivery system. However, there are probably many questions that might be asked, e.g.:

- Are residents of community-based facilities aware and informed of their rights?

- How informed are the parents and/or guardians?
- Do people know where to go in order to find an advocate who can assist in meeting instrumental and/or expressive needs?
- How effective are the internal advocacy mechanisms, e.g. monitoring, licensing, complaint investigation, guardianship/conservatorship and other protective services?

Perhaps some of these questions can be answered by looking at some selected data as provided in the following section.

C. Data that Supports the Need for the Improvement of Advocacy Services in Community Settings

Without conducting a fairly comprehensive inventory of the needs for improved advocacy services throughout the State of Minnesota, it is not possible to state emphatically that the rights and needs of persons with developmental disabilities residing in community residential facilities are being adequately provided for or not. Such detailed research is not within the scope of this report and its limited resources.

However, this report is intended to document and analyze what information is available, point out apparent trends and gaps of advocacy services, and indicate where further research might be needed. Certainly, it can be assumed that the needs in different communities and regions will vary widely. Much depends upon the attitudes of direct-care staff in any given residential setting as well as the availability and accessibility of outside advocacy resources.

One particular form of advocacy is commonly disregarded and under-rated as to its importance: expressive citizen advocacy. Such volunteer programs provide one-to-one friendships which foster emotional and social support. Often the citizen advocate is viewed as being an important link to the non-handicapped world, thus broadening the social horizons for the person with a developmental disability. In the few communities that have such programs (e.g. Minneapolis, St. Paul, Duluth, Cloquet, and Mankato), there are usually twice the number of proteges (people with a developmental disability) on the

waiting list than there are matched pairs. In other words, such programs seem to fight a continuous battle of recruiting an adequate number of volunteers.

Following is an analysis of some selected advocacy related activities that address a variety of advocacy needs and services: (1) legal advocacy services, (2) state investigation of health services complaints, (3) abuse and neglect of the vulnerable adult, and (4) the consumer self-advocacy movement. These are only a small selection of the possible areas to explore. However, the data should provide some inclination of the kinds of problems being experienced and where future development may occur.

1. Services and data provided by Legal Services for Persons with Developmental Disabilities in Minnesota. Specialized legal services have been available to persons with a developmental disability throughout Minnesota since 1973. A review of some of the past experiences of this program and the nature of the services provided will be of further assistance in documenting the need for additional advocacy services for residents in community facilities.

The Developmental Disabilities Legal Services Program is administered by the Central Minnesota Legal Services Corporation in Minneapolis. (A branch office of the program also operates in Duluth, serving the Arrowhead Region). On October 1, 1980, this agency became the official designated agency (as designated by the Governor) for the administration of the Minnesota Developmental Disabilities Protection and Advocacy Network, as authorized under P.L. 95-602, the Developmental Disabilities Assistance and Bill of Rights Act, 1978.

Besides providing direct legal services to individuals or groups, many other related services are provided by a staff of five attorneys and two paralegal staff members. Training about human rights, laws and advocacy

techniques is provided for advocacy practitioners, service providers, consumer representatives, law students and attorneys in general practice. Public information and education is disseminated via publications and public presentations.

Probably the greatest impact upon the lives of persons with developmental disabilities has resulted from the influence that the Developmental Disabilities Legal Services Program has had upon legislation, regulations, and administrative policies and procedures. Antiquated laws have been brought up-to-date, such as the Mental Retardation Protection Act, which relates to public guardianship and conservatorship. Restrictive zoning laws that often prevented the development of group homes in communities were circumvented by means of developing a State law that supersedes local zoning ordinances. The enactment of the Vulnerable Adult Protection Act, 1980, is another example of social reform by way of legislation. In addition, results from court litigations and judgements have set precedences for subsequent actions and policy reform.

Clientele Served

In fiscal Year 1980 (October 1, 1979 through September 30, 1980, Legal Advocacy Services for Developmental Disabled Persons in Minnesota reported that there were 474 cases served (providing direct legal advice and representation). This number was derived at by adding the number of open cases at the beginning of the year to the number of cases opened during the year (see Table 1).

An additional 275 people received advice only, such as over the telephone, during the 1980 Fiscal Year (see Table 2). Most of these contacts were on a one-time-only basis.

Among the 474 cases that received direct representation, there are usually an average of five community residential programs (representing all per-

sons within a facility) served each quarter, or an average of 20 facilities served each year.

Regarding the types of problems handled for residents in community facilities, the following kinds of situations have been dealt with:

- eligibility disputes in qualifying a group facility for the Food Stamp Program
- visitation rights under the Patients' Bill of Rights (ICF/MR Standards)
- access to the residents' mail
- eligibility for financial benefits, e.g. Supplementary Security Income (SSI)
- dietary restrictions, money management, and other aspects of an individual's treatment plan
- cost-of-care (Department of Public Welfare Rule #30) issues regarding ancillary services to children, e.g. prosthetics, wheelchairs, hearing aids, etc.
- zoning disputes
- use of behavior modification and aversive techniques

The following tables describe the demographic data and caseload characteristics by number of clients served (those that received direct legal representation only) during Fiscal Year 1980 (October 1, 1979 through September 30, 1980):

Table 1

Legal Advocacy Caseload Movement for Each Quarter of Fiscal Year 1980
 Number of Cases Opened and Closed
 (Minnesota Protection and Advocacy Program Performance Reports,
 October 1, 1979 through September 30, 1980)

Quarter	Dates	Number Cases Open at Start of Period	Number of New Cases Opened	Number Cases Closed or Resolved	Number Still Open
Total		--	282	217	--
1	10/1/79 to 12/31/80	192	84	59	217
2	1/1/80 to 3/31/80	217	90	69	238
3	4/1/80 to 6/30/80	238	55	53	240
4	7/1/80 to 9/30/80	240	53	36	257

Table 2

Number of Legal Advocacy Cases/Clients Receiving Advice Only*
 For Each Quarter in Fiscal Year 1980
 (Minnesota Protection and Advocacy Program Performance Reports,
 October 1, 1979 through September 30, 1980)

Quarter	Dates	Number of Cases Receiving Advice Only*
Total	FY 1980	275
1	10/1/79 to 12/31/79	113
2	1/1/80 to 3/31/80	77
3	4/1/80 to 6/30/80	25
4	7/1/80 to 9/30/80	60

* Most Advice Only cases are conducted over the telephone.

Table 3

Number of Legal Advocacy Cases/Clients Served by Age Category
During Fiscal Year 1980
(Minnesota Protection and Advocacy Program Performance Reports,
October 1, 1979 through September 30, 1980)

Age Categories	Number
Total*	266*
0-12	93
13-18	46
19-30	68
31-59	50
60-64	6
65-69	2
70-Up	1

*Total does not equal 474 (total number served) because the 18 community group facilities served are omitted or all of the ages were not documented/reported.

Table 4

Number of Legal Advocacy Cases/Clients Served by Type of
Developmental Disability in Fiscal Year 1980
(Minnesota Protection and Advocacy Program Performance Reports,
October 1, 1979 through September 30, 1980)

Primary Disability	Number
Total*	262
Mental Retardation	142
Cerebral Palsy	12
Epilepsy	26
Autism	27
Additional D.D. ACT Categories	27
Other	28

*Total does not equal 474 (total number served) because the 18 community group facilities are omitted and/or complete data were not reported.

Table 5

Number of Legal Advocacy Cases/Clients Served by Residence
in Economic Development Regions in Minnesota, F.Y. 1980
(Minnesota Protection and Advocacy Program Performance
Reports, October 1, 1979 through September 30, 1980)

Economic Development Region	Number
Total*	266*
1	4
2	5
3 (Arrowhead)	96
4	8
5	5
6E	3
6W	-
7E	12
7W	14
8	1
9	13
10	14
11 (Metro)	91

*Total does not equal 474 (total number served) because of
incomplete data reported.

Table 6

Number of Legal Advocacy Cases/Clients Served by Source
of Referral
(Minnesota Protection and Advocacy Program Performance
Reports, October 1, 1979 through September 30, 1980)

Source of Referral	Number
Total*	197*
Court, Bar Association, Other Attorney	8
Community Organization	3
Prior Client with New Case	21
Publicity	16
Community Legal Education Program	3
Government Agency or Institution	86
Private Agency or Institution	10
Other Legal Service Program	2
Other Source (e.g. Consumer Agency)	48

*Total does not equal 474 (total number served) because of
incomplete data reported.

Table 7

Number of Legal Advocacy Cases/Clients Served by Legal Problems Identified
(Minnesota Protection and Advocacy Program Performance Reports, October 1, 1979 through September 30, 1980)

Legal Problem Identified	Number
Total*	281*
Family Law	1
Welfare	51
Juvenile Law	3
Consumer Law	10
Housing Law	2
Probate Law	30
Employment	3
Education Law	122
Civil Rights	21
Problems relating to Institutions	30
Miscellaneous	8

*Total does not equal 474 (total number served) because of incomplete data reported.

Table 8

Number of Legal Advocacy Cases/Clients Served by Type of Intervention and Remedy Sought
(Minnesota Protection and Advocacy Program Performance Reports, October 1, 1979 through September 30, 1980)

Type of Intervention/Remedy Sought	Number
Total*	228*
Problem Resolved--Negotiations	98
Problem Resolved--Instrument Drafted	7
Administrative Proceeding	27
Litigation	10
Legislative or Administrative	2
No Further Contact	25
Client Withdrew	4
Office Withdrew	2
Conflict of Interest	--
Other	37
Office Advice Only	6

*Total does not equal 474 (total number served) because of incomplete data reported.

