

**COMMONWEALTH OF VIRGINIA
COMMISSION ON MENTAL HEALTH LAW REFORM**

REPORT

OF THE

**TASK FORCE ON EMPOWERMENT AND SELF
DETERMINATION**

March 2008

PAGE INTENTIONALLY LEFT BLANK

COMMONWEALTH OF VIRGINIA

COMMISSION ON MENTAL HEALTH LAW REFORM

PREFACE

The Commonwealth of Virginia Commission on Mental Health Law Reform (“Commission”) was appointed by the Chief Justice of the Supreme Court of Virginia, Leroy Rountree Hassell, Sr., in October 2006. Commission members include officials from all three branches of state government as well as representatives of many private stakeholder groups, including consumers of mental health services and their families, service providers, and the bar. The Commission was directed by the Chief Justice to conduct a comprehensive examination of Virginia’s mental health laws and services and to study ways to use the law more effectively to serve the needs of people with mental illness, while respecting the interests of their families and communities.

Goals of reform include reducing the need for commitment by improving access to mental health, mental retardation and substance abuse services, avoiding the criminalization of people with mental illness, making the process of involuntary treatment more fair and effective, enabling consumers of mental health services to have more choice over the services they receive, and helping young people with mental health problems and their families before these problems spiral out of control.

The Commission has been assisted by five Task Forces charged, respectively, with addressing gaps in access to services, involuntary civil commitment, empowerment and self-determination, special needs of children and adolescents, and intersections between the mental health and criminal justice systems. In 2007, the Commission established a Working Group on Health Privacy and the Commitment Process (“Working Group”) and, in 2008, established a sixth Task Force on Advance Directives. Information regarding the Commission and its Reports is available at <http://www.courts.state.va.us/cmh/home.html>.

The Commission also conducted three major empirical studies during 2007 under the supervision of its Working Group on Research. The first was an interview study of 210 stakeholders and participants in the commitment process in Virginia. The report of that study, entitled *Civil Commitment Practices in Virginia: Perceptions, Attitudes and Recommendations*, was issued in April 2007. The study is available at http://www.courts.state.va.us/cmh/civil_commitment_practices_focus_groups.pdf.

The second major research project was a study of commitment hearings and dispositions (the “Commission’s Hearings Study”). In response to a request by the Chief Justice, the special justice or district judge presiding in each case filled out a 2-page instrument on every commitment hearing held in May 2007. (There were 1,526 such hearings). Findings from the Commission’s Hearing Study have been presented to the Commission and have served an important role in shaping the Commission’s understanding of current commitment practice. The study can be found at http://www.courts.state.va.us/cmh/2007_05_civil_commitment_hearings.pdf.

Finally, the Commission’s third project was a study of every face-to-face crisis contact

evaluation conducted by CSB emergency services staff during June 2007 (the “Commission’s Crisis Contact Study”). (There were 3,808 such evaluations.) A final report of the CSB Crisis Contact Study will be released in late 2008.

Based on its research and the reports of its Task Forces and Working Groups, the Commission issued its *Preliminary Report and Recommendations of the Commonwealth of Virginia Commission on Mental Health Law Reform* (“Preliminary Report”) in December, 2007. The Preliminary Report, which is available on-line at http://www.courts.state.va.us/cmh/2007_0221_preliminary_report.pdf, outlines a comprehensive blueprint for reform (“Blueprint”) and identifies specific recommendations for the 2008 session of Virginia’s General Assembly.

This document is the Report of the Commission’s Empowerment and Self Determination Task Force. It was available for Commission consideration in November, 2007 and final drafting was completed in March, 2008. Although the Commission embraced many of the Recommendations of the Empowerment and Self Determination Task Force in its Preliminary Report, this Report is the work of the Empowerment and Self Determination Task Force and has not been adopted or endorsed by either the Commission or the Supreme Court. It was prepared as a resource for the Commission and for the public.

From my perspective, the Task Force Report was immensely useful to the Commission and its recommendations are currently being considered by the Commission as it formulates proposals for the second phase of comprehensive mental health law reform in the Commonwealth.

Richard J. Bonnie, Chair
Commission on Mental Health Law Reform
September 2008

**MEMBERS OF THE
TASK FORCE ON EMPOWERMENT AND SELF-
DETERMINATION**

Chair

Terry Grimes, Ed.D.
President
Empowerment for Healthy Minds
Blacksburg, VA

Friends of Loudoun Mental Health
Leesburg, VA
Cynthia L. Kemp
Executive Director
Arlington Community Services Board
Arlington, VA

Co-Chair

Vicky Mitchell Fisher, Ph.D., RN, APRN
Director of Nursing
Catawba Hospital
Roanoke, VA

David Mangano
Strategic Manager, Consumer and Family
Affairs
Chesterfield Community Services Board
Chesterfield, VA

Members

Charles Thomas Collins, Esquire
Regional Advocate
Office of Human Rights
Western State Hospital
Staunton, VA

James M. Martinez, Jr.
Director, Office of Mental Health Services
Department of Mental Health, Mental
Retardation and Substance Abuse
Services
Richmond, VA

Charles M. Davis, M.D.
Director
Central State Hospital
Petersburg, VA

Kenneth N. Moore
Consumer Advocate
Region Ten Community Service Board
Charlottesville, VA

H. William Farrington
President
NAMI Virginia
Richmond, VA

Carolyn L. Peterson, LCSW
Director of Care Coordination and Recovery
Services
Highlands Community Services
Bristol, VA

Michael R. Gray, Esquire
Staff Attorney
Virginia Office of Protection and Advocacy
Roanoke Extension Field Office
Roanoke, VA

Henry A. Smith, LCSW
Director of Mental Health Services
Cumberland Mountain Community Services
Cedar Bluff, VA

Judith D. Hines
President

Karen A.D. Walters, Esquire
Special Counsel
Office of the Attorney General
Richmond, VA

Katherine Acuff, Commission Editor
Health Policy Consultant
Charlottesville, VA

PAGE INTENTIONALLY LEFT BLANK

GUIDING PRINCIPLE AND GOALS

The Empowerment and Self Determination Task Force conducted its work with an eye toward the following Guiding Principle of the Commonwealth of Virginia's Commission of Mental Health Law Reform and the five overarching Goals set out below.

Guiding Principle of the Commission of Mental Health Law Reform

Commonwealth of Virginia's mental health services system, whatever the source of financing, should assure access to recovery-oriented services needed by persons with severe mental illness, should facilitate consumer choice, and should protect consumers and others from harm.

Task Force on Empowerment and Self Determination Goals

Facilitate engagement and empowerment of persons with severe mental illness based upon the fundamental and essential principle of human dignity.

1. Emphasize individual choice in the Commonwealth's mental health statutes, regulations, policies and practices.
2. Facilitate the use of crisis plans and advance directives in the event of impaired decisional capacity and make discussion of such plans a standard part of treatment while promoting and respecting individual choice.
3. Explore the utility of linking willingness to accept responsibility for treatment adherence to enhanced services or other incentives, but without compromising basic services to which individuals are entitled.
4. Enhance the support and involvement of families and other close associates to the maximum extent consistent with the individual's preferences.
5. Establish and implement training for stakeholders in the mental health services systems regarding the necessity of facilitating and respecting individual choice to the maximum extent consistent with their ethical and legal obligations.

PAGE INTENTIONALLY LEFT BLANK

PROLOGUE

During the June 1, 2007 meeting of the Empowerment and Self Determination Task Force (“ESD Task Force”), the Virginia Tech Tragedy, which occurred on April 16, was discussed. A broad array of concerns was expressed. A number of these centered on the misconceptions and inaccurate information about mental illness that had come to the surface in media discussion of the Virginia Tech tragedy. The ESD Task Force agreed that now, more than ever, public education efforts must be implemented to offset needless fears and reduce resulting discrimination against persons with psychiatric illnesses or histories. A comprehensive and well-funded public education campaign is needed to offset the fear and reduce stigmatization of mental health consumers.

We realize that there is great concern and much discussion about what to do when individuals do not seek treatment, despite displaying behaviors which indicate that they may be quite ill and in need of a medical evaluation. The following perspective was stated by one of the ESD Task Force members:

“We cannot say often enough or overstate in the ‘reform’ process that there are two ways to deal with the issue of people who don’t seek treatment. One way, perhaps the easier way is to try to coerce this group of people into treatment by expanding the scope and reach of coercive treatment laws. The second way often overlooked and perhaps the harder way is to induce more of these people to seek treatment voluntarily by offering better services. Our reform effort (i.e. that of the Commission) cannot just be about making our coercive treatment laws ‘better’. It must also be about reducing the need to use these laws.”

The ESD Task Force feels strongly that the Commission on Mental Health Law Reform is in a unique position with regard to these sensitive and complex issues. We therefore recommend that the Commission include a statement along the following lines in its final report:

The Commonwealth of Virginia Commission on Mental Health Law Reform recognizes the tragedy of events, which took place on April 16, 2007 at Virginia Tech. We offer our deepest sympathies to everyone affected. These events have served to affirm the urgency and importance of the work of the Commission. While the Commission’s guiding principle directs its labors, the following tenets have been adopted to emphasize certain basic beliefs.

People with mental illness are generally no more violent than people without mental illness. The Commission intends to dispel public misconceptions about mental illness and to promote their inclusion and acceptance in society, while avoiding processes that lead to isolation, prejudice, discrimination or criminalization.

We believe that the vast majority of problems which society associates with people with mental illness could be avoided if appropriate and timely mental health services were readily available. These services should reflect effective treatment approaches that foster

individual choice and voice to the maximum extent possible.

We believe any changes in legislation must be based upon sound constitutional bases, clear and consistent application of the civil commitment process, and rigorous protection of every individual's well-being and liberty interests.

TABLE OF CONTENTS

Preface	3
Members of the ESD Task Force	5
Guiding Principle and Goals	7
Prologue	9
Introduction. The Importance of Empowerment and Self Determination	13
Chapter I. Emphasizing Individual Choice	17
Chapter II. Advance Directives	25
Chapter III. Incentives	40
Chapter IV. Family/Close Associate Involvement	43
Chapter V. Peer Support	48
Appendices	
Appendix A. DMRMHSAS Uniform Preadmission Screening Forms	57
Appendix B. Opt-Out Option for Advance Directives	67
Appendix C. Illustrative Family/Close Associate Education Programs	71
Appendix D. Acronyms	73
Appendix E. Empowerment and Self Determination Task Force Recommendations	75

PAGE INTENTIONALLY LEFT BLANK

INTRODUCTION

The Importance of Empowerment And Self-Determination

The construct of empowerment has been studied by social sciences for decades and, depending on the study, can be applied in many different ways. Empowerment can refer to something that occurs at a personal level, to whole groups that are empowered to act or be or do something that they may not have done before, or it can refer to the actions of entire organizations and countries.

For this Report of the Empowerment and Self Determination Task Force, it is an understanding of the importance of *personal* empowerment that we believe is critical. Personal empowerment leads not only to overcoming feelings of powerlessness but, also, having a sense of self-agency, mastery, and accomplishment. Empowerment is, of course, important for all individuals. However, for many persons with mental illness, both the characteristics of their illness as well as the medical and legal interventions that have long been in place, significantly undermine not only a sense of having the power to act on one's behalf but actually having the acknowledged authority to do so. Personal empowerment in the context of persons with mental illness means knowing one has a role in setting personal and treatment goals, making decisions, taking risks, having meaningful relationships, and being viewed as having valuable input not only in treatment but in other life choices as well. For some individuals with mental illness who have been in environments where personal preferences and choices have been long ignored, the first feelings of empowerment are almost foreign and the supports to foster the emerging sense of empowerment are essential. Mental health providers attest to the challenges of trying to elicit self-identified goals for individual service plans, because many consumers have been accustomed to someone else making those essential decisions. It is our belief, documented in the research literature, that supporting the development of a personal sense of empowerment improves treatment outcomes and overall functioning. But supports for the growth of personal empowerment include more than having well trained mental health providers. Also important are having clear information for consumers about their rights, educating families, law enforcement, attorneys, the courts and the public about mental illness, providing access to housing, and jobs, and active campaigns to reduce the stigma of having a mental illness.

One of the clearest descriptions of personal empowerment is found in *The Recovery Workbook* from the Center for Psychiatric Rehabilitation:

“Empowerment is the realization that we have the right, the ability, and the resources to determine what our needs and wants are and to pursue them. Feeling empowered means feelings that we are worth while and that we could; that we are real, have choices, can make decisions, can trust our feelings, respect our strengths and limitations, can call on others for assistance; that there is more to us than our illness.”¹

¹ Spaniol, L., Koehler, M, Hutchinson, D., *The Recovery Workbook: Practical Coping and Empowerment Strategies for People With Psychiatric Disability*, Center for Psychiatric Rehabilitation Sargent College of Health and Rehabilitation Sciences Boston University, Boston, MA (1994).

Self-determination is usually considered in tandem with empowerment and emphasizes concepts such as free will, civil and human rights, freedom of choice, and the right to make decisions concerning their health and well being to be free from involuntary treatment, and to have meaningful leadership roles in the design, delivery, and evaluation of services and supports.² Self-determination is empowerment in action. Key for persons with mental illness (and other vulnerable groups) are having economic independence, overcoming discrimination, advocating for one's rights, and becoming a fully self-determining individual.

This Report discusses personal empowerment and self-determination in more detail and makes concrete Recommendations for policy makers to consider that will support individuals becoming active collaborators in their treatment.

The Task Force on Empowerment and Self-Determination (“ESD Task Force”) met seven times during the period from October 2006 through October 2007. The ESD Task Force is loosely grouped into four subcommittees: 1) the Individual Choice subcommittee, 2) the Advance Directives and Incentives subcommittee, 3) the Family/Close Associate Involvement subcommittee, and 4) the Training subcommittee. Members of these subcommittees worked together through conference calls, email communications and individual research. Although the ESD Task Force maintained the subcommittee structure, each aligned according to the specific ESD Task Force goals, issues emerged which sometimes did not keep within those subcommittee boundaries and members worked together at all times bringing their knowledge, skills and resources in a true group effort.

From its first meeting, the ESD Task Force members preferred to use the word “individual” as in referring to an individual with mental illness, rather than “consumer.” By emphasizing the individual, we held that the person would be more likely engaged as a person with strengths, disabilities and also the commonalities every human being shares. The person can best be viewed as a unique individual rather than as a member of an ill-defined group or group whose very name can engender negative reactions, discrimination, possible abridgment of civil rights and other restrictions.

Each Chapter is organized around a discussion of and Recommendations advancing one of the goals articulated at the beginning of this Report.

