REPORT OF THE
DEPARTMENT OF MENTAL HEALTH, MENTAL
RETARDATION AND SUBSTANCE ABUSE SERVICES ON

The Rights of Parents of Persons with Mental Disabilities

TO THE GOVERNOR AND
THE GENERAL ASSEMBLY OF VIRGINIA

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COMMONWEALTH of VIRGINIA
DEPARTMENT OF
Mental Health, Mental Retardation and Substance Abuse Services

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MEMORANDUM:

TO: The Honorable Lawrence Douglas Wilder
Members of the General Assembly

THRU: Howard M. Cullum, Secretary
Health and Human Resources

FROM: King E. Davis KED

DATE: January 22, 1993

Attached is a copy of the Department's report on the "Rights of Parents of Persons with Mental Disabilities."

This report was prepared in response to House Joint Resolution 129 and the Assembly's directive to the Department of Mental Health, Mental Retardation and Substance Abuse Services to study the roles and rights of parents of mentally disabled persons receiving services within state programs.

KED/nmd

Attachment

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I. INTRODUCTION

Over the last thirty years, extraordinary changes have occurred in the mental health field. Changes in treatment philosophies, the availability of new medications, and shifts in funding priorities within mental health systems have moved the traditional focus away from inpatient, facility based care and toward community based care. The language of diagnosis and service delivery has also changed dramatically. Some obsolete, offensive terms were discarded completely. Other phrases, such as "mentally ill," "mentally retarded" or "handicapped" have been replaced by the more inclusive and less stigmatizing term "disabled". In an attempt to be sensitive to the ongoing evolution of the language in this field, the Committee has decided that all those who make use of services traditionally covered under the rubric of "mental health" will be generally designated in this report as "consumers".

During this same time period, a heightened awareness of human rights has led to expanded consumer participation in planning their own treatment and involvement in structuring the programs and systems from which they will receive services.

Changing perceptions of the consumer's role often proceeded from changes in laws. Courts recognized previously undefined rights, legislatures granted new and specific protection to consumers, and administrative agencies developed extensive regulations elaborating procedures for invoking those legal rights. Outdated legal presumptions that took away choices from those labeled mentally ill or mentally retarded were replaced by a new perspective: we now assume that all people retain their ability to make life decisions despite their disabilities, unless the law specifically prescribes for others to decide in their behalf.

> *While consumers have undoubtedly benefitted from the legal and social recognition of their rights to autonomy and self-determination, the proper roles of the significant other people who continue to assist, support and provide care for them have become less clear. Though parents and families no longer have the automatic legal power they may have wielded in the past to speak for consumers, they continue to function as the strongest advocates and best representatives of the desires and needs of disabled family members. Yet, they sometimes report an attitude of indifference on the part of service providers toward their concerns and suggestions. Consequently, those who feel the most compelling moral*

responsibility for the care of persons with mental disabilities feel least able legally to ensure that appropriate care is given.

In recognition of this dilemma, a group of parents approached the Virginia General Assembly in 1992 with a request for clarification of their rights -- as parents. In response, the Assembly adopted House Joint Resolution No. 129 [HJR 129 is included as Appendix A]. The Resolution recognized the need for clearer definitions of and publicity for the rights of parents, guardians and other authorized representatives of persons with mental disabilities. It directed the Department of Mental Health, Mental Retardation and Substance Abuse Services (DMHMRSAS), with consultation from the Office of the Attorney General, to study the appropriate roles and rights of parents of mentally disabled persons who receive services within state programs. Specifically, the Assembly mandated: 1) a review and determination of rights currently accorded to parents of the mentally disabled under state laws, rules, regulations and administrative policies; 2) an identification of problems or deficiencies in those laws, rules, regulations and policies; and, 3) recommendations for change.

Following the Assembly's direction, the DMHMRSAS convened a Study Committee that included representation from a broad spectrum of the mental health community. In addition to DMHMRSAS staff members, participants included parents of persons with mental disabilities, representatives from consumer groups, state and private facility administrators, human rights advocates, members of community service boards, and staff from the Department for Rights of Virginians with Disabilities. Legal consultation was provided by the Office of the Attorney General and the Committee was chaired by an attorney from the Institute of Law, Psychiatry and Public Policy of the University of Virginia. [A list of Committee participants is included as Appendix B].

The Committee met formally four times during the summer of 1992 to explore questions raised by HJR 129. The Committee's conclusions are contained in the body of this report.

II. THE ROLE OF PARENTS

The issue most thoroughly discussed by the Study Committee involved the language of "rights" as applied to parents or others who act on behalf of consumers. Deliberations made it clear that many rights were recognized in order to protect consumers from discrimination.

exploitation and abuse, or to ensure equitable treatment along with other members of society. This evolution in the law has led to a gradual empowerment of persons with disabilities, giving them the legal right to make their own decisions and directing their own lives.