From the above data, the following observations and conclusions can be drawn:

- (a) There were almost an equal number served under 18 years of age (139 children) as those over age 18 (127 adults).
- (b) A majority of disabilities represented were people with mental retardation (142). However, a considerable number of people (119) had other types of handicapping conditions.
- (c) Geographic distance was a major factor in the utilization of services, i.e. the location of the offices in the metropolitan areas of the Twin Cities and Duluth served greater numbers in their immediate areas as opposed to the more distant regions of the State. On the other hand, it can be noted that almost all of the outlying regions are receiving services, but at an extremely low rate, by comparison.
- (d) Most referrals came from service providers (86). However, a substantial number came from community organization, such as consumer groups (61).
- (e) Most problems related to education (122) and welfare matters (51).
- (f) Most problems are resolved by means of negotiation (98) rather than through litigation (10) or administrative proceeding, e.g. appeals (27).
- (g) The above data generally describes a fairly consistent pattern of the scope and nature of the legal services provided over the past few years.

A Past Community Residential Advocacy Pilot Program

It is important to learn from mistakes as well as successful experiences. In 1974, the Developmental Disabilities Legal Services attempted to provide advocacy services that were targeted at a specific population of people resid-

ing in licensed, community-based facilities. The legal advocacy staff at that time suspected that there were many advocacy needs (that were of a non-legal or quasi-legal nature) of community facility residents that were not being met. Such needs, it was thought, could be addressed by trained, lay advocate volunteers. A dozen volunteers received an extensive training program and were each assigned to one or two community residential programs in the Twin Cities. Back-up support and supervision was provided by the legal advocates.

This pilot attempt lasted for only a few months and was ultimately abandoned. A few volunteers continued to serve for two years, however. Important lessons learned from this pilot endeavor should be noted, as summarized below:

- a. The very term "advocacy" is threatening to many service providers. If an adequate substitute for the term could be provided, this might be the recommended path to follow. On the other hand, adequate time and energy should be given in communicating the full scope and meaning behind the term "advocate" to the service provider, e.g. that an adversarial approach to problem resolution is usually used as a last resort.
- b. Mutual expectations and understandings should be clearly communicated, negotiated and provided in writing, e.g. in the form of an inter-agency agreement. Such agreements should cover such important items as:
 - (1) Confidentiality
 - (2) Times and methods of access, via telephone and in person, that are most convenient for all concerned
 - (3) Complaint procedures for internal and external problem resolution

- (4) Respective roles and responsibilities of direct-care staff
supervisory personnel, management, and the advocate
 - (5) Provisions for ongoing supervision, communication and evaluation
- c. As a change agent, an advocate should not move too quickly and expect miraculous changes overnight. Adequate time and patience is necessary for establishing sound relationships founded on trust and mutual respect.

In summary, from this experience, the key factors for setting up a successful community residential advocacy program consist of doing adequate planning, training, communicating and evaluating. Central to the entire process is to always keep the needs, rights, and best interests of the person with a developmental disability in mind. In this light, advocacy becomes less of a threat to community residential administrators and can be more positively perceived.

2. Findings from the Office of Health Facility Complaints (OHFC). This office is primarily an investigative unit of the State of Minnesota that addresses problems in health care facilities, both publicly and privately operated. OHFC serves many facilities that house people with developmental disabilities, such as State Hospitals, ICF/MR licensed programs and nursing homes. Although data are not extracted that relates specifically to facilities that serve people with a developmental disability, the overall function of this office and its activities are of primary importance to the scope and purpose of this report.

The Office of Health Facility Complaints was established under provisions of Minnesota Statutes, 1976, Section 144A.51-144A.55, to receive, investigate and act upon complaints from anyone, anonymous or identified, regarding services provided by health facilities, health care providers or administrative

agencies. OHFC is an office of the Minnesota Department of Health with statutory authority for:

1. the receipt, investigation and resolution of complaints from any source concerning matters relative to services provided by health care facility, and certain administrative agencies;
2. making recommendations to the Commissioner of Health and the Legislature;
3. the publication of an annual report concerning the activities of the office during the preceding year;
4. assistance to residents of health care facilities in the enforcement of their rights;
5. working with administrative agencies, health facilities, health care providers and organizations representing consumers on programs designed to provide information about health facilities to the public residents of the facilities.

OHFC Jurisdiction

In 1979, the Office of Health Facility Complaints had jurisdiction over a total of 74,490 beds in several types of facilities. See Table 9.

Table 9

OHFC Jurisdiction by Type of Licensed Facility and Number of Beds (Minnesota Office of Health Facility Complaints, 1979)

Type of Licensed Facility	Number of Beds
Total	74,490
Hospitals	18,919
Convalescent and Nursing Care	4,439
Nursing Homes	36,687
Boarding Care	6,106
Supervised Living Facility	8,339

Staffing

In regard to staffing, the OHFC has four health facility evaluation positions, an Executive Director and a Deputy Director.

Complaint Procedures

The Office of Health Facility Complaints receives complaints by telephone, letter, walk-in and referral. Before accepting a complaint for investigation, OHFC recommends that the complainant pursue all other available remedies or channels of grievance and that they make reasonable effort to resolve the complaint by first contacting the agency, facility, provider or their designated representatives with their concerns. After the acceptance of a complaint for active investigation, an unannounced site visit is made to review the facts and situation surrounding the case. If an allegation is unjustified, the complainant is so informed. If justified, appropriate steps are taken to resolve the problem.

Legal Proceedings

A brief synopsis of Section 144A.10 of the Minnesota Statutes, 1976, provides the language requiring the use of correction orders and penalty assessments for non-compliance. Subdivision 4 specifically directs the issuance of correction orders at the time a facility is found not to be in compliance with existing rules and regulations. Subdivision 6 states that a nursing home that is issued a notice of non-compliance following a reinspection, shall be assessed a civil fine; recovery of the fine is stayed in those instances that a facility requests a hearing within 15 days.

The OHFC issued forty-eight (48) penalty assessments during calendar year 1979, of which twenty-five (25) were appealed. At the request of the assessed facilities, twenty-three (23) hearings were scheduled, fourteen (14) held and \$12,300 assessed.

Analysis of Complaints in 1979

The OHFC accepted 950 cases for investigation in 1979. An additional, significant amount of time was spent responding to inquiries and requests for referrals from the public to appropriate agencies, organizations, departments and individuals.

The resolution of complaint investigations are designated as follows:

- Substantiated - in violation. A complaint which correctly and accurately alleged conduct in violation of existing rules, regulations and laws.
- Substantiated - corrected. A complaint which correctly or accurately alleged conduct which was corrected either before or during the investigation.
- Substantiated - non violation. Alleged conduct which, even though true, is not in violation of any existing rule, regulation, or law.
- Indeterminate. Self-explanatory.
- Unsubstantiated - insufficient evidence. The complaint was unable to be verified at the time.
- Unsubstantiated - evidence refutes allegation. Self-explanatory.
- Partially substantiated. A complaint which has been determined to have components that are unable to be addressed individually as separate and distinct items resulting in a combination of substantiated/unsubstantiated determinations.
- Referred. Referrals may be made with or without investigation.
- No Jurisdiction. Self-explanatory

Table 10

Nature of Components within Complaints Received in 1979 by Order of Frequency (Minnesota Office of Health Facility Complaints, 1979)

<u>Problems</u>	<u>Frequency</u>
Negligent Nursing Care	289
Inadequate Staff	265
Patient Rights	137
Dietary: Quality, Quantity, Food Temperatures	123
Inadequate Housekeeping	86
Personnel Performance	82

Table 10 (Continued)

<u>Problems</u>	<u>Frequency</u>
Medication Administration/Abuse	69
Patient Abuse - Physical/Verbal	63
Offensive Odors	55
Inadequate Laundry Services	52
Other	52
Physician's Orders Not Followed	47
Clean Indoor Air Act	41
Missing Personal Funds, Belongings	35
Ethical Practices	35
Lack of Orientation/In-Service Training	32
Safety Factors, Disaster/Emergency Plans	31
Inadequate Pest Control	30
Unsatisfactory Room Temperatures	30
Inadequate Supplies/Equipment	29
Dietary: Sanitation, Storage, Food Handling Techniques	27
Administrative Problems	24
Physician Performance	23
Sanitation Problems	22
Activities: Lack of or Inappropriate	22
Inadequate/Inappropriate Clothing	21
Improper Placement of Residents/Patients	18
Dietary: Physician's Orders Not Followed	17
Infection Control	17
Compliance with Federal/State Laws	17
Licensure	11
Inadequate/Incorrect Water Temperatures	10
Financial Problems	7
Medical Records	6
Rate Increase, Private Pay Problems	6
Grievance Mechanism	3

Nature of Correction Orders Issued by OHFC - 1979

Substantiated violations of the rules and regulations of the Minnesota State Board of Health for the licensing of nursing homes, boarding care homes, hospitals, and supervised living facilities are addressed by the issuance of correction orders. The correction orders issued by OHFC during 1979 are listed in order of frequency in Table 11 below:

Table 11

Nature of Correction Orders Issued by OHFC in 1979
By Order Of Frequency and Applicable Regulations
(Minnesota Office of Health Facility Complaints, 1979)

Nature of Correction Orders	Regulations Applied	Frequency
Total		283
Staffing and Services	MHD 50	58
Housekeeping	MHD 56	33
Dietary Services and Sanitation	MHD 55	32
Care of Patients and Residents	MHD 51	28
Medications	MHD 53	18
Mechanical and Electrical Systems	MHD 67	18
Minnesota Clean Indoor Air Act	MHD 443/444	19
Patients' Rights	MHD 144.651/652	20
Furnishings and Equipment for Care	MHD 52	11
Records and Reports	MHD 48	9
Personnel	MHD 47	6
Administration	MHD 45	5
Linen Service and Laundry	MHD 54	5
Other		21

Methods of Communication

Most complaints (out of a total of 919) were made by telephone, or 790 (86%). 107 complaints were submitted in writing (11.6%) and 22 (2.4%) were in person.