Chapter I looks at the aspects of Virginia's Civil Commitment Code including an-depth study of the prescreening process conducted by professionals from Community Services Boards and the Uniform Preadmission Screening Form, which is under revision.

Chapter II includes the extensive work the ESD Task Force completed on the topic of Advance Directives. The section outlines the ESD Task Force's work and recommendations in some

² UIC National Research & Training Center on Psychiatric Disability and the UIC NRTC Self-Determination Knowledge Development Workgroup, *Self-Determination Framework for People with Psychiatric Disabilities*(Chicago, IL, 2002).

detail about issues central to developing legislation, policies, and practices concerning advance directives for non end-of life healthcare in the Commonwealth.

Chapter III explores the use of rewards to encourage treatment adherence in the area of mental health, seeing that these types of inducements to encourage healthy lifestyles and follow prescribed regimens for chronic illnesses are being tested with private insurers, Medicaid, and large corporations with the general public.

Chapter IV stresses the importance of the involvement of family and others designated by the individual to that person's wellness and stability. This Chapter includes information about some of the educational programs available to family and friends in the Commonwealth. Identified are several practices, which could significantly improve the likelihood of family/close associate involvement, and some of the barriers, which make this difficult.

Chapter V includes specific information on the topic of peer support services and in particular that of the Peer Specialist. Included is a description of the important role the Peer Specialist can play, recent developments in federal and state health and human services of how the services of Peer Specialists may be a Medicaid billable service, and the availability of training programs in Virginia.

PAGE INTENTIONALLY LEFT BLANK

CHAPTER I. EMPHASIZING INDIVIDUAL CHOICE

Goal 1. Emphasize individual choice in the Commonwealth’s mental health statutes, regulations, policies and practices and in the work of stakeholders in the mental health system

In meeting its broad goal to emphasize individual choice in the Commonwealth’s mental health statutes, regulations, policies and practices, the ESD Task Force examined aspects of Virginia’s Civil Commitment Code, with an in-depth study of the prescreening process. The ESD Task Force also had a presentation and discussion about the new Human Rights Regulations, effective September 19, 2007,³ with an emphasis on sections that particularly promoted individual choice.

The ESD Task Force identified the following as concerns relating to empowerment and self-determination upon its examination sections of Title 37.2 of the Code of Virginia, which addresses civil commitment:

- The definition of “mental illness;”
- The definition of “abuse;”
- Current training and oversight of magistrates, special justices, and attorneys representing individuals;
- Training and certification requirements of prescreeners;
- Language contained in the Uniform Preadmission Screening Form;
- Assurance of all individual rights during the commitment process; and
- Loosening certain commitment criteria.

The definition of “mental illness” was of concern to ESD Task Force members because it focuses on the need for treatment and intervention based mainly on the need for safety of the individual and others. Currently, it is defined in the Code as

“a disorder of thought, mood, emotion, perception, or orientation that significantly impairs judgment, behavior, capacity to recognize reality, or ability to address basic life necessities and requires care and treatment for the health, safety, or recovery of the individual or for the safety of others.”⁴

This became the definition in 2005 when the civil commitment section was recodified as Title 37.2. It is possible that the definition of “mental illness” in 37.2 is intended to apply only to Title 37.2, and is tied specifically to the commitment criteria. However, the ESD Task Force questions the necessity for having a definition of mental illness that has the potential for perpetuating stereotypes, even for the limited purpose of a civil commitment statute. The ESD Task Force recommends that the General Assembly consider a definition that does not define individuals’ mental health in terms of dangerousness. Rather, the General Assembly should consider a

³ [12 VAC 35-115-10](#) et seq. Rules and Regulations to Assure the Rights of Individuals Receiving Services from Providers of Mental Health, Mental Retardation and Substance Abuse Services.

⁴Va. Code section 37.2-100.

definition that clearly recognizes that persons subject to civil commitment are a small subset of all persons with mental illness.

In addition, the ESD Task Force believes the definition of abuse may not be broad enough. Under the current definition of “abuse” in the Code, example six reads:

“Use of physical or mechanical restraints on a person that is not in compliance with federal and state laws, regulations, and policies, professionally accepted standards of practice, or the person’s individualized services plan”⁵

There is concern that that use of pharmacological restraints is not also listed within the definition of abuse; the ESD Task Force suggests it be made clear that abuse includes the use of pharmacological restraints that are not in compliance with law and policy.

Several of the ESD Task Force concerns are also addressed in the work of other Commission Task Forces, particularly the need for more extensive training and oversight of magistrates, special justices and attorneys representing the individuals as well as modifying certain commitment criteria. As a result, in some of these areas the ESD Task Force deferred to other Task Forces. In others, there is some overlap in the ESD Task Force Recommendations and those of the Civil Commitment Task Force.

The ESD Task Force studied the training of prescreeners and the preadmission process in depth. Two Department of Mental Health, Mental Retardation and Substance Abuse Services (“DMHMRSAS”) staff working with other department staff and emergency clinicians participated in ESD Task Force meetings. Our review included a DMHMRSAS update on this topic based on 1998 legislation, proposed certification requirements for Community Services Board (“CSB”) Preadmissions Screening Evaluators,⁶ and the draft Uniform Preadmission

⁵Va. Code section 37.2-100

⁶ CSBs are local government agencies that operate under a contract with DMHMRSAS to provide mental health, mental retardation, and substance abuse services to their communities. One or more local governments can be represented by a single CSB, and these governments oversee and fund the CSBs. Thirty-nine CSBs (and one behavioral health authority) exist in Virginia, and all localities are members of one of these CSBs. Virginia Code § 37.2-500 establishes Community Services Boards as the single point of entry for the publicly funded Mental Health, Mental Retardation and Substance Abuse Services System. The statute sets forth the mandated core services to be provided by CSBs including:

- Emergency Services
 - Crisis intervention, stabilization, preadmission screening for hospitalization, discharge planning for consumers in acute inpatient settings, short-term counseling, and referral assistance
- Case Management (subject to availability of appropriations)
 - Assistance with locating, developing or obtaining services and resources for consumers; needs assessments and planning services; coordination of services

Screening Form (“UPSF). This update included the following commentary:

“Emergency Services Clinicians are tasked to make decisions that may suspend an individual’s liberty, decisions that regularly impact the health and welfare of the citizens of the Commonwealth, and decisions that directly impact the successful transformation of our current system of mental health care.”⁷

The ESD Task Force’s review of the status of training materials and certification requirements for emergency services clinicians showed that in practice there has been inconsistent use of the training materials and inadequate oversight of meeting the requirements for CSB Preadmission Screening Evaluators. The ESD Task Force supports the recommendations of the DMHMRSAS staff that training modules should include the following topics:

- Recovery
- Advance directives
- Completion of the uniform preadmission screening form
- Statutory provisions of the Virginia Code (including outpatient commitment and monitoring)
- Clinical assessment
- Capacity to consent
- Risk assessment
- Human rights
- Confidentiality
- A general overview of medical conditions and medical screening; continuity of care
- Local resources
- Psychotropic medications and side effects and
- Information unique to special populations, including individuals with co-occurring disorders (mental health and substance abuse and mental health and mental retardation), children and adolescents, and the geriatric and forensic populations

Training specific to the co-occurring population (people with both mental health and substance abuse problems) has taken place, and a DVD that will be distributed to CSBs for use in training pre-admission screening evaluators has been completed and is in the process of being readied for distribution.

with service providers, monitoring service deliver, identification of and outreach to individuals and families in need of services

- In addition, the statute also outlines a comprehensive system of services that *may* be provided by CSBs (§ 37.2-500) including
 - Inpatient services, outpatient services, day support services, residential, prevention and early intervention, and other appropriate mental health, mental retardation and substance abuse services.

⁷The DMHMRSAS Emergency Services Training and Certification Work Group, communication, January 2007.

There appears to be some confusion within the DMHMRSAS concerning the funding of Prescreening Training that could affect how much training is actually taking place. For example, during one of the ESD Task Force meetings on the topic of Prescreener Training, we were informed that there were no dedicated dollars allocated for such training. It is notable, however, that the following is stated in the draft 2008-2014 DMHMRSAS Comprehensive State Plan pertaining to Preadmission Screening Evaluators Training:

The Department in collaboration with the VACSB Emergency Services Council and consumer and family representatives, is reviewing, revising, and updating the certification process and will make recommendations regarding the minimum qualifications for preadmission evaluators and the core training curriculum. Approximately \$47,500 annually has been allotted on an ongoing basis to support preadmission screening training.

The availability of such funds should be clarified at the Department level and also communicated to the CSBs.

Finally, the consensus of the ESD Task Force is that the certification program for emergency services clinicians might best be developed and implemented by contracting it out to a third party with an educational mission.

The ESD Task Force also conducted a thorough review of the current prescreening activity and the draft Uniform Preadmission Screening Form (“UPSD”). Discussions about the preadmission screening process elicited concerns about the general lack of documentation of significant comments or preferences of the individual being screened as well as the absence of a procedure for family members and close associates to be involved and provide information to the prescreener. When an individual neither meets the statutory civil commitment criteria nor needs an inpatient hospitalization to meet his or her health needs, assuring that the prescreening process gathers important information and assistance is critically important in securing other appropriate services.

Because the DMHMRSAS is revising the UPSD, the ESD Task Force has had the opportunity to provide significant input about what should be included. The ESD Task Force made suggestions that strengthened the UPSD’s clear adherence to the legal underpinnings of the prescreening process, engaging the individual in the assessment and exploring preferences, and assuring individual protections under the law. The first ESD Task Force suggestion was to require documentation that the individual was given the opportunity to provide input about his concerns beyond what has been asked by the prescreener. As a result, a Personal Statement is now incorporated into the draft UPSF providing the opportunity for an individual to write his comments or have his comments recorded for him, to provide answers to several guiding questions. This section also documents an individual’s choice not to comment. Such “collateral preferences” have rarely been studied since they are seldom recorded. A recent article about decisions made in psychiatric emergency services (PES) suggested that patient and collateral preferences may be quite important and could lead to more positive outcomes and patient

satisfaction.⁸ (Such opportunities for being heard throughout during the commitment process can be helpful in promoting feelings of being respected and valued as an individual.)

Some additional changes recommended by the ESD Task Force also have been incorporated into the draft revision of the UPSF. They include:

- Deleting the word “psychiatric” before the term “advance directive”
- Using alternative words to document harm to self or others instead of “suicide” and “homicide”
- Adding a section on individual preferences for services and supports
- Changing a heading from “Legal Finding” to “Clinical Opinion”
- Not including is/is not mentally ill and/or abusing substances in the same statement, thereby clearly separating the issues
- Not including is/is not an imminent danger to self or others in the same statement, thereby clearly separating the issues

The UPSF is still under revision within the DMHMRSAS. The ESD Task Force’s input along with other likely recommendations from the Commission will be included prior to the development of a final revision. The original UPSF draft that was first presented to the ESD Task Force and the UPSF draft that includes all the ESD Task Force recommendations are labeled original DMHMRSAS UPSF draft and UPSF draft with ESD Task Force recommendations and are attached to this Report as **Appendix A**.

Finally, the ESD Task Force agreed that several additional steps could be taken throughout the commitment process to strengthen individual rights. First, there should be a greater opportunity for family members or other support persons to be present during the commitment process. Some members suggested having peer supports available throughout the entire commitment proceedings.

Second, legal representation both before and during the commitment hearing should be strengthened. Currently, the respondent’s attorney often meets his or her client only moments before the preliminary and commitment hearings providing little time to review the records or question the individual. Also it should be stressed that the appropriate role of the attorney in commitment proceedings is to advocate for the client’s wishes, regardless of what they may be, rather than to defer to others’ assessment of what might be in the client’s best interests.

Third, individuals should be given consistent, written information about the commitment process and their corresponding rights as early as possible. They should also be given a copy of Virginia’s Human Rights Regulations. Often individuals are left without written information, peer or family support, or legal counsel until immediately prior to a commitment hearing. Given that the trigger to being detained and subject to a civil commitment hearing is a mental health crisis (real or perceived by others), providing so little information or support is particularly

⁸ Way, Bruce, B. ,” Relationships Between Patient, Family, and Significant Other Disposition Preferences in Psychiatric Emergency Services and the Clinical Symptom Ratings and Disposition Decisions of Psychiatrists,” *Psychiatric Rehabilitation Journal* 29 (2005): 132-137.

troubling.

Finally, as has been well documented by the Commission's Study of Commitment Hearings, May 2007, there is substantial inconsistency in both how commitment hearings are handled as well as in the dispositions of the courts. Jurisdictions vary significantly on whether CSB representatives or the Independent Examiners attend the hearing, whether family members' attendance is sought, how long attorneys spend with their clients and attorneys' behavior in the hearings. In addition, the likelihood of a civil commitment hearing ending in inpatient hospitalization, mandatory outpatient treatment or dismissal varies considerably. As a result, the ESD Task Force recommends that a concerted effort be put into making the application of these laws consistent across the Commonwealth.

Recommendations

The ESD Task Force Recommendations regarding the emphasis of individual choice and empowerment in the mental health laws, policies, practices and work of various stakeholders are as follows:

Recommendation I.1. Various sections of Title 37.2 of the Code of Virginia and the Rules and Regulations to Assure the Rights of Individuals Receiving Services from Providers Licensed, Funded or Operated by the Department of Mental Health, Mental Retardations and Substance Abuse Services, 12 VAC 35-115 et seq. ("Human Rights Regulations"), should be re-worded to emphasize individual choice and decrease stigmatization.

Recommendation I.2. Assurance of the rights of the individual involved in the commitment process should be guaranteed through vigorous advocacy of the person's wishes, conscientious and ongoing notification of their rights throughout the process, and thorough presentation of evidence and argument before the special justice.

Recommendation I.3. Family and close associates whom the individual wants to be present should be notified of the hearing, and opportunities for their participation should be arranged.

Recommendation I.4. Attorneys appointed to represent individuals in civil commitment proceedings should first complete a certification process similar to that enacted for *guardian ad litem* attorneys. The Office of the Executive Secretary should develop this certification process.

Recommendation I.5. Certification of emergency services clinicians as Preadmission Screening Evaluators should be awarded based upon a written examination covering essential knowledge, skills and abilities. Regular and documented completion of continuing education and training should also be implemented.

Recommendation I.6. The Uniform Preadmission Screening Form ("UPSF") should be revised to emphasize the individual's involvement in treatment planning and his or her personal preferences and to avoid stigmatization.

Recommendation I.7. The rights of the individual involved in the commitment process should be assured through vigorous advocacy of the person's wishes, conscientious and ongoing notification of their rights throughout the process, and thorough presentation of evidence and argument before the special justice.