The rights of consumers do not belong to their families, but to each individual consumer. Thus when parents, guardians, advocates or other representatives act on behalf of consumers, they act as agents. The rights representatives exercise are derived from the rights of the consumers they speak for, and should be understood as derivative rights. Often, the most important role undertaken by parents of consumers is exercising derivative rights on-behalf of their children.

The Committee also realized that the ability of consumers to understand their rights and communicate their preferences varies greatly. Different laws apply to adults and minors. Among all persons with mental disabilities, no uniform desire for family involvement can be assumed. By law, parents have extensive power to make decisions on behalf of any child who is still a minor. Parents have fewer prerogatives in regard to adult children. For example, the decision-making role that may be available to parents who become guardians of a profoundly retarded, and never legally competent adult is very broad. In contrast, the parents of an adult whose level of decisional competence fluctuates through episodes of mental illness may have no legally recognized decision-making role. People can live with major limitations and still be legally competent to make their own decisions. These adults, despite their disabilities, do not require guardians and may not wish to delegate personal choices to parents. The desire for and the capacity of consumers to make or delegate personal decisions must be assessed individually.

The law already reflects the important role of families and parents as "surrogate decision-makers" in cases where a delegation of decision-making has taken place. For example, the Health Care Decisions Act of 1992 gives automatic priority to family members to make medical decisions for incapacitated people when no legally authorized surrogate has been named. State law on civil commitment of minors or admission of the mentally retarded to state facilities also refers directly to parental involvement; but defining the appropriate role for parents requires going beyond statutorily defined rights.

The following list includes many of the choices that should be available to parents of persons with disabilities. Some are implied in the rights already established in law for consumers while others may be inferred from facility procedures or agency guidelines. The list represents a sample of the kind of choices–for receiving information, for participating in care, for being involved in decisions–that should be made clear to all parents of persons with disabilities. In the listing below, the term "consumer" is used to describe anyone who receives services.

A SAMPLE LISTING OF PARENTAL RIGHTS

- The right to exercise all legal rights delegated by a consumer, including the right to lodge complaints or provide assistance to the consumer, without fear of retribution or punishment.
- The right to courteous treatment by care provider staff, particularly in dealing with parental concerns or dissatisfaction with the quality of services rendered to a consumer.
- The right to receive an explanation from the care provider of fees charged for services to the consumer and procedures for collection of such fees, when the parent shares responsibility for paying.
- The right to give consumers gifts on birthdays, holidays or other personally significant days.
- The right to receive a copy of the human rights plan of any facility or agency, including applicable laws, rules, regulations and administrative policies.
- The right to file complaints on behalf of a consumer alleging violation of the consumer's human rights, and the right to pursue such complaints through the legal and administrative process.
- The right to be informed in writing of the name, business address, and telephone number of the DMHMRSAS regional advocate, and community or program advocates, and to receive a written description of their roles.
- The right to confer with and obtain assistance from advocates of their choice on matters affecting the welfare of consumers.
- The right to petition local human rights committees for review of policies or procedures which may adversely affect the rights or welfare of consumers.
- The right to receive a copy of the care provider's staff rules of conduct, policies and procedures.

- The right to apply for services on behalf of a consumer, including a request for evaluation of the consumer's mental and other personal capabilities.

- The right to request short-term placement of the consumer under emergency conditions.

- The right to visit the consumer at a reasonable hour in the residential setting without prior notification, unless notice has been given that visits are not welcomed by the consumer or are behaviorally or medically harmful.

- The right, with prior notification, to bring other family members or friends at a reasonable time to visit the consumer in the residential setting.

- The right to communicate with a consumer by mail or by telephone at a reasonable hour.

- The right to be informed of applicable policies and procedures concerning the reporting and investigation of suspected abuse or neglect of consumers including clear explanations of what constitutes abuse or neglect and how those conditions are recognized.

- The right to be informed of policies and procedures used in dealing with maladaptive behavior in consumers.

Methods for publicizing these rights are suggested in the Recommendations section of this report, below.

III. DEFICIENCIES IN EXISTING LAWS, REGULATIONS, AND POLICIES

Guardianship

While the Committee is aware of the extensive legislative study, discussion and debate that has surrounded the topic of legal guardianship, it nevertheless concluded that this procedure remains a major cause of parental frustration and a source of confusion. The Committee wishes to emphasize the continuing seriousness of this problem, but offers no additional specific solutions beyond those contained in the recommendations below.

Committee members who are parents of the mentally disabled reported legal fees associated with the guardianship process that exceed $700. Confusion over legal definitions of incapacity and incompetency, and the use of a plenary guardianship versus a limited guardianship were also reported. Parents also do not know when they may need to be named guardians of their adult children. Finally, the Committee noted the chronic difficulty of finding guardians for many people who need them.