Source of Complaints

Most of complaints were made by relatives or other interested persons, 64.8%.

Table 12

Number, Percent and Sources of Complaints
(Minnesota Office of Health Facility Complaints, 1979)

Complaint Source	Number Cases	Percent
Total	919	100.0
Patient	129	14.0
Relative	295	32.1
Employee	195	21.2
Other	300	32.7

Case Distribution

69% of the complaints investigated by OHFC in 1979 involved nursing homes.*

Table 13

Case Distribution (Number and Percent) by Type of Facility
(Minnesota Office of Health Facility Complaints, 1979)

Type of Facility	Number Cases	Percent
Total	919	100.0
Hospitals	128	13.9
Conv. & Nursing Care Units	22	2.4
*Nursing Homes	634	69.0
Boarding Care Homes	28	3.0
NH/BCH	53	5.8
Supervised Living	25	2.7
Providers	29	3.2

Case Resolution:

Regarding the total percentage of substantiated (in any manner) complaints versus those found to be unsubstantiated, there were 54.7% substantiated as opposed to 42.9% unsubstantiated. Of substantial significance was the comparative increase of allegations of potential violations of the Patients' Bill of Rights and patient abuse, either physical or verbal.

Table 14.

Case Resolution by Number and Percent (Minnesota Office of Health Facility Complaints, 1979)

<u>Case Resolution</u>	<u>Number Cases</u>	<u>Percent</u>
Total	919	100.0
Substantiated - In Violation	65	7.0
Substantiated - Corrected	26	2.8
Unsubstantiated - Insufficient Evidence	81	8.8
Unsubstantiated - Evidence refutes allegation	312	34.1
Partially substantiated	370	40.3
Referred/No Justification	22	2.4

In summary, there are rightfully many questions that should be asked. Does this information suggest only the tip of the iceberg? How can a staff of six people effectively cover so many facilities throughout the State? Do people know where to go with their complaints regarding health care services? Are people with developmental disabilities equally protected and aware of their rights under the Patient Bill of Rights provisions? Are there an adequate number of third-party advocates available to help in resolving complaints at the local level, before and after official investigations are made by OHFC?

3. Physical and Sexual Assault of Disabled People/Creation of the Vulnerable Adult Protection Act of 1980. On July 14, 1979, the United Handicapped Federation, a coalition of twenty-eight organizations, held a conference on "Sexual and Physical Assault of Disabled People." The Federation first began investigating sexual and physical assault of handicapped people in March, 1978. This research was prompted by a phone call from a disabled woman in St. Paul, who had been raped in her home. This woman was concerned about the fact that many of the conditions that had made her vulnerable to a sexual assault were common conditions for many disabled people. Numerous interviews in the Twin Cities were held with social workers, police officers, attorneys, county officials, disabled assault victims and others. A total of 60 cases of rape, battering and other assaults against disabled people were discovered. In informal interviews, police officers, attorneys and others repeatedly stated their perception that disabled people were frequent victims of assault and especially vulnerable to such crimes. It was discovered that there were a number of barriers that limited effectiveness of supportive, legal and protective services that were set up to assist victims.

The conference addressed some of the myths about handicapped people and about the severity of the problems. Besides a heightened awareness that resulted from the discussions, a group of concerned people continued their involvement after the conference, wanting to do something constructive about it. With the assistance of legal advocates, the Vulnerable Adult Protection Act was enacted by the Minnesota State Legislature in 1980. Similar to child abuse laws, this law will encourage responsible citizens to report suspected abuses against vulnerable adults to authorities without being liable. This law became effective January 1, 1981. Through greater public awareness and responsiveness, the intent to assuage such crimes and improve services to victims will hopefully occur.

4. Consumers Speak Out. The information provided on previous pages presents formal data that point out the array of human conditions that exist and the types of responses of the system to prevent, identify and act upon the infringement of human and civil rights. For the past two years, however, the Association for Retarded Citizens of Minnesota has sought information from another important source--from the consumers, themselves.

Much can be learned from the many persons with mental retardation and other disabilities that appeared and spoke out at the several "Consumer Forums" that were held throughout the State.

Only a few examples of their comments are provided below, many of which are pertinent to the ear of any advocate who is geared for remedial action:

"Staff doesn't allow the residents to do for themselves, e.g. do own dishes."

"I have to play childish games in the summertime. I would prefer to bicycle."

"Rain gutters are needed around the house. In winter there are ice problems. Someone could slip and fall."

"Rules are not explained when people move into residences. Rules should be on bulletin boards."

"They won't let us go to the disco. They won't let us date. We're allowed to go home only once a month. Visiting is only on Sunday, once a month."

"We're human. I don't think it's right to take away all these rights."

"I wanted to go out in the competitive workshop, but they told me I was so efficient at the clinic that they didn't want to let me go."

"At our place we have locked doors. It's just like an institution."

"I'd like to be able to make a cake once in a while for a treat."

The list goes on. The statements speak for themselves.

It is important to notice the growing trend of the Self-Advocacy movement, which has been relatively slow in growth and sporadically experienced in Minnesota. "Self-advocacy is speaking or acting for one's own rights -

assuming one has the necessary information and skills to be effective." (Welter, 1978). Self-advocacy can be an individual or collective action. (Woodyard, 1980). The philosophy of self-advocacy is to help persons with a handicap to speak for themselves and to help them to develop into competent and participating self-advocates. Who can speak better about specific needs and conditions than the individuals who are the recipients of human services?

Traditionally, there has been little or no emphasis on developing self-advocacy skills of persons with handicaps. It has always seemed much faster and easier for professionals, parents, families and guardians to speak and act on behalf of the person with a handicap. The problem is that such advocates have assumed "they knew" what the needs were. However, now that people with handicaps are being asked what their needs are, significant discrepancies have surfaced. People with handicaps, once discovering that they have a significant voice and that they have the right to "free speech," have finally come forward to say, "This is the way it really is!"

IV. RIGHTS OF PERSONS WITH DEVELOPMENTAL DISABILITIES

In addition to the United States Constitution, the rights of persons with a developmental disability have been described in many laws and regulations including a few "Bills of Rights" which provide appropriations for the enforcement of such rights.

Title II of the Developmental Disabilities Assistance and Bill of Rights Act of 1978 (P.L. 95-602) is probably the most pertinent piece of legislation related to this report. It is one of the rare occurrences where the U.S. Congress appropriated money to assist the states in carrying out its provisions. (See Appendix #2).

Other important federal and state legislation and regulations that specify rights and services for persons with developmental disabilities are as follows:

- The Minnesota Hospitalization and Commitment Act (M.S. Chapter 638)
- The Mental Retardation Protection Act, 1975 (M.S. Chapter 252A)
- The Minnesota Vulnerable Adult Protection Act, 1980 (M.S. Chapter 626.557).
- The Human Rights Act, 1964 (Both Federal and State Statutes)
- The Patient Bill of Rights Act (Title XIX, Medicaid, Social Security Act)
- The Minnesota Residents Bill of Rights (M.S. Section 144.651-144.652)
- The Rehabilitation Act of 1973 (Section 504 of the Social Security Act)
- Education for All Handicapped Act (P.L. 94-142)
- DPW Rule #34 - "Standards for a Community Residential Services" (November, 1972)
- DPW Rule #185, "Community Mental Health Board and County Welfare or Human Service Board Responsibilities to Individuals who are Mentally Retarded"
- DPW Rule #18 - "Semi-independent Living Standards"

In addition, consumer organizations often produce their own lists of basic rights, such as the following that was published by the American Coalition of Citizens with Disabilities (1979) presented in Table 15.

Table 15

Disabled Peoples' Bill of Rights
(American Coalition Citizens with Disabilities, 1979)

PREAMBLE

We believe that all people, disabled or not, should enjoy certain rights. Because people with disabilities have consistently been denied the right to fully participate in society as free and equal members, it is important to enumerate and affirm these rights, and to strive toward them daily. All people should be able to enjoy these rights, regardless of race, creed, color, sex, religion, or disabilities.

1. The right to live independent, active, and full lives.
2. The right to the equipment, assistance, and support services necessary for full productivity, provided in a way that promotes dignity and independence.
3. The right to an adequate income or wage, substantial enough to provide food, clothing shelter, and other necessities of life.
4. The right to accessible, integrated, and convenient affordable housing.
5. The right to quality physical and mental health care.
6. The right to training and employment without prejudice or stereotypes.
7. The right to accessible transportation and freedom of movement.
8. The right to have children and a family.
9. The right to a free and appropriate public education.
10. The right to participate in and benefit from entertainment and recreation.
11. The right of equal access to and use of all businesses, facilities and activities in the community.
12. The right to communicate freely with all fellow citizens and those who provide services.

13. The right to a barrier free environment.
 14. The right to legal representation and full protection of all legal rights.
 15. The right to determine one's own future and make one's own life choices.
 16. The right of access to all voting processes.
-

In summary, the rights of persons with developmental disabilities and other handicaps have been established by law and have been upheld by the courts. However, the actual enforcement and acquisition of these rights is directly proportional to the provision of adequate financial support in order to inform the public about these rights and to assist people to achieve equal rights and protection under the law.

V. THE VARIETY OF ADVOCACY AND PROTECTIVE SERVICE NEEDS OF PERSONS RESIDING IN COMMUNITY RESIDENTIAL SETTINGS

As indicated in the attached Glossary and in the above sections, there are many types of advocacy services that have evolved in order to address the needs and rights of persons with developmental disabilities. The purpose of this section is to point out that many forms of advocacy services are needed by certain persons at different times and in different circumstances. Many of the following services are already available in many communities and should be utilized according to a resident's best interests and needs. Where specific advocacy services are lacking and needed, communities should actively plan and develop such services.