Recommendation I.8. Individuals involved in the civil commitment process should have the right to have family and close associates notified of the hearing and have their participation in the process either in person or by other means.

Recommendation I.9. Certification of emergency services clinicians, as Preadmission Screening Evaluators should be awarded based on a written examination covering essential knowledge, skills and abilities. Regular and documented completion of continuing education and training should also be implemented.

PAGE INTENTIONALLY LEFT BLANK

CHAPTER II. ADVANCE DIRECTIVES

Goal 2. Facilitate the use of crisis plans and advance directives in the event of impaired decisional capacity and make discussions of such plans a standard part of treatment while promoting and respecting individual choice.

Advance directives are legal instruments that may be used to document a competent person's specific instructions or preferences regarding future health treatment. The Virginia Health Care Decision Act is contained in 54.1-2981 et seq. of the Code of Virginia. Much attention has been paid to advance directives about care at the end of life, particularly about refusing life-sustaining treatment. The discussions of the ESD Task Force focused advance directives allowing individuals to make known, their wishes regarding other types of health care, including mental health care, should they become incapable of making an informed decision at some point in the future. People can make their health care wishes known either through an agent (or health care proxy, as the agent is sometimes called) and/or through an instructional directive. Currently, Virginia law specifically authorizes designations of health care agents for all types of health care, but addresses the use of instructional directives only in connection with end-of-life care. A key goal of the ESD Task Force is to remedy this deficiency.

Advance directives not only promote and support individual choice and self-determination, but can also encourage truly collaborative treatment planning, increase patient "ownership" of treatment plans and improve patient engagement and foster better communication not only with health care professionals but with family members and care givers.

The ESD Task Force arrived at the following guiding principles not only to assist in our work in developing advance directives recommendations but also to assist those who will be considering changes in legislation and framing policies about the use of these instruments, particularly with individuals with mental illness. The Commission requested the ESD Task Force to discuss the basic principle and rules that should guide the use of advance directives outside the unique context of end-of-life care rather than setting out to draft a statutory proposal. This chapter outlines the principles and rules that ought to govern the use of advance directives for health care, including mental health care. In the discussion that follows, the reader should assume, unless the context indicates otherwise, that the ESD Task Force is addressing the use of advance directives *only* outside the context of end-of-life care. The principles and rules that govern end-of-life care would remain entirely intact and unchanged.

The following are the Guiding Principles for the use of advance directives outside the context of care at the end of life endorsed by the ESD Task Force:

Guiding Principles:

Virginia law should promote:

1. increased use of advance directives by individuals with mental illness;
2. the ability of individuals with mental illness to plan and direct their future mental

health care;

3. co-equal relationships between mental health providers and the people they serve, such as generally exist between the providers and recipients of other kinds of health care services;
4. recognition that individuals with mental illness can make good mental health care decisions, that they also have the right to make what may be perceived by others as “bad” or “unwise” decisions, and that their decisions should not be circumvented except in the most dire of circumstances;
5. recognition that, at least during periods of decisional capacity, the individual is generally best situated to determine what his or her own “best interests” are;
6. recognition of the individual’s responsibility for the consequences of the decisions he or she makes;
7. reduction of non-patient-directed involuntary treatment and other forms of force and coercion in mental health treatment;
8. development of trusting and collaborative relationships between individuals and their providers of mental health services;
9. recognition that adequate and appropriate services are essential to the ability of advance directives to promote good clinical and recovery outcomes; and
10. other recovery-based values and principles.

Due to the importance of advance directives to Virginians with mental illness and other stakeholders, the ESD Task Force devoted a large portion of its time to the study of advance directives and to the development of recommendations relating to them. Advance directives for mental health care not only promote and support individual choice and self-determination, but they also encourage truly collaborative treatment planning, increase patient “ownership” of treatment plans, and improve patient adherence to treatment. In addition, advance directives, and the exercise of completing them, may offer other benefits such as improved patient satisfaction with treatment, enhanced therapeutic alliances, reduced need for hospitalization, diminished perceptions of coercion, improved patient/family relationships, and so on. However, the benefits of advance directives for mental health care go largely unrealized in Virginia, since few Virginians with mental illness have them.

The ESD Task Force identified four obstacles (and recommended solutions) to the increased and more effective use of advance directives for mental health care in the Commonwealth.

First, Virginia’s existing advance directives are poorly suited for use in mental health planning, especially by individuals who are alone or alienated and do not have anyone to appoint as their health care agent. We recommend that the General Assembly fix this by enacting new advance

directive legislation that is more adaptable to the needs of people with mental illness.

Second, Virginians with mental illness often do not make advance directives because they are not offered the services most of them require to complete advance directives. We recommend that this be addressed through the establishment of a program or mechanism to ensure that information about and assistance in completing advance directives are regularly offered to persons with mental illness.

Third, advance directives often have no effect in practice because health care providers cannot effectively identify those patients with advance directives or access the documents when they do learn of them. This is particularly true when the patients are in crisis. To facilitate the use of advance directives, the ESD Task Force recommends resolving this by making arrangements for providers to have instant access to the advance directives of their patients *via* an electronic advance directives repository.

Fourth, we are concerned that the “best interests” standard used in Virginia Code § 37.2-1101 undermines the role of advance directives in judicial authorizations of treatment. We recommend replacing the best interests standard in Virginia Code § 37.2-1101 with the “substituted judgment/best interests” standard used elsewhere in the Code.

The ESD Task Force sees tremendous potential for advance directives to positively transform mental health care decision-making in the Commonwealth, particularly if the use of these documents could become so widespread and normalized that they would become “a standard part of treatment.” Based on the available research, we believe this goal is not only worthwhile and morally commendable, but also quite attainable.

Recommendations and Commentary

The following Section includes the ESD Task Force’s Recommendations and provides commentary on the rationale for the recommended policy changes concerning non-end-of-life advance directives.

Recommendation II.1. The General Assembly should amend the Health Care Decisions Act to authorize and govern the use of instructional directives in connection with all health care decisions to supplement the current provisions that pertain only to end-of-life care. This recommendation has 5 parts.

Recommendation II.1 (A). There should *not* be a separate statute for a *psychiatric* advance directive.

Although some states have enacted statutes authorizing psychiatric-specific advance directives (“PAD”s), the ESD Task Force is not convinced that such separate mental care instruments afford enhanced protections or promote respect for individual choice beyond that which could be provided in general advance directives. To the contrary, the ESD Task Force fears that use of a separate advance directive for people with mental illness more likely has the potential for continuing to promote inequality and discrimination in medical treatment. The ESD Task Force

also noted that the very use of the term “psychiatric advance directive” would adversely label persons who might otherwise benefit from and adverse directive and the potential stigma would be a disincentive to their use.

The ESD Task Force is apprehensive about supporting an advance directive law that would treat a define minority group differently than similarly situated others.⁹ There has been some concern specifically stated about PAD statutes “which on their face single out and treat people with psychiatric disabilities differently and disadvantageously on the basis of their status as people with mental disabilities”.¹⁰

We believe that a general advance directive statute governing all health care would provide the greatest benefit not only to persons with mental illness but to others who might become incapacitated as well. Perhaps the strongest support for a general health care directive advance directive is the recognition by the medical community of the co morbidity of serious health conditions and mental illness. Every effort needs to be made in the direction of integrating mental health and physical health care.¹¹

Having a strictly psychiatric focus seems unjustified and ill suited for addressing the overall health care needs of the individual. As was pointed out in the 1999 U.S. Surgeon General's report on mental illness “the relationship between our mental health and our physical health and well-being is inextricably intertwined.” Other authorities have also reiterated that having the position of making a distinction between physical and mental health given the complex health care decisions and serious health conditions facing individuals with mental illness does not make good health sense whether developing an advance directive or an overall coordinated treatment plan.

Recommendation II.1 (B). The General Assembly should amend the Code of Virginia to add a “stand-alone” (agent optional) instructional advance directive for all types of health care to supplement the existing provisions of the Virginia Health Care Decisions Act governing care at the end of life. This is to supplement, and not to replace, living wills and health care powers of attorney already permitted under Virginia law.

At present, Virginians can make two types of written advance directives: an instructional advance directive for end of life care (sometimes called a “living will”) and a general health care power of attorney in which an agent is appointed for medical decisional making of all types. One of the features of psychiatric advance directives that has been cited as particularly responsive to

⁹ See www.mentalhelp.net/poc/view_index.php?idx=119&d=1&w=6&e=281.

¹⁰ Stephan, Susan, “Unequal Right: Discrimination Against People with Mental Disabilities and the Americans With Disabilities Act,” American Psychological Association (2001). *See, also*, *Hargrave v. Vermont*, 340 F.3d 27 (2nd Cir. 2003) (U.S. Court of Appeals upheld injunction enjoining enforcement of advance directive override statute found to discriminate against people with mental illness).

¹¹ *See re comorbidity*: National Association of State Mental Health Program Directors: *Technical Report: Morbidity and Mortality in People with Serious Mental Illness*, October 2006, National Association of State Mental Health Program Directors. www.nasmhpd.org.

the needs of individuals with mental illness is that they offer the option of an instructional directive for identifying the individual's wishes within this limited area without the requirement of having to designate an agent. Several states have chosen to enact statutes authorizing both instructional and agent options for non end-of life general health care decisions recognizing that the stand-alone instructional directive permits an additional valid option for some individuals. The ESD Task Force recommends that the Virginia Code also allow for this option of a stand-alone instructional general health care directive. Throughout this section and indeed this chapter on the ESD Task Force's study of Advance Directives, naturally much of our discussion and examples are specific to individuals with mental illness because this group was our focus. Not only this recommendation but most of the other Recommendations and suggestions identified about advance directives apply to the general population as well.

One of the known barriers that prevent people from making advance directives is that the individual is unable to identify anyone they feel can serve as his or her health care agent. This problem is not unique to Virginia, but is widely reported by individuals with mental illness in other states also.¹² It is important that the legal structure be put into place for non-end-of-life instructional directives so that individuals without an agent may make their health care choices known.

The ESD Task Force does, however, recognize the advantages of agent-driven advance directives. A recent DRHMRSAS study also noted some of the advantages.

“Typically instructional directives may address only a limited range of medical situations that occur frequently enough to be of general concern to people and may also be an example of voluntary self-determination emerging from a patient-professional relationship after being counseled about a particular medical situation. Generally these instructional directives are likely to be more useful in excluding certain procedures that are totally unacceptable to the patient than in fine-tuning decisionmaking about a full range of possible health care choices.”¹³

We believe that most people who make an advance directive will appoint an agent if they can, even though they may also make an instructional directive. By combining a proxy directive with specific instructions, an individual could control both the content and the process of the decision making about care in case of incapacity.

Studies which offered those with mental illness an opportunity to complete a quality advance directive showed that almost all produced health care instructions that were highly consistent with community practice standards for prescription of psychotropic medication and included

¹² DMHMRSAS Emergency Services Training and Certification Work Group, communication, January 2007.

¹³ President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Making Health Care Decisions* (Washington, D.C., October 1982): Chapter 7. See <http://hdl.handle.net/1805/960>.

feasible plans for hospitalization and/or alternatives for hospitalization, etc.¹⁴ In the studies reviewed by the ESD Task Force, virtually no one used an advance directive to refuse all medications and treatment.

The ESD Task Force recommends that the Commission consider the following language adapted from New Jersey Code 26:2H-113:

- a. If the patient has executed an instruction advance directive but has not designated a health care representative, or if neither the designated health care representative nor any alternate designee is able or available to serve, the instructional advance directive shall be legally operative. If the instructional advance directive provides clear and unambiguous guidance under the circumstances, it shall be honored in accordance with its specific terms by a legally appointed guardian, if any, family member, health care professional and facility or other health care provider involved with the patient's health care, and any other person acting on the patient's behalf, except as provided in [refer to whatever limiting provisions are recommended.].
- b. If the instructional advance directive is, in the exercise of reasonable judgment, not specific to the patient's particular health condition and the treatment alternatives, the responsible health care professional, in consultation with a legally-appointed guardian, if any, family member, or other person acting on the patient's behalf, shall exercise reasonable judgment to effectuate the wishes of the patient, giving full weight to the terms, intent and spirit of the instruction directive.

Recommendation II.1(C). Any legally competent person who has capacity should be able to make a non-end-of-life advance directive at any time.

The ESD Task Force believes that the following criteria should be used to determine whether a person has the capacity to make a non-end-of-life advance directive:

- (a) *“Capacity” for these purposes means an individual’s ability to make and communicate a decision regarding the issue to be decided.*
- (b) *An individual has capacity to appoint a health care agent if the individual has a basic understanding of what it means to have another individual make health care decisions for oneself and can identify whom the individual wants to make health care decisions for him or her.*
- (c) *An individual has capacity to make treatment decisions through advance health care instructions if the individual:*

- (1) *understands the general nature and purpose of advance health care*

¹⁴ J. Swanson, M. Swartz, E. Elbogen, R. Van Dorn, J. Ferron, H. Wagner, B. McCuley, and M. Kim, “Facilitated Psychiatric Advance Directives: A Randomized Trial of an Intervention to Foster Advance Treatment Planning Among Persons With Severe Mental Illness,” *American Journal of Psychiatry* 163 (November 1950):11.

instructions, and,

(2) has a basic understanding of the health care issues addressed, including common risks and probable consequences of the individual's decision.

(d) There should be a rebuttable presumption that any legally competent person who executes an advance directive possessed, at the time of execution, all requisite capacity and information needed to make any decisions expressed in the advance directive, to consent to health care authorized in the advance directive, and to otherwise make a valid advance directive.

(e) Professional certification of an individual's capacity to make an advance directive should not be required as a prerequisite for valid execution of the advance directive. Nor should Virginia enact any "safe harbor" provision under which an individual could obtain a professional certification of capacity before executing an advance directive, and thereby preclude future challenges to his or her capacity at that time.

(f) The advance directive form provided in the Virginia Code should include witness attestations affirming that the person executing the advance directive appeared to understand both the advance directive and the issues addressed therein, and that the individual did not appear to be under duress, coercion or undue influence at the time of execution.¹⁵

Recommendation II.1(D). An individual should be able to revoke all or portions of his advance directive at any time, unless he has clearly expressed in that directive his or her intention that he not be able to do so at times when he is determined to lack capacity.