Legal Definition of "Authorized Representative"

The term "authorized representative" has evolved from a term of convenience, used to designate the person to whom caregivers turned for consent for medical procedures when patients were unable to consent, to a term with several legal definitions in state law and regulations. For example, the law on consent for research subjects, the Rules and Regulations to Assure the Rights of Residents of DMHMRSAS' facilities, and the law concerning substitute decisions for medical treatment each contains a different definition of the term. This multiplicity of definitions has led to confusion among parents of persons with mental disabilities, who are occasionally called upon to act as authorized representatives in some contexts (for example, medical care) and do not understand why that designation cannot be extended to cover other decisions for their children as well.

Lack of Statewide Policy on Training for Parents and Providers

Committee members repeatedly noted that no regular statewide program exists to provide instruction to parents of consumers on what their rights are, how they may best carry out the parental role, and what informational resources are available to them. Training that does exist does not focus upon the relationship of caregivers to parents or others who represent consumers. No statewide policy exists to encourage, organize or fund training of parents. The resulting vacuum of information and understanding leads to widespread frustration and dissatisfaction both on the part of families and service providers.

Lack of Notice of Consumer and Parental Rights

Existing regulations and policy statements do not give adequate notice to legally competent consumers that they may delegate any of their rights as recipients of services or ask for assistance and involvement from a representative of their choice, including parents and consumer advocates. Parents and others who are named by consumers to represent them are often unaware of the procedures to follow in undertaking the representative role.

IV. RECOMMENDATIONS

In order to remedy some of the problems outlined above, the Committee offers three specific recommendations. The Committee agreed that statutory change is unnecessary at this time. Achieving appropriate recognition of the role of parents requires providing information and direction to parents and modifying the attitudes of some care providers. Changes in the law are of little value unless other changes come first.

The Committee discussed a number of avenues for increased participation by those who share concerns about available services. While the Committee makes no specific recommendation on this point, it encourages enhanced involvement of parents, families and consumers in all aspects of the service delivery system.

The Committee agreed that one critical role parents may play is the role of delegated decision-maker for children with disabilities. The Committee endorsed the following statement to acknowledge both the rights of consumers and a role parents may be asked to assume.

> *The legal rights of any competent person with a mental disability may be delegated by that person to a representative of his or her choice. Parents who act as representatives of their children and are subsequently involved in decisions about care and treatment should be encouraged to become active participants in and advocates for the best interests of their children without fear of retribution from facility staff or caregivers. Likewise, parents or other family members acting in this representative capacity must recognize the rights of their disabled family member to exercise individual choices which may or may not be in concert with their family's values and preferences.*

Specific recommendations unanimously endorsed by the Committee are listed below.

Recommendation I

In order to facilitate delegation of legal rights to or request involvement or assistance from parents by willing consumers, the Committee recommends that future revisions of the Rules and Regulations to Assure the Rights of Consumers include include prominent notice that every consumer has the right to delegate decisions about treatment, residential conditions, and sharing of information to the parent, family member, consumer advocate, or other representative of his or her choice. This policy should be prominently displayed by all programs funded through or licensed by the DMHMRSAS. It should be communicated to all consumers when they enter a facility or program and repeated at least annually.

Recommendation II

Parents should be alerted to their role and rights, and to meet that objective, DMHMRSAS should prepare printed materials, such as a handbook, that will focus on parents' rights. The handbook should include an explanation of parents' rights and an illustrative list of rights (as suggested earlier in this report). It should also contain references to resource materials available to parents, including information on the function of the Office of Human Rights and the office addresses and phone numbers of facility directors and human rights advocates.

The DMHMRSAS should compile the handbook in consultation with advocacy organizations of parents and consumers.

Recommendation III

The handbook relative to parents' rights should form the basis for training by DMHMRSAS that should be made available to anyone who wishes to represent a DMHMRSAS consumer. Training sessions should include information on participation during formulation of treatment plans, periodic evaluations, and at discharge. To the extent possible, consumers, parents, and advocates and consumers should be involved as instructors during this training. Guidance on the proper working relationship between parents, consumer advocates, other representatives, and staff members should be available. In addition, staff training which is provided should include the sensitivity needed in working with parents and family members. Training should include topics such as consultation on health and medical care matters, vocational services and other areas that would benefit from additional parental involvement.

All reference materials and working papers reviewed by this Committee will be forwarded to DMHMRSAS for consideration in carrying out these recommendations.

V. APPENDIX A
HJR 129

APPENDIX B
MEMBERS OF THE STUDY COMMITTEE

House Joint Resolution 129 Study Committee Members

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