The following types of advocacy services should be considered:

- A. Citizen Advocacy -- The use of trained volunteers to meet the expressive and/or instrumental needs. The instrumental citizen advocate usually helps to solve specific problems over a short period of time. The expressive citizen advocate serves as a friend and helps to meet the social and emotional needs of the person with a developmental disability.
- B. Surrogate Parents -- Substitute parents can be used where there are no blood relatives available to represent the resident, especially in situations involving the person's individual habilitation or treatment plans in settings where such plans are required, e.g. schools, Developmental Achievement Centers, residential programs, and vocational rehabilitation programs. Under P.L. 94-142 (Federal Regulations 45 C.F.R., Section 121A.514) Education for All Handicapped Act, an individual is assigned as a surrogate for the child's own parents, who are deceased or not available. The regulations further provide that the surrogate has knowledge and

skills that insure adequate representation of the child and that the surrogate may not be an employee of a public agency which is involved in the education or care of the child.

At the time of this writing, the Minnesota special education regulations and State Plan do not comply with the federal rules, nor are surrogate parents being utilized as required by law. This is a statewide need.

Another possible use of surrogate parents could be in the residential placement process. There is real concern that wards of the State may be placed in inappropriate settings. For example, a social worker may place a ward in a state institution because it is cheaper for the county (only \$10 per month) than a community placement (at \$40-\$80 per month plus day program costs).

A surrogate parent, therefore could act as a third party on behalf of a child regarding individual educational plans and in residential placement procedures.

- C. Legal Advocacy provided by a professional lawyer, a paralegal person (under the supervision of a lawyer), lay legal advocate (usually a volunteer, instrumental citizen advocate who is trained about laws, policies and procedures), and guardian ad litem, who is officially appointed by the court to represent the resident.

There is a current need that relates to court review of all children placed in out-of-home care after eighteen months. There are three state laws that require court hearings, (M.S. Chapters 555, 580, and 602) and there is confusion between these laws regarding the purpose for such hearings. While originally intended to prevent endless shuffling of foster children, never affording children a sense of permanence, one law (Chapter 602) requires that a petition be filed for dependency, neglect, neglected and in foster care, or termination of parental rights. Otherwise, the natural par-

ent must take the child home. The other laws provide for review of developmental disabled children in foster care for 18 months or longer. If the court finds the child's needs are being met, then the case can be scheduled for another review in two years. It is anticipated that specially trained volunteers can be of tremendous help as appointed guardians ad litem on behalf of the child and the parents in the future hearings.

- D. Training in self advocacy, which will encourage a resident to assert his/her rights and to better understand the responsibilities of citizenship which accompany these freedoms.
- E. Guardianship/Conservatorship (Over person and/or property)
 - Public Guardianship
 - Private Guardianship
- F. Protective Services, particularly regarding situations where there is abuse, neglect or exploitation. Under the new Vulnerable Adult Protection Act, providers of services must prepare and submit plans that will prevent abuse and neglect.
- G. Ombudsman, where there is need to have an impartial person to intervene regarding departmental policies and procedures.

The above list is not complete. It is only a suggested list of what each community should consider when planning for an array of advocacy services. There are many creative programs that have been developed and tested, e.g. having an entire family informally "adopt" a resident so that the resident has a place to go and a family to be with on weekends, holidays and special community events. The point is, the needs are there and there can be many ways to meet these needs.

VI. TWO MODELS OF EXISTING RESIDENTIAL ADVOCACY PROGRAMS IN MINNESOTA

This section describes two kinds of residential advocacy services that are already in operation in Minnesota. The State Hospital Advocacy Program represents the functions of an advocate within a public institution. The Long Term Care Ombudsman Program describes how advocacy is being provided in community-based health care facilities for senior citizens.

A. The Minnesota State Hospital Advocacy Program. Today, Minnesota has a full time advocate in each of the State hospitals who operate under the Department of Public Welfare. Most state hospitals serve a diverse population: mentally ill, mentally retarded, and chemically dependent. The State Hospital Advocacy concept was an outgrowth of the many expressions of concern by people who served on the Humane Practices Committees in each of the state institutions during the 1960's. Consequently, the first advocate in the state hospital system was appointed on August 1, 1972 at the Fergus Falls State Hospital. (DPW, 1978).

In mid-1972 a committee was appointed by the Medical Services Division to work on policies and procedures for the advocacy function in the system. Among the difficulties experienced by the committee was the question of whether an ombudsman (impartial fact-finder) or an advocacy (adversary) system would be the more appropriate. After much debate, the advocacy approach was selected and a policy was promulgated on May 18, 1972.

This policy formerly launched the Minnesota State Hospital Advocacy Program. The advocates are "in-house" advocates in that they are responsible to the Chief Executive Officer in their respective settings. The advocates in the state hospital system operate with broad wuthority, which includes:

1. Access to all treatment areas, resident treatment plans, programs, and records;

2. Access to all available human and material resources to carry out the advocacy function;
3. Authority to take a case, which cannot be resolved, directly to the Chief Executive Officer;
4. If not resolved at the local level, the authority to refer cases to appropriate resources outside the facility.

In practice, the advocates have been able to move freely throughout the facility, have been able to offer their services directly to the client, and submit their observations concerning programs and living conditions directly to the responsible program director and Chief Executive Officer. Much depends on the assertiveness and the advocate's individual personality. The advocacy position has also provided an additional channel for treatment staff to bring their concerns about conditions of care and treatment to the attention of the administration. Most of the advocates are members of the hospital management group and can, therefore, represent the residents' point of view at this level.

The advocates consult with residents in the areas of: (a) legal status, (b) legal rights, (c) treatment plans, including length of hospitalization, (d) facility, unit, and ward policies as they affect residents, (e) living conditions, (f) resident-staff relationships, (g) criminal and civil matters and welfare policies outside the jurisdiction of the involved facility, and (h) appeals and grievance procedures.

Leadership and coordination among the several State Hospital Advocates is provided by the Client Protection Office in the Department of Public Welfare. This office interprets departmental policies to the local level and, if needed, provides case follow-up. Policy changes are also initiated by this central office.

According to a 1978 report from D.P.W. and the advocates, approximately 12,000 individuals have been served since the inception of the advocacy program. On a typical multi-purpose campus (those serving persons with mental

illness, mentally retardation and chemical dependency) an advocate averages about 75 cases a month, or approximately 900 cases a year. In facilities that serve primarily persons with mental retardation, the average cases served are usually fewer than the overall average, probably due to the difficulties of this group to verbalize their concerns. A significant percentage of the cases (over 50%) involve rights under the Minnesota Hospitalization and Commitment Act (M.S. Chapter 638) and the Mental Retardation Protection Act, 1975 (M.S. Chapter 252A).

Recent events, in the past few years, indicate potential efforts that may strengthen the advocate's role and function in the state hospitals. A special Task Force that studied the mental commitment procedures and the courts strongly recommended that the advocacy positions be administered by an outside (unbiased and free from conflict of interest) agency and that the advocates receive specialized training regarding laws and legal rights/procedures. (Minnesota Supreme Court, 1979).

In addition, Congress is currently responding to the 1978 recommendations of the President's Commission on Mental Health as it considers the passage of the Mental Health Systems Act (S.1177 in the Senate and H.R. 4156 in the House of Representatives). Title III of the Senate version, as proposed by Senators Javitz and Kennedy, has been referred to as the "Rights and Advocacy Amendment." This amendment proposes the funding of a Protection and Advocacy System for the mentally ill and would be comparable to the Protection and Advocacy System that was created in 1975 in the Developmental Disabilities Assistance and Bill of Rights Act (P.L. 94-103 and as amended by P.L. 95-602 in 1978). Such a Protection and Advocacy System could greatly enhance the State Hospital Advocacy Program.

In summary, the 1978 DPW report concludes with the following statements about the experiences in Minnesota while establishing advocate positions in each of the State Hospitals:

The preceding might give the impression that advocacy was easily conceived and implemented in Minnesota. This was not, in fact, the case. As has been true elsewhere, resistance to the concept occurred during its development and remains to some degree in some quarters. While the concept of advocacy is rather universally embraced within the state hospital system, it is less evident in some other segments of the delivery system. There are, so far, only a few advocates operating within the county welfare departments and there are few, if any, advocates in place among the mental health centers and private treatment facilities. It would appear therefore that the Department of Public Welfare, through its Division of Mental Health, is at present the main supporter of the advocacy concept. Although the advocates are sometimes seen as interfering with the treatment efforts of the team, it must be said that the advocacy system generally has the active understanding and support of treatment personnel and decision-makers in the department. (p. 7)

Minnesota can look at its advocacy efforts with some pride. From a rather rocky beginning, advocacy now finds itself operating from a firm foundation (via DPW policy). With the continuing support of the leadership of the Department and the leadership of individual state hospitals, we are confident the State will continue to provide consumers of psychiatric services a method of appeal that is recognizable, immediately responsive, and effective. (P. 8)

B. The Minnesota Long Term Care Ombudsman Program. The Minnesota Long Term Care Ombudsman Program is a coordinated system of state and local advocacy and ombudsman services responsive to the concerns and problems of residents of Minnesota's long term care facilities. The purpose of the program is to encourage community based assistance to protect the rights of seniors in long term care facilities through development of a statewide network of long term care ombudsman and advocacy projects. Informed involvement by concerned citizens familiar with their own communities has proved to be of key importance to ensuring maintenance of quality standards of care for seniors receiving long term care services.