The ESD Task Force believes that individuals should have the right to choose whether or not to make their advance directives unalterable or irrevocable during periods of incapacity, and this decision should not be forced upon them by statutory mandate. To be valid, all unalterable and irrevocability provisions must either specify the portions of the advance directive to which they apply or state that the entire advance directive is unalterable/irrevocable. A warning should be placed in the statutory form to clearly explain that an individual who makes part or all of an advance directive irrevocable during periods of incapacity is waiving important legal rights and should obtain legal or other appropriate advice before selecting that option.

Some experts have argued that the default rule (unless the person says otherwise) should be that the advance directive should not be revocable if the person lacks decisional capacity; they argue that allowing revocation under those circumstances would often defeat the purpose of having the directive and that most people would probably want caregivers to follow their competently enunciated directions. (In the current context, non-revocability would be the default rule unless the person making the directive expressed a specific desire to "opt-out" of it). However, the ESD Task Force strongly favored the opposite default rule -- i.e., the default position would be revocable even if the person lacks decision-making capacity; to change the rule, the person

¹⁵ Adapted from 18 VSA 9703 (b).

would have to specifically opt for the non-revocability rule. The ESD Task Force favors the “revocability” default position in order to maximize individual choice and flexibility, avoid surprise and unintended effects and promote confidence in and the use of advance directives.¹⁶

Recommendation II.1(E). The legislation governing advance directives outside the context of end-of-life care should include an “override” section to address the particular circumstances under which advance directives of this kind should not be binding.

In every state the ESD Task Force reviewed, PADs and other advance directives are subject to “override” provisions. Overrides generally appear to be tailored to the scope and enforceability of each state’s statute, and well as underlying values and practical considerations. Override provisions are intended to strike a balance between these considerations and the individual’s right to control her health care, and in some cases, other aspects of her life. Since these provisions infringe the individual’s ability to control what is done to her own body, they must be as few and as narrowly tailored as possible.

Because of the detailed relationship between an override provision and the other provisions of the statute, we did not find it practical to discuss proposals for an override provision in any detail at this time. We settled on the principle that automatic overrides are justified in some particularly urgent and compelling situations, but that most overrides should only occur after some form of process has taken place.

Example:

a. An advance directive, or a provision of such a directive, would not control to the extent it is inconsistent with:

- i. treatment in an emergency, if compliance poses a high probability of imminent death or permanent disability to the individual or death or severe physical injury to another person; or*
- ii. the act of placing an individual in an involuntary status according to the civil commitment code, forensic statutes, etc. This does not affect treatment provision of a properly executed advance directive during the individual’s involuntary hospitalization if that is the outcome.*

b. An advance directive, or a provision of such a directive, may be suspended if:

- i. compliance poses a high probability that death or severe and permanent disability will result and the risk cannot be reduced to acceptable levels without overriding the provision;*

¹⁶ It should be noted that absolute revocability of the instructional directive is the governing rule for end-of-life care. See Section 54.1-2985. At the request of the Commission at its August 2007 meeting, the ESD Task Force has outlined the recommendations it would make if an “opt-out” default rule were adopted regarding the revocability of the advance directives during incapacity. The summary appears in **Appendix B** of this Report.

- ii. *compliance would be inconsistent with applicable law;*
 - iii. *compliance is so contrary to standards of good medical practice or medical ethics that no reasonable practitioner would agree to carry out the provision; or*
 - iv. *the requested treatment or provider is not reasonably available;*
- c. *Only those parts of the non-end-of-life advance directive that directly conflict with the above may be suspended. The remaining provisions of the non-end-of-life advance directive remain in force.*
- d. *Override Process:*
 - i. *If a provider is unwilling to comply with an advance directive under the circumstances set out in b above, he must assist the patient with transfer to another provider who is willing to carry out the directive (existing law).*
 - ii. *If no other provider is available who is willing to observe a provision in a stand-alone instruction directive, then the provider may either carry out the directive or petition a court of competent jurisdiction for an order invalidating the provision.*

The ESD Task Force discussed the possibility of empowering Special Justices to adjudicate these proceedings, especially in the state hospitals. We believe it is important that, whenever possible, the provider be required to seek permission to deviate from an advance directive, as opposed to requiring the incapacitated person to take action to prevent her advance directive from being unilaterally set aside.

Recommendation II.2. Virginia Code 37.2-1101, Judicial Authorization of Treatment should be amended to replace the “best interests” standard with the “substituted judgment/best interests” standard used elsewhere in the Code.

Among the criteria that must be met for Judicial Authorization of Treatment under authority of the Virginia Code 37.2-1101 are requirements that the “proposed treatment must be in the “best interests of the person,” and that it must not have been proven to be contrary to the patient’s religious beliefs and basic values. This criterion should be revised because it strips the person of much of his or her individuality and is inconsistent with the recovery principles of patient autonomy and self-determination that underlie advance directives.

As defined by the President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, a “best interests” decision is the one a “hypothetical average person” would make.”¹⁷ Under this criterion, the individual’s advance directive and other evidence of his individual characteristics are irrelevant, and he can be ordered to accept treatment without consideration of his personal needs, wishes, or desires.

¹⁷ President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Making Health Care Decisions: Substantive and Procedural Principles of Decision-making for Incapacitated Patients* (Washington, D.C., 1982): 177-178.

Virginia Code 37.2-1101 (G) softens the “best interests” standard somewhat by forbidding authorization of treatment that violates the person’s religious beliefs or basic values. This limited protection, however, has two failings. First, it is not a part of the criteria for authorization of treatment. Rather, it is a defense that the person (who, by definition, lacks capacity at the time) has to raise and prove to avoid such treatment. Second, while religious and similar beliefs are certainly important parts of a person’s individuality, they are not the only important considerations. For example, one individual may be more or less risk-averse than average, or she might order her hierarchy of needs and life goals differently than the fictitious average person.

By comparison, Virginia Code 54.1-2986, Procedure in the Absence of an Advance Directive, requires treatment decisions to be based “on the patient’s religious beliefs and basic values and any preferences previously expressed by the patient regarding such treatment to the extent they are known and, if unknown or unclear, on the patient’s best interests.” This bifurcated substituted judgment/best interests standard allows much greater considerations of the person’s individuality, so his or her advance directive and other evidence of the decision he would make if he had decisional capacity become more relevant.

Treatment may not be authorized under Virginia Code 37.1-1101 unless there is no legally authorized person to make the decision. Therefore, judicial authorization of treatment is only available if no person is available to make the decision under authority of 54.1-2986 or other law. Since the court is basically standing in for the legally authorized representative, it should use the same decisional criteria as the representative.

Given today’s pervasive ethic of recovery, emphasis on individualized treatment planning, voice, and the right to participate in treatment planning even when a person lacks decisional capacity, retaining an unqualified “best interests” standard in Virginia Code 37.2-1101 seems dehumanizing and archaic. It should be replaced with the bifurcated substituted judgment standard used in Virginia Code 54.1-2986.

Recommendation II.3. The Secretary of Health and Human Resources should establish an effective program for informing stakeholders about advance directives for health care, including peer-provided advance directive facilitation services for individuals with mental illness who wish to complete the documents. The programs should regularly offer and provide free facilitation services to, at a minimum, all public sector consumers of mental health services who are willing and able to make an advance directive.

While many health care providers, health care service entities, and individuals have some information about advance directives, services have not been readily available to assist individuals understand the usefulness and how to create these important documents. Having accessible and effective facilitation services for those with mental illness will be essential to any serious effort to increase utilization of advance directives by members of this disability group. Although the ESD Task Force is not recommending separate directives for psychiatric decisions, the research that we reviewed about facilitation involved assisting individuals complete psychiatric advance directives. The results of the studies yield pertinent information concerning

working with this population as well as generally effective facilitation strategies.

Research Studies about Facilitation Strategies and the Utilization of Advance Directives

Half of the United States now have enacted specific stand-alone PADs statutes, and the remaining states have authorized some form of advance directive that can be used for mental health care. Nevertheless, based on a sampling of consumers of public sector mental health services around the country, a recent study found that only about 4% to 13% of those individuals had actually executed advance directives for mental health care.¹⁸ However, 66% to 77% of consumers surveyed told researchers that they would like to have an advance directive and said that they would complete one if the necessary assistance were available.¹⁹

Two groups of researchers have conducted systematic studies of the effect of facilitation services on the utilization and/or quality of advance directives for mental health care. The first of these studies was conducted in 2001-2003 by a group headed up by Debra Srebnik from the University of Washington at Seattle.²⁰ In this study, 133 community mental health center outpatients were given peer-led advance directive facilitation services in small groups of up to six people. Participants made their own advance directives using interactive AD-Maker software.²¹ The specially trained peer leaders gave the group basic information about advance directives and also provided individualized assistance to group members upon request or if it appeared to be necessary.

The results were dramatic. Eighty percent of the study participants completed advance directives for mental health care. The study psychiatrist reviewed the directives and rated them as uniformly “feasible, useful, and at least 95% consistent with clinical practice standards.” None of the study participants used an advance directive to reject all psychotropic medications, and all participants authorized hospitalization and/or feasible alternatives to hospitalization.²²

A subsequent study headed by Jeffrey Swanson from Duke University used a different approach to facilitation but came up with similar results.²³ In this study, 489 individuals with severe

¹⁸J. Swanson, PhD, M. Swartz, MD, J. Ferron, MSW, E. Elbogen, PhD, R. Van Dorn, PhD, “Psychiatric Advance Directives Among Public Mental Health Consumers in Five U.S. Cities: Prevalence, Demand, and Correlates,” *Journal of the American Academy of Psychiatry Law* 34(1)(2006):43-57.

¹⁹*Id.*

²⁰D. Srebnik, L. Rutherford, T. Peto, J. Russo, E. Zick, C. Jaffee, P. Holtzheimer, “The Content and Clinical Utility of Psychiatric Advance Directives,” *Psychiatric Services* 56(2005):592-598.

²¹The Ad-Maker software is described at Srebnik, et al. *infra* Note 4, at 593-594. *For additional information see* P. Sherman, “Computer-Assisted Creation of Psychiatric Advance Directives” *Community Mental Health Journal* 34 (1998): 351-362.

²²Srebnik, et al. *infra* note 4, page 595.

²³J. Swanson, M. Swartz, E. Elbogen, R. Van Dorn, J. Ferron, H. Wagner, B. McCuley, and M. Kim, “Facilitated Psychiatric Advance Directives: A Randomized Trial of an Intervention to Foster Advance Treatment Planning Among Persons With Severe Mental Illness,” *American Journal of Psychiatry* 163(11) (November 2006): 1943.

mental illness were divided between facilitation and control groups. Each member of the facilitation group received an individual 120-minute hands-on session with a trained advance directives facilitator.

By the end of the Swanson study, 61% of the facilitation service recipients had completed a psychiatric advance directive (84% of those who actually met with a facilitator). Similar to Srebnik's results, the directives produced by Swanson, et al.'s facilitation program produced high quality directives that were legally valid, feasible and highly consistent with North Carolina community practice standards.²⁴ At least 89% of the directives included advance agreement to hospitalization, and 93% gave advance consent to at least one specified psychotropic medication. None of the study participants used their advance directive to refuse all medications and treatment. In addition, the researchers found evidence that individuals who had completed an advance directive with the aid of a facilitator experienced a significant improvement in their working alliance with their clinicians and in their subsequent perception of whether their treatment needs were met."²⁵

The persons in the control group did not receive individualized "hands-on" assistance to complete their advance directives. Instead, they were given an introduction to psychiatric advance directives and provided printed information about the purposes of psychiatric advance directives, standard psychiatric advance directive forms, and the toll-free telephone number of an organization that advises people who want to make psychiatric advance directives.²⁶

Only 3% of the control participants completed an advance directive by the end of the study.²⁷ The researchers requested the few directives that were completed, and examined those that were submitted for review. The quality of these non-facilitated directives was low, and the people who made them did not experience as large an improvement in working alliance with their clinicians. None of the examined control group directives met legal validity requirements.²⁸

The results of these two studies demonstrate that hands-on facilitation services can produce very high utilization and quality of advance directives for mental health care. They also support the projection that these services and the resulting advance directives will increase patient satisfaction with treatment and improve therapeutic alliances. Further, the studies appear to show that some form of "hands-on" assistance will be required to produce the benefits these studies produced. In the Swanson study, merely informing individuals with mental illness about advance directives produced almost no benefit--even when printed materials and explanatory forms were also provided.

Facilitation appears to increase utilization and quality of advance directives whether it is done individually or in small peer-led groups, and with or without computer assistance. The cost of providing facilitation services on a large scale would also appear to be reasonable, especially in

²⁴Id. page 1948.

²⁵Id. page 1950.

²⁶Id. page 1944.

²⁷Id. page 1950.

²⁸Id. pages 1949-1950.

view of the effectiveness of a single 120-minute session demonstrated in the Duke study and a small amount of administrative/clerical assistance per individual.

The results of these studies appear to allay concerns that increasing the use of advance directives for mental health will produce a flood of unreasonable treatment requests relatively few people with mental illness will complete and advance directive if these services are available.

Advance Directives and Crisis Plans

The Srebnick study demonstrated that peer facilitators could be effective in an advance directive facilitation program. We recommend the use of trained peers in this capacity to maximize trust and minimize conflicts of interest. In Chapter V of this Report there is a detailed description of a WRAP (Wellness Recovery Action Plan), which includes a section identified as a Crisis Plan, which is being implemented in some parts of the State.²⁹ There was concern raised at the August 2007 Commission meeting that there was confusion about whether such Crisis plans could serve as valid advance directives. The ESD Task Force wishes to clarify that, for the purposes of this Report, a document is only an advance *directive* if it has inherent legal force.³⁰ If we are to equalize the power imbalances that impede true collaboration in treatment planning, the wishes of individuals with mental illness will have to be accorded some increased degree of legal force.

Advance directives are distinct from Wellness Action Plans (“WRAPs”), which are described in some detail in the Peer Support section of this Report, crisis plans, and other non-legal expressions of an individual’s preferences or wishes. The Crisis Plan section of a WRAP and similar devices may contain (or in some situations even become) a legal advance directive if certain legal requirements are met. But, if those legal requirements are not met, the Crisis Plan of a WRAP or similar document has no greater legal status than other expressions of an individual’s wishes or preferences.

This is not to say that WRAPs are not very useful and constructive documents. They certainly are. However, we believe it is counterproductive to perpetuate the misconception that a person who has completed a WRAP, which includes a Crisis Plan, has necessarily completed a legally binding advance directive. Unfortunately, the originator and key proponent of WRAPs has added to the confusion about advance directives. In an article entitled *Advance Directive*, Mary Ellen Copeland, she states: “an Advance Directive is like the living will of mental health. You may have heard it referred to as a Crisis Plan.”³¹ Although promoting the idea of advance planning for a possible mental health crisis, she fails to distinguish broad health care planning outlines from legally enforceable documents, and uses the terminology of “advance directive”

²⁹ In several sites in Virginia, trained WRAP facilitators assist groups of individuals with mental illness to develop WRAPs within a recovery workshop series. It would take little to expand this to include facilitation of advance directives.