Authority and Administering Agency. Sponsored by the Minnesota Board on Aging, the Ombudsman Program provides statewide coordination and backup to participating community-based projects. The program has been developed in response to Title III - B of the Older Americans Act as amended in 1978, (P.L. 95-479), which requires each state to provide an ombudsman program which:

- investigates complaints;
- monitors laws and regulations;
- provides public information;
- promotes development of consumer organizations;
- provides volunteer training; and
- advocates the well being of older persons in long term care facilities.

Role of State Staff. The State level staff (two positions) provide coordination, technical assistance training, investigative back-up and data collection and analysis for a network of local projects. State staff also assists the Board in developing legislative positions and testimony and advocates development of state regulations and policies beneficial to nursing home residents, disseminating this information to consumer groups.

Regional/Local Ombudsman Projects. Each regional Area Agency on Aging (AAA) is encouraged to assist the funding and development of local advocacy (ombudsman projects) which may be sponsored by a variety of groups and agencies including senior citizen groups, legal services programs or other community service organizations. In areas in which no project has been developed, state ombudsman staff are available to assist residents with concerns or to provide referral to other appropriate agencies.

Grants Administration. On October 20, 1980, the Minnesota Board on Aging, Long Term Care Ombudsman Program issued a Request for Proposals in order to encourage the development of local/regional advocacy and ombudsman programs. Grants, in the amount of \$20,000 each were awarded to eligible applicants in the following five service areas:

- Northwest (Development Regions 1, 2, and 4)
- Northeast (Development Region 3)
- Central (Development Regions 5, 7W, 7E)
- Southwest (Development Regions 6W, 6E, 8, and 9)
- Southeast (Development Region 10)

(The Metropolitan area, Region 11 is already being funded through a variety of sources). The Long Term Care Ombudsman Program must be located in a public or private non-profit agency, free from conflict of interest from providers of long term care services. According to regulation, the grantees may not be "...associated or affiliated with, or in control of or controlled by persons who, or interests which, are providers of long term care services, facilities or supplies, or which are associations of employees working in long term care facilities." (Board on Aging Request for Proposals, October 20, 1980).

Services to be Provided at the Local/Regional Level. In accordance with P.L. 95-475, the local/regional Long Term Care Ombudsman Programs are to:

1. Resolve problems and/or investigate complaints. Appropriate referrals, e.g. to the Office of Health Facility Complaints, is also a part of this process.
2. Provide information and education regarding the Long Term Care System and the rights and concerns of residents and potential residents.
3. Provide assistance to citizen organizations and consumer groups.
4. Identify and follow-up on major issues affecting the well being of residents.

The local/regional projects cooperate with the state ombudsman staff through an interagency agreement which provides for sharing of data on problems and issues encountered. A uniform system of complaint reporting and confidentiality procedures has been established (See Appendix #1) and program staff meet regularly to discuss common concerns.

VII. POSSIBLE ROLE AND FUNCTIONS OF A COMMUNITY RESIDENTIAL ADVOCATE.

The above discussions illustrate that there are many advocacy issues and unmet needs relating to the population with developmental disabilities who reside in community-based facilities. Both internal and external forms of advocacy functions and procedures have been recognized as being beneficial and essential to the overall delivery of human services. During the past decade, both internal and external mechanisms have been developed that recognize and address the acquisition and protection of people's rights. Although many advocacy resources and safeguards have already been established for people receiving residential services in the community, there is an apparent need not only to assure that external intervention (advocacy) is available and accessible, but also to provide a planned, coordinated approach for an array of external advocacy resources and services that can further facilitate the actualization of the normalization principle. This added ingredient can best be described as the possible role for a "community residential advocate."

A primary condition, as learned from past experience, is that a community residential advocate must be located in and administered by an independent agency or organization that is outside of the service delivery system (an agency or organization that does not provide treatment, services or habilitation to persons with a developmental disability). Such placement is necessary in order to avoid the potential for conflict of interest.

As an external change agent, the role of the community residential advocate should be flexible and dynamic, an ever-changing role that adjusts to the particular needs and circumstances of the clientele over the passage of time. The community residential advocate could be considered to be a "professional" person in the human service field where a great deal of knowledge would be required, e.g. about:

- the human service delivery system;
- local, state and federal legislation, regulations and funding patterns;
- political and economic processes;
- human rights issues and procedures; and
- human growth and development, especially in light of individual differences because of disability, culture and socio-economic factors.

Also, certain skills would be required, e.g. in:

- training and education of others,
- counseling,
- public relations,
- legislation and policy reform,
- community organization;
- grantsmanship, and
- working with individuals, groups, organizations and agencies as a change agent.

A primary premise to keep in mind is that the community residential advocate cannot be all things to all people and there must be maximum utilization of every other possible advocacy resource that is available in a particular community. Where there is a scarcity of advocacy resources available, such as citizen advocacy (volunteer) services, the community residential advocate could act as a community organizer to develop such a resource.

Following are a few examples of specific activities in which a community residential advocate might be engaged:

A. Provide individual, instrumental advocacy:

- aggressively/actively, seek out situations where there are apparent wrongs, especially where residents are non-verbal, unable to communicate or understand. (Here, access to records and gaining parent or guardian consent is necessary).
- passively, receive complaints from residents or staff and resolve issues at the most primary level within the residence (or other agency that may be involved) before proceeding to higher levels in the system.

- B. Train and counsel parents, guardians or relatives for example:
- Train/counsel parents who are seeking a residential placement about where and what to look for as an appropriate setting for their child or adult sibling.*
 - Train parents about rights, procedures, etc. and how to become effective change agents, especially encouraging parents and relatives to remain actively involved in the resident's future.
- C. Train and advise residents (individually and collectively) in techniques of self-advocacy, or assertiveness training.
- D. Contract for or directly administer citizen advocacy services.
- E. Provide information and refer clients to other appropriate advocacy services, e.g. legal advocacy, citizen advocacy, guardianship/conservatorship, and protective services for children or adults.
- F. Assist in the transition of a person who has been institutionalized and is being placed in a community residential setting.
- G. Actively go about the prevention of institutionalization, which might include trying to change county/state funding patterns, helping to organize and develop community alternative programs and support services, or changing attitudes.
- H. Advocate for improved services within residential facilities, e.g. use of volunteers, transportation, recreation, nutrition, removal of architectural barriers and other possible problem areas.
- I. Promote movement of persons through the continuum of services so that they can gain greater independence and can continue to gain new skills, particularly movement into semi-independent or independent homes and competitive employment.

*A very thorough handbook has been developed by the Association for Retarded Citizens of St. Paul entitled, Guideline for Locating a New Home for Persons Who are Mentally Retarded. It includes every conceivable question that might be asked by the home seeker.

- J. Work with residential staff and policy boards or committees, e.g.:
- Provide training regarding human and civil rights,
 - Assist in preparing abuse and neglect prevention plans that will be required by the Vulnerable Adult Protection Act,
 - Analyze and recommend improvements in policies and procedures,
 - Assist in the resolution of staff complaints, if related to the best interests of the residents.
- K. Assist in the development of public information/education programs that will improve neighborhood acceptance and attitudes and encourage greater citizen involvement and participation.

"There are no hard and fast rules of advocacy or monitoring (of residential facilities), wrote Taylor (1980, p.ii) in a recent publication. Taylor offers some very helpful suggestions and techniques for a community residential advocate including strategies on how to find and understand public information on institutions and community services. A checklist is provided for collecting the right kinds of information about a residential setting, stressing the importance of observational skills. Other topics covered: (a) conducting independent investigations of events or conditions at institutions and other settings, (b) how to read and make sense out of individual residents' case records, how to identify gaps in community-based services in your state or locality, and advocacy strategies used in conjunction with monitoring. Taylor concluded the introductory section of the text by adding:

"While (this document) offers some general guidelines and describes some strategies which have worked in specific situations, this is not to say there is a single best way to monitor residential services. The intent is not to establish a set of rigid principles, but to share some ideas that some groups have found effective. (p.ii)

The job description of a community residential advocate should not be too narrowly defined or restrictive so that creativity, imagination and individual

talents are stifled. On the other hand, the parameters of the advocate's authority, responsibility and activity must be clearly spelled out and continuously evaluated so that there is a healthy environment for ongoing communication, acceptance and support. Conflicts will be inevitable and should be viewed as positive necessities if "the best interests" and self-expressed aspirations of the residents are to be respected and nurtured.

VIII. HOW A SYSTEM OF COMMUNITY RESIDENTIAL ADVOCACY MIGHT BE ESTABLISHED IN MINNESOTA

The foregoing information is provided in order to document the need for a coordinated approach for assuring the acquisition and protection of individual rights for persons with developmental disabilities living in licensed, community residential facilities. The utilization of existing advocacy resources is strongly encouraged, avoiding further duplication and fragmentation of efforts. This section addresses the possible means for the employment of stronger measures for assuring that external advocacy services are made available and are provided to all community residential facilities throughout the State of Minnesota. Using the terms provided in the Department of Public Welfare Advocacy Policy (1978), this section proposes a means for "the development and implementation of advocacy procedures...(for community residential advocacy services)...that would ensure that legal, civil and human rights would be upheld in a way that is recognizeable and immediately responsive to grievances of individuals and families and would, at the same time, provide an approach for modifying the decision making process." (p.87)

Should a statewide system of community residential advocacy be provided on a voluntary basis, as it is now, or, should such a system be mandated by law and/or regulation and publicly financed? The voluntary approach has its merits and has worked to a certain extent through the use of legal and other outside advocacy sources, e.g. citizen advocacy and parent groups. In fact, the concept of community residential advocacy is now being tested out (on a voluntary basis) in two areas of the State, one rural and one urban.

Provided with one-year demonstration grants from the Minnesota Developmental Disabilities Protection and Advocacy Network, ACT, Inc. (Advocating Change Together) in Minneapolis and the Association for Retarded Citizens in Region 9 began residential advocacy projects on October 1, 1980. They will

be demonstrating how community residential advocacy services can be provided in their respective community settings. With assistance from legal advocates, both projects will be developing model inter-agency agreements with the cooperating residential programs. Critical to their success will be the receptivity of the individual residential facility operators as well as the advocate agencies' capabilities in procuring ongoing financial support after their first year of operation.

Central to either a voluntary or a mandatory approach is the issue of "right of access to private property." The voluntary approach depends on the ability of the outside advocate to persuade and maintain the cooperation of the property owner, or, in this case, the residential facility operator. Here, the right of access is clarified in an inter-agency agreement which specifies the mutually accepted conditions and limitations regarding accessibility and authority.

The mandatory approach would be enacted through legislation and/or regulation and would empower responsible outside organizations or groups with the right to regularly enter licensed, community residential facilities and would ensure outside contacts for the residents. Such activities would serve to supplement the inspection and licensing processes and would lead to a true community presence within a facility. In addition, outside advocacy services could be financed by means of purchase of service agreements, thus assuring a sound funding base.

If this were to occur, the following DPW Rules, regarding services for people with mental retardation and physically handicapped would be affected:

- DPW Rule #34, "Standard for the Operation of Residential Facilities and Services for Persons Who Are Mentally Retarded.
- DPW Rule #80, "Standards for Residential Facilities and Services for the Physically Handicapped."

- DPW Rule #52, "Per Diem Costs in ICF/MR Facilities"
- DPW Rule #30, "Cost-of-Care for Children with Mental Retardation."

Amendments to rules should address some of the following types of requirements and issues:

- A. Adequate training and/or certification of community residential advocates would be important. Such training would include ethical responsibilities and how to avoid unauthorized practice of law.
- B. Advocacy could be negotiated by way of contracts by one or more community residential facilities and should be provided by an independent non-profit agency that does not provide direct services to clients, other than that of providing advocacy services. This is to avoid any possible conflict of interest.
- C. To the maximum extent possible, advocates should proceed in a manner which is consistent with the program and routine of the facility. Problems should be attempted to be resolved first within the facility and outside assistance should be sought only as a last resort.
- D. Advocates should not represent any resident who is a minor child without the consent of the child's parent or guardian. Adult residents could be directly represented on their own request. Where the resident is under guardianship or conservatorship, the advocate should seek to involve the guardian, but should primarily be responsible to the resident. The advocate should be available to anyone who seeks his or her assistance.
- E. It should not be the advocate's function, to monitor a facility's compliance with regulations. Unless there is a gross violation of human and legal rights requiring immediate action (e.g. corporal punishment, gross neglect, sustained use of seclusion), advocates should

provide services only at the request of a client or his parents/relatives/guardians, or an involved residential facility staff member.

- F. Advocates should not substitute their own judgement or that of the program staff, but should always represent the residents' viewpoint. If in good conscience, the advocate cannot take such a stance, the resident should be referred to a second advocate.
- G. Advocates should have access to the records of any resident with the informed consent of the particular resident/parent/relative/guardian. Access to records is provided by federal regulation under the Developmental Disabilities Act (P.L. 95-602) for Protection and Advocacy Systems. If a community residential advocate was a formal part of the Protection and Advocacy Network, these regulations may very likely apply. (May 9, 1980).
- H. In addition to regularly scheduled visits, advocates should have access to the facility at all reasonable times. Advocates should give advance notice of any unscheduled visits at times (i.e. unannounced visits) that will not be disruptive to the facility's program and routine.
- I. Advocates should assist facility staff to learn about the legal rights of the residents, e.g. through in-service training, informal discussions, and other appropriate techniques.
- J. Advocates should be reimbursed according to rates established by the Department of Public Welfare (via Rule #52 and #30) in conjunction with the independent non-profit agency.
- K. An advocate may be discharged for a substantial violation of his or her contract. Any advocate so discharged should be entitled to a hearing before a special hearing officer appointed by the independent

non-profit agency. Further dissatisfaction and appeal should be made available through such mechanism as the State Hearing Officer.

A state-wide system must be managed by an appropriate central administrative agency. Such an agency would need the necessary legal authority and financial support to do the job. Federal provisions already exist, e.g. the Developmental Disabilities Assistance and Bill of Rights Act (P.L. 95-602), that would permit states to set up such a system. Under this authority the Governor has already designated Central Minnesota Legal Services Corporation as the administering agent for the operation of the Minnesota Developmental Disabilities Protection and Advocacy Network.

The responsibilities and functions of the central advocacy office could include:

- A. Train, certify and provide technical assistance to community residential advocates.
- B. Provide technical assistance to community or regional groups in establishing and operating community residential advocacy programs.
- C. Provide a system of accountability and evaluation of advocacy programs.
- D. Provide legal back-up services to advocates and residents.
- E. Serve as liaison to state agencies regarding individual cases as well as the promotion of regulation and policy reform.
- F. Promote and coordinate public information and education activities.

There may be other alternatives to consider if and when a statewide community residential advocacy system is desired. A broader perspective might be considered. For example, rather than just focus upon the population with developmental disabilities, additional populations in community treatment programs could be considered as well. This broader view would provide a means

for possible combining and interrelating some of the following programs or issues:

- What agency should administer the State Hospital Advocates?
- Should ombudsman functions be combined under a single, quasi-governmental agency, as supervised by the State Legislature and/or the Governor's Office? (e.g. the Corrections Ombudsman, the Long Term Care Ombudsman, and the Vocational Rehabilitation Ombudsman).
- Could or should a Community Residential Advocacy Program for People with Developmental Disabilities be combined with other advocacy programs, as mental health, chemical dependency, corrections, or nursing homes?
- Would co-mingling of funds and programs bring about cost effectiveness and a broader funding base?

Serving a broader population base would make sense in regions with lowest population densities, e.g. in the following table that combines the number of programs and populations that serve people with mental retardation, physical handicaps and emotional disturbances.

Table 16

Number of Community-Based Facilities by Development Region That Serve Populations with Mental Retardation, Physical Handicaps and Emotional Disturbances.
(Minnesota Department of Public Welfare, December 31, 1979)

REGION	DPW RULE #34 FACILITIES NO. FACILITIES	(MENTAL RETARDATION) CAPACITY	DPW RULE #80 (PHYSICALLY) HANDICAPPED)	P.H. CAPACITY	GROUP HOMES DPW RULE #8	(EMOTIONALLY DISTURBED) CAPACITY
TOTAL	223	4,098	10	472	61	539
1	7	104			1	6
2	5	63			3	25
3	31	374			9	87
4	14	169			1	10
5	3	28			2	29
6 (E&W)	12	268			2	17
7 (E&W)	18	260			7	112
8	12	310	1	45	1	10
9	11	162				
10	23	431	1	41	6	53
11	87	1,929	8	386	29	290

Other combinations of services at the local/regional level could include nursing homes, half-way houses, and other types of out-of-home care. Being that the Long Term Care Ombudsman Project is currently developing regionalized advocates, a coordinated effort with the Board on Aging might be the most feasible as a first step in view of this broader perspective and long range goal.

In summary, there are ample number of issues and problems relating to human rights of people residing in community residential facilities that a locally based advocate might address. The role of a highly qualified, professional advocate should be flexibly administered in order to respond to the ever-changing/emerging problems as they occur in each community. In order for such advocacy services to become available statewide in a coordinated fashion, certain regulations relating to specific target populations (e.g. the elderly, mentally retarded juvenile and/or adult offenders, emotionally disturbed, or physically handicapped) could be amended according to the criteria outlined in this report. If a broadly based clientele are to be served (that is, more than just the population with mental retardation), a concerted attempt to unite the efforts of various state agencies, such as the Department of Public Welfare, Health, and Corrections would have to be accomplished toward that end.

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APPENDIX A
GLOSSARY

GLOSSARY

Advocacy (General Definition):

Advocacy is the representation of the interests of one person or a group. The advocate typically functions as a "third party", representing a person with a developmental disability (the "first party" or "protege") in relation to a service provider (The "second party") so as to secure the interests of the person (or group) having a developmental disability in relation to the provision of services and the securing of other interests (individual rights as an example).

Case Management or Services Management:

Case Management or Services Management is the function of a professional or skilled manager who is charged with mobilizing all the resources, including those within the protege, to the solutions of the protege's multifaceted problems and needs. The resources mobilized are typically not within the direct control of the manager, who exercises coordinating and persuasive powers. The caseload almost always consists of several specific protege's. The authorization of this advocating role is usually given by an agency to which the protege' has applied for this and related services, the manager being an employee of that agency. The service is akin to counseling but it is an active mobilizing role.

Class Action, Legal:

There are two kinds of class actions. One is brought on behalf of a group of people in a similar situation. The other is brought against a group of people who have acted or will act in a similar way to harm the plaintiff. The former variety of class action is by far the most common. The original plaintiff in whose name the suit is brought is called the "named plaintiff."

A hearing is held before the class is certified before the court, that is, before the case can be officially considered a class action. At this hearing, the person who wants a class to be certified, must prove there are a large number of people in the class and that the named plaintiff will adequately represent the interests of those individuals in the class. In a class action, the judgement in the case applies to all members of the class. Two purposes of a class action are to ensure that all members of the class get the relief to which they are entitled and to avoid the problem of mootness.

Community Residential Advocacy:

A coordinated approach for assuring the acquisition and protection of individual rights for persons with developmental disabilities living in licensed, community residential facilities.