³⁰ This legal force may, of course, be qualified or limited, as is the case with Virginia’s existing living will and health care power of attorney.

³¹ Mental Health Recovery Newsletter, May 2004

<http://www.namiscc.org/ecoverly/2004/AdvanceDirectives.htm>.

interchangeably with that of Crisis Plans in a WRAP.³² It is acknowledged in the more recent editions of WRAP Crisis Plan forms do include the statement that “It will further increase its potential for use if you appoint and name a durable power of attorney” the advance directive terminology is used without distinguishing those with legal effect from those planning documents that cannot be legally enforced. As reported in Chapter 5 of this Report, about 75 WRAP facilitators have been assisting groups of individuals throughout Virginia in developing these Crisis Plans. The ESD Task Force recommends that all training of facilitators include clear information about the differences between legally binding advance directives and other documents in which an individual can express preferences about health care treatment and support persons.

Recommendation II.4. The Commonwealth should create or support a single, secure electronic repository for advance directives. This would enable health care providers to identify quickly patients with advance directives and to access these documents in an emergency. Individuals would be able to choose whether to have their advance directives stored in the repository.

A Repository is Needed To Ensure That Health Care Providers Have Timely Access To Their Patient’s Advance Directives.

No matter how beneficial advance directives may be, or how widespread their use may become, they cannot be effective if the people who must implement them do not know about them or cannot access them when they are needed. Ensuring that providers have timely access to advance directives is especially problematic for people with mental illness.³³ These individuals are often introduced to new health care providers when they are in crisis—a time when their care needs are most urgent but their ability to notify the provider and provide access to their advance directives may be at its lowest.³⁴

Researchers have found that failure to assure that providers know about and can get timely access to mental health advance directives is a major barrier to the effective implementation of the documents.³⁵ Mental health professionals appear to agree. In a recent survey, the lack of access to advance directives, and related operational problems, were the most widely reported concerns of mental health professionals.³⁶ It appears to us that the most effective way to resolve these problems will be through the provision of a single, electronically accessible repository for the advance directives of Virginians.

³² See, e.g. www.mentalhealthrecovery.org,

³³D. Srebnik, “Benefits of Psychiatric Advance Directives: Can we Realize Their Potential?” *Journal of Forensic Psychology Practice*, (Nov. 2004): 71-82.

³⁴Virginia Code § 54.1-2983 places the responsibility on the individual to ensure that his attending physician is notified that he has an advance directive.

³⁵See, e.g. D. Srebnik, footnote 33.

³⁶R. Van Dorn, M. Swartz, E. Elbogen, J. Swanson, M. Kim, J. Ferron, L. McDaniel, A. Scheyett, “Clinicians Attitudes Regarding Barriers to the Implementation of Psychiatric Advance Directives” *Administration and Policy in Mental Health and Mental Health Services Research*. 33:4(2006):449-460.

Providers would have secure access to the repository and would be required to search for and retrieve the advance directives of patients under their care. While individuals would be informed of the benefits of filing advance directives in the repository, they would not be required to do so. The law would not permit or require placement of any advance directive on the repository either automatically or by default.

Participation would be free or with a minimal charge for registering, and accessible to people with disabilities. Information about the repository would be widely disseminated and providers would be required to give their patients basic information about the repository. In addition, the advance directive facilitation services or program we advocate in Recommendation II.4 would include an explanation of the repository along with an offer to provide any assistance an individual might require to place an advance directive there.

The Commonwealth could provide for the repository by contracting with an existing advance directives repository service like U.S. Living Wills, or by setting up a state-operated repository in an administrative agency. The ESD Task Force would also support the use of “smart card” technology in combination with the repository, to give individuals a practical and secure way to carry their advance directives and other information on their persons. To help ensure that advance directives are kept up-to-date, the repository could send annual reminders to participants.

The Advance Directives Study Pursuant to HJR 603, House Document No. 75, A Report of the Joint Commission on Health Care, 2000,³⁷ refers to a number of methods to increase and improve the utilization and acceptance of advance directives. At that time, the Joint Commission did not reach a conclusion concerning implementing a state repository but it noted, “However, the inclusion of advance directives in a state registry, particularly one that utilizes the existing infrastructure of a state organ donor registry, should be considered at a later time.”³⁸ Many of the issues raised during the Advance Directives Study should continue to be included in framing legislation and policies on advance directives in the Commonwealth.

³⁷Access this Virginia Joint Commission on Health Care report online at: <http://jchc.state.va.us/report.htm>.

³⁸ Page 29 of the Advance Directives Study.

PAGE INTENTIONALLY LEFT BLANK

CHAPTER III. INCENTIVES

Goal 3. Explore the utility of linking willingness to accept responsibility for treatment adherence to enhanced services or other incentives, but without compromising basic services to which individuals are entitled.

The ESD Task Force reviewed and discussed information related to providing incentives for treatment adherence. It soon became evident that the larger concern about treatment was that most mental health consumers living in Virginia were having difficulty accessing even basic levels of services.

Nonetheless, to address spiraling health care costs and what appears to be lack of personal responsibility, both public and private health care entities have developed leverage-based health care plans. For example, a West Virginia health plan incorporates reduced benefits for enrollees for failure to adhere to prescribed programs.³⁹ A Florida plan rewards compliance for certain behaviors with points which can be redeemed for services not in the standard benefits package.⁴⁰ Private health care insurers, such as United Health Group, also are testing financial incentive programs targeted at people with chronic illnesses such as diabetes, asthma, and heart disease and using financial incentives as a mechanism to reward healthy behavior.⁴¹ Other insurers are offering reductions in policy rates for certain behavioral commitments related to healthy living. Several large corporations also try to encourage healthy lifestyle changes with rewards, for example, IBM now offers cash rebates through a 'Healthy Living Rebate Program' that seeks to encourage exercise and changes in behavior like quitting smoking.⁴² Virginia's Medicaid Revitalization Committee also was directed to consider several reforms, which included incentives to foster and facilitate healthy behaviors.⁴³

Although leverage-based provisions in health plans, generally, are becoming more common, members of the ESD Task Force found little information in the psychiatric literature about applying these strategies to prescribed mental health treatments. However, according to a recent analysis by Monahan, et al., making the availability of such ancillary services such housing and money, contingent upon adherence to mental health treatment is not uncommon.⁴⁴ Two

³⁹ See Department of Health and Human Services, Centers for Medicare and Medicaid Services, *West Virginia State Plan Amendment*, § 3.1, a. 2, p. 1 (2006), available at http://www.wvdhhr.org/bms/oAdministration/bms_admin_WV_SPA06-02_20060503.pdf.

⁴⁰ See Florida Agency for Health Care Administration, *Florida Medicaid Reform: Application for 1115 Research and Demonstration Waiver*, p. 26-32. (2005), available at http://ahca.myflorida.com/Medicaid/medicaid_reform/waiver/pdfs/medicaid_reform_waiver_final_101905.pdf).

⁴¹ See http://www.definityhealth.com/marketing/newsroom/pressreleases/2006/RFA_Press_Release.pdf

⁴² See <http://www.ibm.com/ibm/responsibility/people/wellbeing/incentives-to-health.shtml>.

⁴³ House Bill 758, April 2006.

⁴⁴ John Monahan, Marvin Swartz, and Richard J. Bonnie, "Mandated Treatment In The Community For People With Mental Disorders," *Health Affairs*, 22(5)(September/October, 2003): 28-38.

newspaper articles reporting on the study by Monahan et al. indicated that paying mental health consumers to comply with depot injections) had some success with the small sample involved to improve treatment adherence and reduce hospital admissions.⁴⁵ The researchers cautioned that this type of intervention should only be considered when all others have failed and only with a very high-risk group of non-adherent patients. A brief report on a study which evaluated the effect of \$10 payments for attending therapy appointments among 50 low-income African American did show that 54% had better attendance when receiving payments lead the authors to conclude that incentive payments may have potential to improve appointment adherence in this group.⁴⁶

It does seem that adherence to medication is the primary treatment area of concern for mental health consumers. Actually, as recently noted, study after study shows that in the USA and other developed countries only about half of people with chronic health conditions continue to take medication as directed. Reporting researchers included physicians from University of Colorado Health Sciences Center, Ontario, Canada, Trinity College in Dublin, Columbia University, and Kaiser Permanente. Among those who do not regularly take their medication or stop altogether are heart attack survivors, epilepsy patients, breast cancer patients, those with asthma, high blood pressure, and high cholesterol. Obviously this is a huge problem and the reasons seem to be complex and may differ for different groups. Perhaps understanding some of the reasons that result in so many failing to adhere to prescribed medication regimens may offer some important guidance to assisting individuals with mental illness and underscore the importance of having the individual engaged and informed in their own health care.⁴⁷

The ESD Task Force members, given the promotion of person-centered health care and recovery based services, took the following position:

The ESD Task Force concurred that these types of strategies would not significantly advance individual recovery and that such measures are not recommended. At the same time, no policy precludes clinicians and programs from incorporating “rewards” when appropriate into an individual’s services as long as they have been developed with the person’s input and in accord with their preferences.

⁴⁵ Belfast Telegraph, January 1, 2007, BBC News, January 1, 2007.

⁴⁶ Post, E., Cruz, M., Harman, J., “Incentive Payments for Attendance at Appointments for Depression Among Low-Income African Americans, *Psychiatric Services* 57 (2006): 414-416.

⁴⁷ Medication compliance issues are being studied at Yale University in the Department of Psychiatry headed by researcher Joyce A. Cramer, among others. Another resource, which may be helpful, is the ISPOR Bibliography of Medication Compliance Barriers Related to Medication Non-Compliance. This document can be downloaded at www.ispor.org/sigs/medcompliance/MCbarriers_byauthor.pdf.

CHAPTER IV. FAMILY/CLOSE ASSOCIATE INVOLVEMENT

Goal 4. Enhance the support and involvement of families and other close associates to the maximum extent consistent with the individual's preferences.

The ESD Task Force's Recommendations regarding family/close associates support and involvement are as follows:

Recommendation IV.1. All public and private facilities and providers should facilitate opportunities for families and other close associates to be involved in the treatment of an individual with mental illness to the maximum extent desired by that individual. These opportunities should include education, training and support groups.⁴⁸

Recommendation IV.2. The DMHMRSAS and CSBs should require staff education regarding the benefits of facilitating support from families and close associates and regarding protocols for inviting discussions with consumers and offering them opportunities to identify individual(s) whom they desire to be informed and involved regarding their treatment

Family /Close Associate Support

Changes – significant changes – have been taking place in the critical relationships between people facing mental illnesses and their families. Family psychoeducation is known as an evidence-based practice; the benefits of the support of family and close associates to an individual's well-being and quality of life are well documented.⁴⁹ To provide support and advocacy for their loved ones, family members, close friends, and significant others require education, training programs, and on-going support groups.

A 2002 survey of family and consumer education programs offered in Virginia's Mental Health System ("Survey")⁵⁰ indicated about 70% of Virginia's CSBs provided some form of family psychoeducation either directly or through a National Alliance on Mental Illness ("NAMI") Program.⁵¹

⁴⁸ Appendix C of this Report provides several examples of family/close associate education programs.

⁴⁹ Substance Abuse and Mental Health Services Administration's National Mental Health Information Center, *Evidence Based Practice: Shaping Mental Health Services Toward Recovery Family Psychoeducation*; Center for Mental Health Services, *Information for Public Mental Health Authorities*, Resource Kit, Draft Version, 2003.

⁵⁰ Anita Everett, M.D., *Survey of Family and Consumer Education Programs Offered in the State Mental Health System*, a study commissioned by the Inspector General for Mental Health of the Commonwealth of Virginia, (June 2002).

⁵¹ Id.

The Survey documented the uniqueness of each CSB's organization, staffing, and populations served as well as barriers to involving families and close associates in care. Notable among the barriers in implementing family and close associate psychoeducation programs are lack of transportation (particularly a problem in rural areas of the Commonwealth), stigma, the burdens of caregiving, and cultural issues. Lack of trained staff and financial resources were identified as systems obstacles. The Survey Report recommended the continued support and availability of two programs—NAMI's Family-to-Family and NAMI Virginia's Mutual Education Support Advocacy ("MESA").⁵² The Survey Report recommended not only providing financial support for these programs, but, also, developing new programs through staff training and family focus groups to address the unique needs of different geographical areas, designating a family education and support coordinator in each CSB, nurturing relationships with family advocacy groups, such as NAMI and Mental Health America ("MHA"), and moving beyond to offer a range of options for family caregivers including respite, education, support, access to a caring professional and other resources. Although more needs to be done, recently, there has been promising growth in the education and training offerings available to family members, close associates and individuals with mental illness in Virginia.

Family/Close Associate Involvement with Treatment

The official policy of the State Board of the DMHMRSAS, which endorses Consumer and Family Member Involvement and Participation, broadly supports these individuals as partners in the design, operation, and evaluation of the public services system.⁵³ The DMHMRSAS policy emphasizes the importance of their participation in treatment planning and service evaluation as having a positive effect on service quality and outcomes. However, what is most needed now is attention to the more personal level of involvement that is often desired by consumers and family members and by others persons identified by the consumers as important to be involved in their recovery.

"Significant evidence exists that providing information to families about their relatives' illness decreases the frequency of relapse and thereby reduces rehospitalization. Practice guidelines for the treatment of severe mental illness have integrated these findings and other evidence and now recommend involving families in all phases of routine care.

Although the guidelines call for families to be involved in a collaborative treatment process to the greatest extent possible, few strategies for implementing provider-family collaboration have been developed. As a result, many families are not involved in the treatment process or given any information about their relatives' illness."⁵⁴

⁵² See Appendix C of this Report for an overview of these programs.

⁵³ Policy 1040 (SYS) 06-3 *Consumer and Family Member Involvement and Participation* (Policy Manual: State Mental Health, Mental Retardation and Substance Abuse Services Board, April 7, 2006) *Department of Mental Health, Mental Retardation and Substance Abuse Services*.

⁵⁴ Id.

The ESD Task Force believes that the Commission's work has demonstrated substantial differences in processes and programs among Virginia's 40 CSBs regarding how they implement more family/close associate collaboration and involvement with an individual's treatment even when those individuals may welcome such involvement. This variability also led the ESD Task Force to examine whether the federal Health Information Portability and Accountability Act ("HIPAA") and its privacy rules would be an actual or perceived barrier to increased family/close associate involvement.