Community Residential Facility:

Any community-based living quarter (s) which provides 24-hour, 7 days-a-week responsibility for room, board, and supervision of persons with a developmental disability with the exceptions of: (a) single family homes providing services to a relative; (b) nursing homes, boarding homes and foster homes that are not formally state licensed or contracted as "mental retardation service providers;" and (c) independent living (apartment) programs which have no staff residing in the same facility.

Conservatorship:

Conservatorship is used to describe the relationship between the conservator (public or private) and the conservatee. A "conservator" is similar to a guardian in that the conservator has the legal authority and duty to care to another's (the conservator's) person and/or property. However, a conservator's powers are generally not as broad as a guardian's and the conservatee retains more rights than a ward.

Consumer Interest Advocates:

This advocacy is directed at furthering the interests of a protégé group. The interests addressed typically include the protégé's perception by society, the benefits that the protégé group may obtain or may have obtained for it, and the public policies that will favor the protégé group. Self-constituted groups and associations (often including protégé individuals or consumers), usually carry out this kind of advocacy.

Developmental Disability:

The Developmental Disability Assistance and Bill of Rights Act of 1978. (Public Law 95-602) provides a new, functional definition as opposed to the previous categorical definition.

"Developmental disability" means a severe, chronic disability of a person that:

- is attributable to a mental or physical impairment or combination of mental and physical impairments;
- is manifested before the person attains age twenty-two;
- is likely to continue indefinitely;
- results in substantial functional limitation in three or more of the following areas of major life activity: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living and economic self-sufficiency; and
- reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services that are of lifelong or extended duration and are individually planned and coordinated.

Expressive Citizen Advocacy:

Expressive Citizen Advocacy is the voluntary, one-to-one offering of self to a protégé in a relationship somewhat like friendship. It is usually matched and supported by a sponsoring agency, and it continues over a substantial or indefinite period of time.

Free-Standing Advocacies:

Free-standing Advocacies are a wide range of advocating activities, unlimited as to group or individual impact, and all characterized by the fact that the advocate is self-proclaimed and has informal, if any, externally funded support.

Group Advocacies:

These are advocate activities on behalf of protégé groups or populations, rather than on behalf of individuals. Group advocacies tend to address policies, legislation and rules, attitudes, and the structures of broader society. They are, almost by nature, change agents.

Guardianship (public and private):

The term "guardianship" describes the relationship between the guardian and the ward (e.g., between the Commissioner of Public Welfare and a child or adult with a developmental disability). A "guardian" is a person who has the legal authority and duty to care for the person and/or property of another (the ward), who, because of minority or disability is unable to exercise such care. In Minnesota, guardianship refers to the designation of almost total power and control over a ward, such as, the power to permit or withhold permission for the ward to marry, sign contracts, buy or sell property, etc. In 1975, a limited form of such powers over a person, was provided by law, "Conservatorship", which takes into greater account each person's functional abilities to retain certain freedoms

determined by the court, as described below.

Instrumental Citizen Advocacy:

Instrumental Citizen Advocacy consists of a volunteer representing, as though they were his own, the practical problem-solving interests of an individual protégé. This kind of advocacy is almost always under the sponsorship of an agency which provides training to the volunteers, back-up services of a technical and professional nature, and the matching of protégés with volunteers. Instrumental Advocates are representatives of the protégé's interests or rights in relation to the services, goods, opportunities, and other benefits that the larger community provides, whether or not the benefits are provided under the rationale that the protégé is disabled (they may be benefits provided to every citizen). Relationships may be ongoing or on a short-term basis.

Internal and External Advocacy:

It is important to relate the differences between two major types of advocacy functions; that which is most commonly referred to as advocacy within the service delivery system (internal) and advocacy which is provided completely outside of the governmental or privately operated services (external). Both types are seen as essential and useful functions for various reasons, but it is important to know the advantages and limitations of each so that the end result can best serve the interests and needs of the person with a developmental disability.

"In-House" Advocacy (within the service delivery system) has built-in resources readily available: an information base; communications network; supportive, experienced personnel; and established financial support. Making use of these resources in advocacy to meet the best interests of

the client is seen as practical and constructive from both a short term and long term view.

In comparison, the external advocate has certain advantages by nature of being independent from the system. Should at any point system maintenance or staff interest conflict with client needs, the external advocate is a critical resource for the client. The external advocate may intercede with system representatives on a casual, informal level, but if necessary, may bring pressure through confrontation, the communications media, pressure groups, or appeals to legislative or judicial authority.

Legal Advocacy:

This is a service provided or supervised by an attorney, in relation to common law and to constitutional law, and to specific laws together with their derived regulations and rules. Its power lies in legal skill and in potential court action, and its application may include the reminder to benefit controllers of their legal obligations. Its ultimate remedy is appeal to the courts, and pursuit of the case in court. It is often provided under the sponsorship of an agency-funded project.

Ombudsman Services:

An ombudsman is literally 'one to whom pleas are addressed)'. The service has come to mean something broader than this and to imply an element of active alertness to potential problems, especially in 2 and 3 below.

1. Agency-free Public Ombudsmanship is the service of a public official to whom appeal can be made in relation to any service agency. The service is provided by an ombudsman who is not in the employ of any of the service agencies, and ombudsmanship can therefore

be applied with partiality. (See IV.D below for potentially confusing type of advocacy.)

2. Location-specified Advocacy. This term denotes an instrumental type of advocacy provided by an advocate who is assigned to the clientele of a particular agency or facility, but who is not employed by that agency. The scope of services offered is usually broad, and not necessarily limited to matters relating to the agency whose clientele constitute the protégé's. The advocacy service may or may not be housed in the physical plant of the specified agency.
3. Clientele-specified Advocacy. This is instrumental advocacy given by an advocate who is devoted to a particular class of protégé persons, usually scattered throughout a community and defined as a class of persons. The advocacy is generally broad in scope, and there is usually not a caseload as such; all persons who meet the definition of their class may seek or be sought by the advocate.

Policy Planning:

This is advocacy dedicated to the interests of protégé populations in relation to public policy and to the nature and delivery of services. It is carried out as a public responsibility by a group or committee or administrative unit, usually under the authority of a public body. There is a proper component, in public policy planning, of taking into account the interests of society in general, even though the advocacy is on behalf of a particular protégé group.

Protective Service Investigation:

Protective Service Investigation is an official's investigation of the

need for court action to establish one of the foregoing protective services. During this investigation, a very substantial amount of negotiation and advocacy for the potential ward may take place, usually in relation to persons who are currently exercising power in the life of the protégé.

In Minnesota, there are provisions in the law that protect the liability of persons who report (in good faith) possible abuse and neglect of children and vulnerable adults. The provision of intervention, prevention, and protective services is often made possible by the initiation/reporting of conditions or situations that are considered harmful to a person with a developmental disability or to others.

Protective Services:

These are public services that are provided because it is legally supposed or determined that a particular protégé needs to be protected against the actions of others or against the consequences of his/her own actions. Protective services may only be given in three conditions: 1) to chronological minors (by natural or adoptive parents); 2) to persons who have been placed into protection by legal action with due process (guardianships, protégé of any age); and 3) as in a negotiation during investigation of potential need for protection.

Quasi-advocate Services:

Quasi-advocate Services are not advocacies in the literal sense. However, they are sometimes said to be advocate services, and they may support actual advocating activities. Such activities would include:

- Counseling
- Follow-Along
- Information and Referral Service

-- Multi-Resource Service Centers

-- Training for 'Self-Advocacy'

APPENDIX B

Minnesota Nursing Home
Complaint System
and
Long Term Care Ombudsman
Program Confidentiality Policy

MINNESOTA NURSING HOME COMPLAINT SYSTEM

The Nursing Home Complaint System in Minnesota consists of a variety of steps and layers of programs and concerned people. It ranges from the individual nursing home staff to concerned citizens, local groups, and State offices.

Most nursing home staff and those who are responsible for nursing home care are generally quite concerned with providing service. Because of this, any complaint should first be brought to the attention of the responsible nursing home staff member. Depending on the concern, this person might be a nursing assistant, social worker, or nurse. It is at this stage that most problems can be resolved and corrected. It is also important that the nursing home administrator be alerted, informed, and involved in the complaint resolution process, since he or she has the primary responsibility for all aspects of the facility's operation. In addition, the resident council of the nursing home serves as the collective voice of all the facility's residents, and can play an active role in the substantiation and resolution of complaints.

To resolve complaints effectively, resident involvement is imperative. A grievance procedure or committee should be established in each nursing home in order to review each complaint and recommend solutions. Written procedures must be also established, clearly outlining the responsibilities of the staff, resident, and complainant, if other than the resident.

If these channels prove unsatisfactory, or if appropriate action is not taken or is unreasonably delayed, then the complaint may need to be directed to other individuals or programs.

In a number of areas in the state, local ombudsman/advocacy programs have been created to assist residents, their families and concerned friends with problems arising out of nursing home living. See attached list. Some of these programs have volunteer friendly visitors who visit residents in the facility. Others primarily utilize professional staff such as social workers and attorneys. Legal service programs are often a resource for local problem solving.

Several consumer organizations and groups of relatives and friends of nursing home residents have been developed in the State. These groups often receive complaints from individuals and offer the vital resources of experience, support, and commitment to the improvement of nursing home quality. They serve to promote the interests of nursing home residents, provide technical assistance, and exert political influence to improve the quality of nursing home care in Minnesota. See attached list of these organizations.

The Minnesota Nursing Home Ombudsman, required by the Older Americans Act and sponsored by the Minnesota Board on Aging, receives non-health-related nursing home complaints that are out of the jurisdiction of local advocate program boundaries. The identity of persons complaining is confidential. The ombudsman assists in developing local ombudsman/advocacy programs and provides coordination for local programs which participate in a state wide network of cooperation.