The HIPAA privacy regulations, and frequently mistaken beliefs about them, are often interpreted as limiting information and involvement available to families/close associates whose loved ones are experiencing mental illnesses. Providers, who otherwise might want to communicate with family members and friends about treatments, sometimes fear they will violate HIPAA rules in doing so.

An excellent article published by the Health Privacy Project, "Myths and Facts About the HIPAA Privacy Rule," dispels some beliefs about the rigidity of HIPAA.⁵⁵ Among the myths listed: "A hospital is prohibited from sharing information with the patient's family without the patient's express consent." The article responds to this myth: "FACT: Under the Privacy Rule, a health care provider may 'disclose to a family member, other relative, or a close personal friend of the individual, or any other person identified by the individual' the medical information directly relevant to such person's involvement with the patient's care . . . if the patient is present, the health care provider may disclose medical information to such people if the patient does not object. If the patient is unable to agree or object to disclosure because of incapacity or an emergency circumstance, the covered entity may determine whether the disclosure is in the best interests of the patient. The professional judgment of the health care provider should inform any decision regarding disclosure of protected health information to a family member or friend who is involved in the patient's care, as these disclosures are permitted, but not mandatory."

Some hospital staff members are not aware that, even when individuals have not given permission to transmit information to family members, the staff members are able to receive information about what is going on in the individual's day-to-day life as long as they do not provide information in response.

A section from an article in the July 12, 2007 issue of *The New England Journal of Medicine*, "Falling through the Cracks – Virginia Tech and Restructuring of College Mental Health Services," by Miriam Shuckman, M.D., adds to the perspective on family rights with regarding to involvement in treatment, especially when we consider what might have happened had Seung-Hui Cho's family been advised of his deterioration:

The laws and professional codes of conduct that protect a college student's right

⁵⁵ Health Privacy Project, "Myths and Facts About the HIPAA Privacy Rule," updated September 22, 2003. See www.healthprivacy.org. See, also, the Report of the Commission's Working Group on Privacy and the Commitment Process due to be released in 2008.

to privacy are so confusing that they have produced ‘massive misunderstanding,’ according to Peter Lake, director of the Center for Excellence in Higher Education Law and Policy at Stetson University . . .

The Family Educational Rights and Privacy Act (FERPA), the college confidentiality law passed in 1974, is often interpreted as prohibiting faculty or staff members from sharing information about a student with one another or with family members unless there is an emergency, but Lake said this is a misinterpretation. FERPA was not intended to block communication between deans and professors, who may share students’ academic records. It’s also not aimed at blocking communication between universities and students’ families, since it restricts only discussion of a student’s academic record, not interactions about, say, strange behavior or illness . . .

“One answer for counseling centers is to find another person on campus who can communicate about a student more broadly. Class deans, who fill that role at Dartmouth, are free to communicate with family and faculty members. Though deans cannot know what is in the student’s counseling or medical records, they can share their own concerns about a student’s behavior or the concerns raised by others. Said Reed [director of Dartmouth; Counseling and Health Resources Departments), “If family call us or the coach calls us, we’ll say, ‘You’re right to be concerned, and you may also want to share that with the dean.’” Information that comes to the dean from these other sources – not the school’s health or mental health services – “is not HIPAA protected,” explained Paul Appelbaum, director of the Division of Psychiatry, Law and Ethics at Columbia University.⁵⁶

Typically obtaining consent for release of information from a consumer fulfills an agency's legal obligation and responds to an immediate request from another agency or professional. Such releases may occasionally be made at the request of the consumer, but only very rarely occur as a result of the proactive initiation of a provider who engages the client in a discussion about the importance of support from others in wellness and recovery, asking about the persons the client might want to be involved and informed. This is the kind of communication and collaboration and support that the ESD Task Force feels needs to be addressed in changes in policy. The Bogart/Solomon article covers this topic very well emphasizing at all times client consent and client trust.⁵⁷

The Bogart/Solomon article ends with simple, straightforward “Steps for developing a policy and a form to release information to clients’ families,” listed below:

⁵⁶ Miriam Shuckman, M.D. “Falling through the Cracks – Virginia Tech and the Restructuring of College Mental Health Services,” *The New England Journal of Medicine* 357 (July 12, 2007):105.

⁵⁷ Tina Bogart, M.S.W. and Phyllis Solomon, Ph.D., “Procedures to Share Treatment Information Among Mental Health Providers, Consumers, and Families,” *Psychiatric Services* 54 (December 2003): 1622-1628.

- 1. Clearly state in the policy guidelines that release of information from the client's clinic record to family members requires client consent.*
- 2. Develop a form specifically for the release of information to family members. Create categories for the types of information that may be released that are applicable to the local agency or system. Consider an appropriate time limit for the release form. Indicate how information will be released (a verbal or a written release, or both). Review state statutes and regulations to ensure that the form is in compliance with the law.*
- 3. Establish procedures for the form to be integrated into routine clinical practice. Present the release form to clients at intake to the agency or mental health system. If a client is too ill to provide consent, determine the procedure for reintroducing the release form once the client is stabilized. Develop procedures for updating the release form (if applicable).*
- 4. Develop training for providers. Train providers in ways to discuss and explore issues about the release of information with both consumers and family members. Include information about the release of general information to family members when consent is not provided. Develop procedures for integrating training into the orientation for new employees.*

The General Assembly of the State of Tennessee recently enacted legislation relative to family member involvement in mental health services.⁵⁸ The aim of the act is to give consumers an opportunity to release information to family members and others designated when they enter an inpatient facility, in an emergency room or in a crisis setting and offered for as long as they are in residence for that treatment. So very many family members and loved ones experience such anguish because they are not informed when their family member has been admitted to a facility or is in crisis. Also as part of this act is the statement that the education of mental health care providers be encouraged about accepting information from family members in the course of the treatment process. This act took effect in Tennessee on July 1, 2007.

The bottom line is to build increasing levels of trust among individuals with mental illness, providers, family and friends.

⁵⁸ “An Act to Amend Tennessee Code Annotated, Title 33, Relative to Family Member Involvement in Mental Health Services,” House Bill 1426; Senate Bill 1489, effective July 1, 2007.

PAGE INTENTIONALLY LEFT BLANK

CHAPTER V. PEER SUPPORT

Goal 5. Facilitate engagement and empowerment of persons with severe mental illness based upon the fundamental and essential principle of human dignity.

The goal above is the main direction given to the ESD Task Force. The ESD Task Force makes the following recommendations:

Recommendations

Recommendation V.1. DMAS and DMHMRSAS should review the recent ruling by the Center for Medicare and Medicaid Services allowing services provided by qualified peer support providers to be billed as a distinct service and should prescribe the necessary criteria for billing peer support as a stand-alone service.

Recommendation V.2. DMHMRSAS should encourage and provide financial support for widespread use of peer support services throughout the mental health system, should obtain specific data on peer specialists and other peer providers and the peer support services they provide, and should establish a peer specialist training program in Virginia, with clear qualification guidelines for enrollment. The General Assembly should provide sufficient funding for such training to assure that the Commonwealth has an adequate workforce of peer support providers.

Recommendation V.3. Peer support specialists should be available to serve as advocates for respondents during the commitment process upon request.

Background

During a meeting of the ESD Task Force on August 15, 2007, the importance of the role of mental health consumers as providers, specifically peer specialists throughout the mental health system was emphasized. Peer specialists are being employed throughout the mental health service system and at junctures of mental health services and the legal and criminal justice systems. In several states, peer support provided by certified peer specialists is a Medicaid reimbursable service. The Substance Abuse and Mental Health Services Administration (“SAMHSA”) is planning to release a toolkit about Peer Specialists soon and research is underway to establish Peer Support as an evidence-based practice.

Peer Support has been shown to facilitate the engagement and empowerment of individuals with severe mental illness in a way that other mental health services cannot. The ESD Task Force over the next couple of months will study Virginia’s plans and current efforts to implement a statewide initiative for the training of peer specialists and its comprehensive strategies for promoting peer support as an effective service option and the employment of peer specialists.

The ESD Task Force recognizes the effectiveness and value of having individuals with

psychiatric disabilities or histories work from this perspective in our mental health system. One of the most difficult problems that families, the legal system, and the mental health system encounters is trying to engage those individuals who refuse traditional services, are homeless and quite ill, have been hurt by mental health treatment, or find themselves in the criminal justice system. It has been shown that these individuals are much more likely to connect with peer providers than other staff and also more likely to accept support.

The Importance of Peer Support Services

Peer Support refers to the provision of services by self identified mental health consumers to others with mental illness. Peer Support can refer to the services from a very informal support group, to a peer advocate working in a CSB, to an employee of an established consumer-operated program (like the Laurie Mitchell Employment Center in Virginia), or to a trained peer specialist working in a crisis stabilization program, just to give a few examples. The Commonwealth's DMHMRSAS' Vision for a System of Services clearly states at the very beginning that “our vision is of a consumer-driven system of services and supports that promotes self-determination, empowerment, and recovery...”

The vision of DMHMRSAS and others is for a consumer-driven system and the current DMHMRSAS State Plan does specifically provide that peer support services and supports are needed to implement recovery principles. Furthermore, one of its goals is “to promote and support the implementation of mental health programs that foster empowerment, peer support, and recovery-based services. However, defining and establishing such a system is not yet reality in Virginia. Much of the mental system is crafted to respond to emergencies, omitting opportunities to be proactive in supporting preventive and recovery-focused services. The remainder of this section will describe the importance of peer support providers in the mental health system and an in-depth treatment of the trained peer specialist.

Peer Support Providers

Peers bring a unique set of skills and assets to their work that can benefit any organization offering mental health services. They work from the perspective of a lived experience that cannot be replicated through education or conveyed through training. This kind of support tends to be more practical, based in personal experience and rooted in a relationship with the consumer that is part helper and that incorporates friendship and encouragement.⁵⁹ “Peer providers can offer hope and reassurance, provide an alternative interpretation of clients’ experiences and convey that they understand what may seem inexplicable to most non-consumers. Peer Support activities often focus on personal responsibility, regaining control over one's life, self-determination, natural supports, and possibilities. In contrast, most traditional clinical relationships are seen as an interaction between a “knowledgeable expert” and a “subordinate client” and focus on such elements as communication and listening skills, confrontation, goal-directed problem solving and

⁵⁹ Solomon, M. L., Cook, J. A., Jonikas, J. A., & Kerouac, J., *Positive Partnerships: How Consumers and Nonconsumers Can Work Together as Service Providers*, (Chicago, IL: Thresholds National Research and Training Center, 1994).

behavior change.”⁶⁰

Stigma still exists among providers and mental health consumers, even in CSBs where there have been peer providers for years. Stigma takes the form of outdated and inaccurate beliefs concerning the debilitating effects of mental illness. Maybe even more stigmatizing are the widely held stereotyped beliefs that consumers have regarding themselves, which are a reflection of having internalized the mental health system’s supposition that certain kinds of jobs are only meant for certain kinds of consumers. It is not unusual to hear consumers refer to themselves as “high functioning” or “low functioning,” when it comes to describing their own potential to live in the community, participate in training or to work.

There is no real estimate of how many peer providers are working in Virginia’s mental health system. To some extent, this is due to the stigma among provider agencies/staff and a general reluctance of mental health consumers to self-identify. However, hundreds of peers are now working openly from the perspective of their lived experience with a psychiatric diagnosis and are being accepted for training as peer specialists based on their self-identification. It can be hoped that, as a result, consumers and others can focus on individual experience and performance rather than labels.

One of the most difficult problems that families, the legal system, and the mental health system encounter is trying to engage those individuals who refuse traditional services, are homeless and quite ill, have been hurt by their experiences with the mental health system or find themselves in the criminal justice system. It has been shown that these individuals are more likely to connect with peer providers than with other staff and also more likely to continue to accept support. To provide not only more ideas about the many important roles that peers providers can serve, but also to document the effectiveness of these services, a brief overview of pertinent research follows.

One eminent researcher, Mark Salzer PhD,⁶¹ has reported that peers have been effective as providers in a number of different types of mental health systems. For example, studies have shown that consumer-delivered case management is as effective as non-consumer-delivered case management, and crisis teams involving consumers are as effective as those with non-consumers. Consumer-provided vocational services added to usual care are associated with, among other things, higher employment. Studies of drop-in centers have shown that they are associated with increased quality of life, enhanced social support and problem solving. Research on mental health self-help groups indicate that they are associated with decreased symptoms, increased coping skills, and increased life satisfaction among long-term members versus short-term members. One unpublished study found decreased rates of hospitalization for participants in one self-help group versus a matched comparison group.

⁶⁰ Ayers, T.D., “Dimensions and Characteristics of Lay Helping,” *American Journal of Orthopsychiatry*, 59(2) (1989): 215-225.

⁶¹Salzer, M., Mental Health Association of Southeastern Pennsylvania Best Practices Team, *Best Practice Guidelines For Consumer-Delivered Services* (Behavioral Health Recovery Management Project, Initiative of Fayette Companies, Peoria, IL and Chestnut Health Systems, 2002).

Research on peer support interventions has also been positive. One study found that case management services plus a peer specialist counselor were associated with enhanced quality of life, fewer major life problems, and greater gains in social support for those receiving such services than for those receiving case management services without a peer. A study of a one-to-one peer support program for persons with co-occurring mental health and substance abuse problems found that program participants had fewer crisis events and hospitalizations, improved social functioning, greater reduction in substance use, and improvements in quality of life compared to a non-matched comparison group. Additional benefits, in terms of enhanced recovery and job skills and reduced hospitalization have also been reported.⁶²

WRAP and Its Place in the Provision of Peer Support Services

WRAP stands for Wellness Recovery Action Plan and can mean a fairly extensive written document created either independently by the mental health consumer, in one of their treatment settings or during a series of WRAP workshops delivered by other trained peers. This plan, the process and the related educational programs were created by Mary Ellen Copeland, a mental health consumer, and nationally recognized author and recovery educator.⁶³

The purpose of WRAP is to create a process and plan focusing on one's wellness and not one's illness or disability. By working on an individualized WRAP, one can identify activities that help the person stay well despite having symptoms, and can also help the person recognize when a crisis may occur and to plan ahead, noting preferences and what has worked and what has not in previous crises. The WRAP document can include extensive information in its main sections which include: a Wellness Toolbox, Daily Maintenance Plan, Triggers, Early Warning Signs, When Things are Breaking Down, Crisis Plan, and Post-Crisis Plan and is often kept in a three-ring-binder. The process of developing a WRAP is experienced as empowering for mental health consumers. Fostering these efforts seems particularly critical in the case of the crisis section of the WRAP. Consumers, peer providers, and mental health staff working with the individual need to work together to see that this component especially is part of the individual's record and clearly noted.

Since Mary Ellen Copeland first published her guide to developing a WRAP plan in 1997 and then developed a curriculum for training peers to assist others in this process, WRAP has made a tremendous impact on millions of mental health consumers.⁶⁴ The WRAP process not only clearly fosters the core principles of recovery, but also has successfully demonstrated the

⁶²Bloomington, I.L. & Draine, J., "The State Of Knowledge Of The Effectiveness Of Consumer Provided Services," *Psychiatric Rehabilitation Journal*, 25 (2001): 20-27.

⁶³ Copeland, M.E., *Community Links: Pathways to Connection and Recovery Programs Implementation Manual*, (Waterbury, VT: Vermont State Department of Mental Health and Mental Retardation, 2005).

⁶⁴ Copeland, M.E., *Involuntary Commitment & Recovery: An Innovative Mental Health Peer Support Program* (Union Institute & University, January 2006). See www.mentalhealthrecovery.org.

effectiveness of peer support and has spawned many education and training programs throughout the nation to train WRAP facilitators. Employment opportunities for peer providers did emerge as a result of the proliferation of the WRAP programs in training and education efforts about this program.

Since 2003 the REACH (Recovery Education and Creative Healing) peer-run program or the umbrella state-wide consumer-operated VOCAL CO-OP of Virginia has trained 75 WRAP facilitators throughout Virginia who then return to their communities to establish WRAP groups who participate in learning about the WRAP process and developing WRAP plans. DMHMRSAS has funded this program. While a few of the newly trained WRAP facilitators may have already been paid employees providing peer support, many were not, and the emphasis of the training is not necessarily on facilitating future employment. Hundreds of consumers have now participated in WRAP groups. That this statewide effort was able to reach so many consumers suggests that peer specialist training is also likely to succeed despite the fact that it is much more intensive and has more stringent requirements than WRAP training. It should also be noted that every Peer Specialist training curriculum includes an intensive WRAP session, and each Peer Specialist is expected to develop his/her own WRAP plan.

Peer Specialist Training and the Work of Trained Peer Specialists

The Peer Specialist usually refers to someone who is employed and priority for receiving this training is given to those who are already working or have been offered a job and need training or certification. An attempt to compile information on every Certified Peer Specialist training program in the US was made in 2006 by Mark Salzer and colleagues at the University of Pennsylvania Collaborative on Community Integration. Thirteen well-known programs responded with complete descriptions of their training programs.⁶⁵ The training curricula tend to cover similar topics and skills, are generic and not geared to specific jobs. Some of the many jobs that certified peer specialists are currently working may be more helpful. Some reported in these programs include: peer advocates (inpatient settings, hearings, community settings), crisis intervention (crisis stabilization programs and part of response teams), peer support in the area of case management services (housing, disability entitlements), acting as an ombudsmen, mental health technicians, peer support in residential settings, wellness group activities in day treatment programs.

Like many other states, Virginia has been slow to develop a certified Peer Specialist program. Eight years ago, however, a formal education program called the Virginia Human Service Center Consumer Provider Training Program (“VHST”) was established and made possible by the combined efforts of the DMHMRSAS, the Division of Rehabilitative Services (“DRS”), the Virginia Community College System and the Region 10 Community Services Board in Charlottesville. Funding for the program is provided through the DMRMRSAS, DRS and the Federal PELL Grant Program. The program consists of 16 weeks of classroom study including college level courses, an internship and then job placement at a participating Virginia CSB. Graduates are assured employment at the CSB where they have completed their internship. After

⁶⁵ See Certified Peer Specialist Training Program Descriptions, November 2006, www.upennrrtc.org.

nine months of supervised employment, they are eligible as “qualified paraprofessionals” under state Medicaid guidelines. To date, there have been sixty-five graduates. Forty-six of these graduates are still employed in some capacity within the mental health system. A limitation of this program is that it does require the participants to live on campus for 16 weeks.

In 2006, Recovery Innovations of Virginia, Inc. (“RIV”), a non-profit peer run program, which offers Peer Specialists training, started operating in Virginia. RIVA is actually part of the well-known META Peer Employment Training Program of Arizona that first graduated Peer Support Specialists from their training program in 2000. As a result of the availability of this program in Virginia, and support from certain CSBs and DMHMRSAS, Virginia held her first graduation of Peer Support Specialists in February 2007. It is estimated that Recovery Innovations trained 38 Peer Support Specialists in Virginia during 2006.

Despite evidence of many meetings, committees, discussions, and even a statewide conference in February of 2006 on Peer Support and Peer Specialist Training, DMHMRSAS approval and commitment of resources to a specific Peer Specialist Training Program only took place very recently in August 2007. A contract was awarded to the Institute for Recovery and Community Integration, a project of the Southeastern Mental Health Association of Pennsylvania. This 75 hour program implemented during two consecutive weeks will be offered to a total of 60 peers over three trainings the first in December 2007 and the last during this cycle in April 2008. Priority as usual will be given to those applicants who have not received any prior Peer Specialist training through another program, are currently working in positions needing this training or have been promised a position in a mental health agency or consumer-run program. The ESD Task Force sees this as a start toward what needs to be an established, ongoing, and permanent program to increase opportunities for mental health consumers to work in the mental health field, both as employees of the system in many varied roles and also within consumer-operated programs.

Availability of Medicaid funding for peer support services is also a critical factor. Through collaboration by their Medicaid agencies and Mental Health Departments, six states (Georgia, Iowa, Arizona, Michigan, Washington, and South Carolina) have been able to establish peer support as a component of a comprehensive mental health and substance use service delivery system. Establishing a new service within Medicaid for Virginia is indeed complex given the many criteria and requirements, which must be specified for each service. So far, Virginia has used existing service codes for consumers working in different settings as Peer Support providers (even those few had been certified through another State's program). For example, when peers also were qualified mental health practitioners (“QMHP”) providing peer support in a crisis stabilization program, there was no problem with their units of service being Medicaid billable when all other criteria were met. Meanwhile, other consumers certified as Peer Specialists who are not QMHPs have had a harder time. The direction of the DMHMRSAS and DMAS has been to qualify Peer Support Providers as para-professionals under current SPO regulations in a few programs.

On August 15, 2007 The Department of Health and Human Services, Centers for Medicare & Medicaid Services (“CMS”) sent a long-awaited for letter to every State Medicaid Director that not only gives the go ahead for State Mental Health Departments and the State Medicaid Agency

to offer peer support as a distinct billable service, but also recognizes that they are delivered by a qualified Peer Support Provider. Under the terms of the CMS guidance, each state can define its own training and certification program.⁶⁶

Despite this clear endorsement from CMS and State Operations, at this time there seems to be more than just an understandable wariness in moving forward within DMHMRSAS and DMAS to establish a distinct peer support Medicaid billable service. It is noteworthy, though, that the training efforts are being implemented by DMHMRSAS.

Although being able to recover Medicaid funds for clearly defined support services delivered by qualified Peer Specialists is important, Peer Specialists are needed in roles beyond the restrictions and boundaries of Medicaid. Peer Specialists could make a significant difference in facilitating more positive outcomes for individuals involved in the civil commitment process. As suggested in the Commissions Report on Civil Commitment Practices, April 2007, most consumers interviewed indicated that they did not understand civil commitment and said that it was difficult to contact an advocate. In an extensive treatment of this subject, Copeland (2006) describes not only how integral peer support is for systems to truly be transformed into ones supporting recovery but also that peer support needs to be a service component especially when mental health consumers are under involuntary commitment orders.⁶⁷ An excellent resource and manual for implementing such a peer support program called Community Links can be obtained from the Vermont State Department of Mental Health and Mental Retardation.⁶⁸

⁶⁶ CMS, on August 15, 2007, sent a policy letter (#07-011) to state Medicaid directors affirming that states may cover peer support providers as a distinct provider type for the delivery of counseling and other support services to Medicaid-eligible adults with mental illnesses and/or substance use disorders.

CMS describes peer support services as an evidence-based mental health model of care, which consists of a qualified peer support provider who assists individuals with their recovery from mental illness and substance use disorders. Peer support providers, as consumers of services, can be an important component in a state's delivery of effective treatment. Accordingly, states have the option to offer peer support services as a component of mental health and substance use service delivery systems and may cover these services through the rehabilitation services category of Medicaid, as part of a home- and community-based waiver (1915(c) or through the 1915(b) waiver authority (relating to managed care).

Peer support services must be provided in accordance with an approved plan of care and reimbursed based on a unit of service. States must provide assurance that they have mechanisms to prevent over-billing, such as prior authorization and other utilization-management methods, and must describe those mechanisms.

⁶⁷ Copeland, M.E., *Involuntary Commitment & Recovery: An Innovative Mental Health Peer Support Program* (Union Institute University, January 2006). See www.mentalhealthrecovery.org.

⁶⁸ Copeland, M.E., *Community Links: Pathways to Connection and Recovery Programs Implementation Manual*, (Waterbury, VT: Vermont State Department of Mental Health and Mental Retardation, 2005).

The focus of the ESD Task Force was on peer support services being provided by Peer Specialists. It seems clear because of the recent developments related to this particular peer support provider that we did take this opportunity to gather information and present our Recommendations. It was beyond the scope of the ESD Task Force to present the much-needed support for the expansion and development of many of the other ways that peer support services can be provided in Virginia, especially peer-run or consumer-operated programs and services.

An excellent document, which provides a good overview of how Virginia can make a serious effort to move forward in supporting peer, led programs and provides information on their effectiveness can be found at www.vocalsupportcenter.org.⁶⁹

⁶⁹ The Virginia Organization of Consumers Asserting Leadership (VOCAL) is a nonprofit organization dedicated to mental health recovery, empowerment and peer leadership. See VOCAL's Recovery Services Funding Application, May 2006.

APPENDICES

PAGE INTENTIONALLY LEFT BLANK

IV. LEGAL DATA

A) Is individual serving a sentence?: Y N Explain, if known: _____
B) NGRI Conditional Release?: Y N C) On Probation/Parole?: Y N Contact: _____
D) Pending Legal Charges?: Y N If known: Nature of charges: _____
Date of hearing: _____ Court of Jurisdiction: _____

V. MEDICAL : Primary Care Provider: _____ Phone () _____

Medical History & Current Medical Problems/Symptoms: _____

Medication: Current prescribed psychotropic and other medications (include dosage, schedule, etc. if known)

<u>Name</u>	<u>Dose</u>	<u>Schedule</u>	<u>Name</u>	<u>Dose</u>	<u>Schedule</u>
1. _____			7. _____		
2. _____			8. _____		
3. _____			9. _____		
4. _____			10. _____		
5. _____			11. _____ Please see attached medication list		
6. _____			12. _____ Please see attached medical addendum		

Has individual followed recommended medication and recovery plans? Y N NA If no, please explain: _____

Recent medication changes: Y N ? (If yes, explain) _____

Allergies (including food) or adverse side effects to medications: Y N ? (If yes, explain : _____)

VI. MENTAL HEALTH TREATMENT HISTORY (Attach psychiatric advance directive if available): If individual has had

inpatient hospitalization(s): 1)a. Approx. number of hospitalizations: _____ 1)b. State facility?: Y N
2)a. Discharge date of last hospitalization: _____ 2) b. From where?: _____

Comments (optional): _____

3) Is individual currently enrolled in **outpatient services**? Y N UNK Primary Care Coordinator: _____

Comments (optional): _____

VII. SUBSTANCE ABUSE ASSESSMENT And TREATMENT HISTORY (Check if no current use _____)

Please list:	Drug of Choice	Age of First Use	Frequency past 30 days	Method	Date of last use
Primary:	_____	_____	_____	_____	_____
Secondary:	_____	_____	_____	_____	_____
Tertiary:	_____	_____	_____	_____	_____

BAC: _____ **Lab Results:** _____ **Unable to Test:** _____

Please check if **HISTORY** of: Tremors ___ Seizures ___ DTs ___ Vomiting ___ Blood present? Y N Diarrhea ___ Blood present? Y N

Please check if occurred in

PAST 24 HOURS : Tremors ___ Seizures ___ DTs ___ Vomiting ___ Blood present? Y N Diarrhea ___ Blood present? Y N

If individual has received inpatient detox services: 1) Number of times in detox? _____

2) a. Discharge date of last detox service: _____

2) b. From where?: _____

3) Is individual currently enrolled in SA **outpatient or residential services**? Y N UNKNOWN

Primary Care Coordinator: _____

Name: _____

VIII. PRESENTING CRISIS SITUATION (Include information such as precipitating events, stressors, strengths, alternative decision makers, accessibility of support network): _____

IX. MENTAL STATUS EXAM (Check all that apply and add specific behaviors under findings)

Appearance: WNL unkempt poor hygiene bizarre tense rigid

Behavior/Motor Disturbance: WNL agitation guarded tremor manic impulse control psychomotor retardation

Orientation: WNL **disoriented:** time place person situation

Speech: WNL pressured slowed soft/loud impoverished slurred other

Mood: WNL depressed angry/hostile euphoric anxious anhedonic withdrawn

Range of Affect: WNL constricted flat labile inappropriate

Thought Content: WNL delusions grandiose ideas of reference paranoid obsessions phobias

Thought Process: WNL loose associations flight of ideas circumstantial blocking tangential perseverative

Perception/Sensorium: WNL **hallucinations:** auditory visual olfactory tactile illusions

Memory: WNL **impaired:** recent remote immediate

Able to provide historical information: Y N If no, explain below in findings.

Appetite: WNL poor **Weight:** loss gain **Appetite:** increased decreased

Sleep: WNL hypersomnia onset problem maintenance problem

Insight: WNL blaming little none

Judgment: Good impaired poor

Name: _____

Estimated Intellectual Functioning: above average average below average diagnosed MR

Reliability of client report (explain below): good fair poor

Explain clinically significant findings, including areas unable to assess:

X. RISK ASSESSMENT

_____ **No evidence of suicidal ideation**

_____ **No evidence of homicidal ideation**

Suicide Risk: Hx of Current ___ Ideation ___ Intent ___ Vague ___ Defined ___ Means ___ Active ___ Substance
 ___ Attempts ___ Attempt

Homicide Risk: Hx of Assault or ___ Ideation ___ Intent ___ Vague ___ Defined ___ Means ___ Active ___ Substance
 ___ Assault ___ Attempt

Explain above: _____

XI. DIAGNOSIS: DSM IV (P=Provisional, H=Historical)

Axis I: _____ **Axis I:** _____ **Axis I:** _____

Axis II: _____ **Axis II:** _____

Axis III: _____

Axis IV: Psychosocial and Environmental (Circle): **Support Group** **Social/Environmental** **Educational** **Occupational**
Housing **Economic** **Health Care** **Legal System/Crime** **Other:** _____

Axis V: GAF Current: _____ **Highest past year, if known:** _____

Name: _____

XII. INDIVIDUAL SERVICE PLANNING

Individuals who can assist in treatment planning (i.e., family, peer specialist, discharge planner, therapist, etc.)