The next layer of the complaint system contains the Office of Health Facility Complaints, a State Agency that investigates any health-related action or

failure to act by a nursing home in Minnesota. Through State Law, it also has the authority to review a resident's medical records and, if necessary, issue Health Department correction orders and assessments. This office is staffed by a team of investigators, and has a 612/296-5562 phone number that can be called collect from anywhere in the State. During the investigation, complaints are handled confidentially. Once a decision is made regarding the complaint, the case is filed under the name of the nursing home. These complaint files are open for public inspection, but the name of the complainant is marked out to respect confidentiality.

Other State Agencies, such as the Office of Consumer Affairs, the Health Department, the Department of Public Welfare, and County Welfare Departments, handle some nursing home complaints relating to a specific problem areas.

Minnesota Nursing Home Complaint Process

1. The Nursing Home

- a) Each nursing home should have a written facility grievance procedure that spells out in detail the steps to take in making a complaint.
- b) The complaint should be taken to the responsible staff member in the facility (e.g. to the nurse if the grievance is nursing-related).
- c) The facility resident council should be informed and involved to the extent appropriate and possible.
- d) The complaint should be brought to the attention of the administrator who is required to answer all written complaints from residents within seven days.

2. Local Ombudsman/Advocacy Programs

- a) Will investigate complaints in area nursing homes.
- b) Will refer appropriate medically-related complaints to the Office of Health Facility Complaints.
- c) If they receive a complaint outside of their service area, they will refer it to the appropriate local advocate group, to the Minnesota Board on Aging Long Term Care Ombudsman if it is non-medical, and to the Office of Health Facility Complaints if it is medically-related.
- d) Identity of complainant is not revealed without his/her consent.
- e) Shares data and cooperates with MBA LTC Ombudsman.

3. Office of Health Facility Complaints

- a) Investigates any medically-related complaint in a Minnesota nursing home.
- b) Refers non-medical complaints to a local advocate program if there is one, and if not, to the Minnesota Board on Aging Long Term Care Ombudsman.
- c) Identity of complainant is not revealed without his/her consent.
- d) Share data and cooperates with the MBA LTC Ombudsman.

4. Minnesota Board on Aging Long Term Care Ombudsman

- a) Will receive and investigate non-medical complaints that are out of the jurisdiction of local advocate program areas or boundaries.

- b) Will receive and investigate any non-medical complaint unresolved by local advocate program.
- c) Will refer complaints to local advocate programs if the nursing home in question falls within their geographical boundaries.
- d) Will refer all medically-related complaints that are out of the jurisdiction of local programs to Office of Health Facility Complaints.
- e) Will investigate any complaint unresolved by OHFC.
- f) Identity of complainant is not revealed without his/her written consent.
- g) Collects and analyzes complaint data from local ombudsman/advocacy programs, OHFC and other sources.
- h) Share data and cooperates with local ombudsman/advocacy programs and OHFC.

LONG TERM CARE OMBUDSMAN PROGRAM

CONFIDENTIALITY POLICY

- 1) Complainants or residents shall be informed of their right to remain anonymous throughout the complaint investigation.
- 2) The identity of a complainant or resident will be disclosed only when written permission from the complainant or resident (or legal representative) is obtained or upon court order.
- 3) When referral to another program is necessary for the resolution of the complaint, the permission of the complainant or resident must be obtained. (For purposes of this provision, local and state level ombudsman programs are considered one program).
- 4) Complainants or Residents shall be informed that information gathered on any complainant or resident shall be used for the provision of services and management of the Ombudsman Program and shall be limited to the information necessary for these purposes. Complainants and Residents shall be informed that summary data derived from private information may be disclosed. However, the identity of a complainant or resident will not be revealed without their written permission.
- 5) Any files maintained by the ombudsman program shall be disclosed only at the discretion of the ombudsman having authority over disposition of such files, except that the identity of any complainant or resident shall not be disclosed by the ombudsman unless:
 - (1) Such complainant or resident or legal representative consents in writing to such disclosure, or
 - (2) Such disclosure is required by court order.
- 6) Files maintained by the ombudsman program which contain information specifically identifying a complainant or resident shall be considered private and will be open only to ombudsman program staff and the complainant or resident or legal representative who is subject of the information.
- 7) The complainant or resident or legal representative may review his/her complaint file upon arrangement with the ombudsman having authority over the disposition of the file and a copy of the investigation report will be made available to the complainant or resident or legal representative.

TITLE II OF THE DEVELOPMENTAL DISABILITIES ASSISTANCE
AND BILL OF RIGHTS ACT OF 1978
(P.L. 95-602)

FEDERAL REGISTER 45 CFR, 1385.3
May 9, 1980

1385.3 Rights of persons with developmental disabilities (rights).

(a) Section 111 of the Act, "Rights of Persons with Developmental Disabilities", is applicable to the programs authorized under the Act, except for the protection and advocacy system. The basic State plan and all applications for university affiliated facilities or special projects grants must contain an assurance to the Commissioner that the grantee will not provide Federal, State or other public funds to any activity which serves persons with developmental disabilities that is not in compliance with these Rights.

(b) Failure to comply with this assurance may result in the loss of Federal funds under the Act.

(c) The Rights include:

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

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

(3) Federal and State funds shall not be expended or provided to any institutional or other residential program for persons with developmental disabilities that--

(i) does not provide treatment, services, and habilitation which are appropriate to their needs; or

(ii) does not meet the following minimum standards:

(A) Provides a nourishing, well-balanced daily diet to the persons with developmental disabilities being served by the program;

(B) Provides appropriate and sufficient medical and dental services;

(C) Prohibits the use of physical restraint unless absolutely necessary and prohibit the use of physical restraint as a punishment or as a substitute for a habilitation program;

(D) Prohibits the excessive use of chemical restraints, and the use of chemical restraints, and the use of chemical restraints as a punishment or as a substitute for a habilitation program;

(E) Provides for close relatives to visit them a reasonable hours without prior notice;

(F) Complies with fire protection standards set forth in 42 CFR, §§ 442.507, 442.508, and 442.509.

(4) All programs for persons with developmental disabilities shall meet standards designed to assure the most favorable possible result for those served, and--

(i) In the case of residential programs serving persons who need comprehensive health-related, habilitative, or rehabilitative service, standards which are at least equivalent to those applicable to intermediate care facilities for the mentally retarded (42 CFR Part 442, (1978) where appropriate, taking into account the size of the institutions and their service delivery arrangements;

APPENDIX D

Advocacy Policy of the
Minnesota Department of
Public Welfare

GENERAL POLICIES OF THE DEPARTMENT OF PUBLIC WELFARE

ADVOCACY POLICY

INTRODUCTION

The purpose of the public welfare system in Minnesota is to help individuals and families deal with their problems by providing the following types of assistance:

1. financial assistance;
2. social services;
3. educational, medical and related services;
4. care and treatment for mentally ill, mentally retarded and other developmentally disabled persons;
5. rehabilitation of the blind and visually handicapped;
6. services for the aged, deaf and hard of hearing; and
7. services for persons with problems of chemical dependency.

This assistance is offered in a manner that preserves the dignity, as well as human, civil, and legal rights of the individual and families. The Department recognizes the fact that in an organization as large as the Department of Public Welfare, variations from the above purpose, as expressed in individual case decisions, can occur in practice. It is also recognized that policies and procedures affecting individuals and families can become obsolete or otherwise unresponsive to the point that they do not fulfill their original intent. It is the Department's objective, through procedures to be developed by operating units of the Department upon the basis of this policy, to ensure that there are means for identifying and correcting problems within the Department. All persons within the Department should be aware of alternative means (e.g., appeals, grievances, etc.) available to ensure that rights and humane practices are in fact guaranteed.

POLICY ON ADVOCACY

The Department hereby authorizes development and implementation of advocacy procedures by departmental units and operating agencies for consumers of human services that will ensure that legal, civil, and human rights will be upheld in a way that is recognizable and immediately responsive to grievances of individuals and families and will, at the same time, provide an approach for modifying the decision-making process.

It is also Department of Public Welfare policy on advocacy that all employees of the public welfare system, welfare boards, human service boards, area boards, institutions, and persons providing services paid from public welfare funds are responsible for helping to protect the individual's and families' (consumer's) human, civil, and legal rights to apply for, as well as receive, if eligible, financial assistance, social services, and medical, educational, and related care and treatment.

PURPOSE OF ADVOCACY POLICY

It is the intent of this policy to assure that:

1. People who are applicants and recipients are made knowledgeable about their rights to financial assistance, social services, care, treatment, medical services, and educational services, and are given humane and civil consideration by all employees and other involved persons within the public welfare system.
2. There are means, including advocacy procedures based upon and authorized by this policy, established by the operational units of the Department, for acting on suspected violations of consumer rights and for correcting laws, rules, policies, and practices that are in violation of consumer rights.
3. Individuals and groups of clientele, as well as public welfare system employees and other persons within the department covered by this policy, are protected from harassment if they call attention to suspected violations of rights.
4. With the written permission of the consumer and appropriate identification of the nature of the role being assumed, it is expected that employees may be consumer advocates and plead for, act on behalf of, speak for, and otherwise assist the cause of consumers of financial assistance, social services, care and treatment, and related services.
5. There is recognition that consumers of the public welfare system's services may want as advocates people other than employees (or other involved persons) within that system.
6. Effective implementation of the advocacy policy requires that persons working within the public welfare system work together in a cooperative fashion to define an operational framework for advocacy procedures.
7. Advocacy activity is viewed as appropriate in all organizational units, including those that have separated aids from services in accordance with Departmental policy, and is seen as a positive and appropriate stage in the development of the human services system.
8. The advocacy policy is viewed as a policy approach that enables and facilitates internal resolution of problems within the state-wide public welfare system.