Name	Phone No.	Relationship to Person
1. _____		
2. _____		
3. _____		

Treatment goals: Please explain **BOTH** the **provider** goals and the **individual's** goals:

Services to be considered:

- | | | |
|--|---|--|
| <input type="checkbox"/> wellness recovery planning | <input type="checkbox"/> long term behavioral interventions | |
| <input type="checkbox"/> medication education | <input type="checkbox"/> substance abuse services | <input type="checkbox"/> housing /residential services |
| <input type="checkbox"/> case management | <input type="checkbox"/> financial support/entitlement | <input type="checkbox"/> medical/dental/nutritional services |
| <input type="checkbox"/> outpatient (ind., fam., group) | <input type="checkbox"/> adult or child protective services | <input type="checkbox"/> legal assistance/advocacy |
| <input type="checkbox"/> psychosocial/day treatment | <input type="checkbox"/> transportation | <input type="checkbox"/> nursing home care |
| <input type="checkbox"/> employment services | <input type="checkbox"/> PACT/ICT | <input type="checkbox"/> peer support services |
| <input type="checkbox"/> co-occurring disorders services | | |
| <input type="checkbox"/> Other: _____ | | |

XIII. LEGAL FINDINGS (Circle)

6. **Is / is not** mentally ill and/or abusing substances.
7. **Is / is not** an imminent danger to self or others.
8. **Is / is not** able to care for self.
9. **Is / is not** capable of consenting to voluntary treatment/hospitalization.
Is / is not able to maintain and communicate choice.
Is / is not able to understand relevant information.
Is / is not able to understand consequences.
10. **Is / is not** willing to be treated voluntarily.

TREATMENT AND SUPPORT OPTIONS

Name: _____

Disposition recommended below indicates the least restrictive alternative to serve this individual.

XIV. DISPOSITION RECOMMENDATION (Check appropriate PreDetention box if evaluation is conducted prior to the issuance of a T.D.O. Check appropriate PreHearing box if evaluation is conducted after the issuance of a T.D.O. but prior to the commitment hearing.)		
PreDetention		PreHearing
	Individual does not meet criteria for hospitalization and/or commitment and should be encouraged to participate in community-based services.	
Not Applicable	Involuntary commitment to outpatient services because individual meets criteria for involuntary commitment, community alternatives are available for involuntary commitment, and individual is incapable or unwilling to consent to voluntary treatment.	
	Voluntary admission and treatment because individual does not meet criteria for involuntary commitment, has the capacity to consent to voluntary treatment, requires treatment and has requested said treatment.	
Not Applicable	Voluntary admission and treatment because the individual requires treatment, has the capacity to consent to treatment, and if, in the presence of the special justice and under court order, the individual agrees to a voluntary period of treatment up to 72 hours and to give 48 hours notice to leave in lieu of involuntary commitment for up to 180 days.	
	Involuntary hospitalization because individual meets criteria for involuntary hospitalization and is incapable of consenting to voluntary treatment.	
	Involuntary hospitalization because individual meets criteria for involuntary hospitalization, is capable of consenting to voluntary treatment, but is unwilling to be treated voluntarily.	

XV. FINDINGS OF HEARING EVALUATOR (To be completed if *PreHearing Disposition Recommendation* differs from *PreDetention Disposition Recommendation*.):

Signature of Prescriber

Prescreening Agency/Board

Print Name Here

Date

Signature of Hearing Evaluator

Date

Print Name Here

Date

Name: _____

PAGE INTENTIONALLY LEFT BLANK

APPENDIX B

Recommendations if an “Opt-Out” Default Rule for Advance Directives Is Adopted

In the ESD Task Force’s August 2007 report to the Commission, we recommended that Virginia adopt an “opt-in” default rule. This rule would allow an individual to revoke an advance directive at any time unless he had taken affirmative steps to render the advance directive irrevocable during future periods of decisional incapacity. We noted that our recommendations were interdependent and predicated in part on the understanding that an “opt-in” default rule would be adopted.

At the August meeting of the Commission, the Commission Chair asked us to report how our recommendations would change if an “opt out” default rule were selected. This rule would render an advance directive irrevocable whenever the individual who made it lacked decisional capacity, unless he had previously taken affirmative steps to retain his right to revoke it at any time.

In selecting a default rule the Commission will balance the value of producing the outcome most people would have intended had they addressed the question explicitly, against the harm that this outcome might impose on those who would have made the other choice.

In the present case, we do not know what ratio of Virginia consumers would want to be able to revoke a non-end-of-life advance directive at any time versus those who would want their advance directives to be irrevocable when they are in crisis. One possible indication of this ratio might be a 2005 study on psychiatric advance directives (“PAD”) study in which a little more than half (57%) of the subjects wanted their PADs to be irrevocable during periods of incapacity.⁷⁰

To the extent that the PAD study may be useful as guidance, any default rule the Commission chooses may be expected to incorrectly predict individual preferences at least 43% of the time. This poor expected performance calls attention to the importance of developing strategies to keep application of the default rule to a minimum, no matter which rule is selected.

The balance of harms is decidedly clearer. If an “opt-in” rule were adopted, some individuals who had intended to have irrevocable non-end-of-life advance directives will end up revoking their non-end-of-life advance directives during crises. This will leave them in the situation they occupy under current law, so it will not prevent them from getting treatment. Depending on the circumstances and inclinations of the professionals and authorized representative involved, the revoked non-end-of-life advance directive may have more or less effect on the treatment the individual receives.

By comparison, the “opt-out” rule is much more threatening to people with mental illness. By automatically making advance directives irrevocable during incapacity, that rule has the propensity to “trap” individuals who erroneously believed they would be able to revoke their advance directives at any time. Whether this occurs because of ignorance, mistake, neglect, or

⁷⁰ D. Srebnik, L. Rutherford, T. Peto, J. Russo, E. Zick, C. Jaffee, P. Holtzheimer, “The Content and Clinical Utility of Psychiatric Advance Directives, *Psychiatric Services*,” 56 (2005): 592-598. *Attached, see Appendix C.*

even the fraud of another, the unintended result is likely to be terrifying. It would not take many such “horror” stories to significantly chill the use of non-end-of-life advance directives.

No matter which default rule is selected, avoiding its application as much as possible is clearly the best strategy. The risks of mistakes and fraud can be contained to varying degrees by strategies such as provision of advance directive facilitation services⁷¹, publication of explanatory non-end-of-life advance directive forms, and the imposition of procedural safeguards such as required forms and explanation requirements. Restricting advance authorizations of the most invasive interventions could also reduce the severity of the potential impact on a “trapped” individual.

However, all of these measures have disadvantages. For example, expense will be a factor in provision of facilitation services, as will difficulties ensuring that they are accessible to the people who need them. Similarly, simple, explanatory, and “user-friendly” non-end-of-life advance directive forms could confront the revocability question directly and explain the default rule. But this will require some balancing between full disclosure and the need to avoid making the form too long, complex, and intimidating to people with mental illness.⁷² In addition, there is probably no practical way to ensure that everyone who makes a non-end-of-life advance directive will use a particular form.

Procedural safeguards such as special explanation rules for individuals in vulnerable circumstances or required use of a particular form could also be employed, but these devices inevitably complicate the process and create “validity traps. These traps may be expected to discourage some people from making a non-end-of-life advance directive altogether, while leaving others with legally invalid but otherwise appropriate non-end-of-life advance directives. If the existence of these traps causes consumers to view non-end-of-life advance directives as unreliable or unpredictable, the documents may not be widely used.

Similarly, restrictions on advance authorizations of the more invasive interventions (hospitalization, ECT, psychosurgery, etc.) can insulate trapped individuals from the most draconian violations of their persons. However, restricting these would also reduce the choices and flexibility that would otherwise be available to individuals who want and need those interventions.

In the end, we believe an opt-out rule would tend to undermine confidence in non-end-of-life advance directives, and decrease both the usefulness and the utilization of the documents. However, if an opt-out rule were adopted, we would recommend the following options as strategies to control the risks:

⁷¹See Recommendation II.2, *infra*.

⁷²Difficulty understanding advance directives and the complexity of advance directive forms and procedures are commonly reported as barriers that impede the more widespread use of the documents by people with mental illness. See e.g. J. Swanson, PhD, M. Swartz, MD, J. Ferron, MSW, E. Elbogen, PhD, R. Van Dorn, PhD., “Psychiatric Advance Directives Among Public Mental Health Consumers in Five U.S. Cities: Prevalence, Demand, and Correlates,” *Journal of the American Academy of Psychiatry and the Law* 34 (1)(2006):43-57.

Provisional Recommendations/Under an Opt-Out Rule:

- 1. In our Recommendation II.1 we recommended that a form for an advance directive relating to care other than care at the end of life be published in the Virginia Code. This form should clearly, concisely, and prominently explain the default rule and set out the individual's options.**
- 2. The revocability question should be addressed directly with individual consumers through the provision of advance directive facilitation services (See Recommendation II.2).**
- 3. The General Assembly should enact the following explanatory requirement to help ensure that persons who are inpatients or live in residential care settings at the time they make a non-end-of-life advance directive understand that their advance directives will not be revocable at all times unless they take affirmative steps to make them so:**

An advance directive for non-end of life health care shall not be effective if, at the time of execution, the principal is being admitted to or is a resident of an inpatient mental health facility or a nursing home, mental health facility, mental retardation training center, group home, ICF-MR or other residential care facility unless an employee of the Office of Human Rights or the Virginia Office for Protection & Advocacy, or a long term care ombudsman or an attorney licensed to practice in this state signs a statement affirming that he or she explained the nature and effect of the advance directive to the principal. It is the intent of this subsection to ensure that advance directives executed by residents of inpatient mental health facilities and all types of residential care facilities reflect the true wishes of the residents and are executed willingly and voluntarily.
(Adapted from Vermont Statutes).

- 4. To reduce the potential impact of a mistake or fraud in the making of an advance directive, the General Assembly could enact legislation restricting or curtailing individuals' ability to employ an advance directive to authorize or direct the most drastic impositions on their liberty and bodily integrity interests.**

A review of state laws indicates that interventions along the lines of advance consent to hospitalization in a psychiatric facility or ward, electro-convulsive therapy, psychosurgery, abortion and sterilization are commonly affected by this type of safeguard.

PAGE INTENTIONALLY LEFT BLANK

APPENDIX C

Illustrative Family/Close Associate Education Programs

NAMI Family-to-Family: The NAMI Family-to-Family Education Program is a 12-week course for family caregivers of individuals with severe mental illnesses. Over 115,000 family members have graduated from the national program. The course is taught by trained family members and includes:

- Information on the major mental illnesses and addictive disorders.
- Information about medications, side effects and strategies for medication adherence
- Current research related to the biology of brain disorders and evidence based treatments.
- Gaining empathy by understanding the subjective, lived experience of a person with MI
- Learning in special workshops for problem solving, listening and communications techniques
- Acquiring strategies for handling crises and relapse
- Focusing on the care of the caregiver, coping with worry, stress and emotional overload
- Guidance on locating appropriate supports and services within the community.

MESA (Mutual Education Support and Advocacy): MESA Family Workshops is a series of classes designed to provide education on mental illness and to promote stress reduction for parents, siblings, spouses, and other relatives and friends as they support their loved one who has a severe psychiatric disorder. A family member and a mental health professional serve as co-leaders. Groups are limited to 10 participants.

NAMI Support Group: The NAMI Support Group model (formerly called the "Family-to-Family Support Group model") operates differently than other, more traditional "share-and-care" groups. The NAMI Support Group model offers a set of key structures and group processes for facilitators to use in common support group scenarios. These structures come with clear guidelines to follow; used together, they encourage full group participation in support group meetings. The structures of the new model feel comfortable for both seasoned and less-experienced facilitators because they guide the support group along in every situation.

NAMI Provider Education: The NAMI Provider Education Program is a 10-week course that presents a penetrating, subjective view of family and consumer experiences with serious mental illness to line staff at public agencies that work directly with people with severe and persistent mental illnesses. The course helps providers realize the hardships that families and consumers face and appreciate the courage and persistence it takes to live with and recover from mental illness.

NAMI In Our Own Voice: Living With Mental Illness: In Our Own Voice ("IOOV") is a unique, informational outreach program, presented by people with mental illness, which offers insight into the recovery now possible for people with severe mental illness. In Our Own Voice shows how people with serious mental illnesses cope with their disorders while recovering and

reclaiming productive lives with meaning and dignity. Additionally, the program provides a safe way for consumers to share the ups and downs of their recovery and learn from others.

NAMI Texas - Visions for Tomorrow: *Visions for Tomorrow* is a curriculum that addresses the needs of younger families who have a child or adolescent with a mental illness. Taught by primary caregivers, *VFT* classes offer families a safe and supportive place to share experiences and learn from other adults who care for children with mental illness. Primary caregivers include not only parents, but also grandparents, aunts, uncles, respite care providers and foster parents, as well. By providing education, empathy and empowerment, families will now have the tools to build visions for their families tomorrow.

FACES (Family Advocacy Creating Education and Services) Programs: This is a new organization – the only group in mental health community located in the greater Richmond area whose sole purpose is assisting families of people with brain disorders. They offer support groups for family members for the purpose of giving hope back to families who have lost hope. They are about to start two new programs:

- A six-week course using a complete curriculum given to them by an expert in Colorado. They hope to start their first session, to include 12-15 people, by the end of March.
- A three-week Communications Workshop, aimed at helping family members learn how to communicate effectively with their loved ones who are ill, with other family members, with police officers, care providers, etc. They hope to run this workshop, with day and evening sessions, on a continuous basis.

Mental Health Awareness and Recovery Seminars

- Grundy, VA. Cumberland Mountain CSB. Some 200 people in attendance. Musical entertainment, recovery stories, and buffet dinner. Good response from the community.
- Seminar held at Southwest Va. Community College in Cedar Bluff, VA with some 150 in attendance.
- Future Seminars: New River Valley-CSB, Dickenson County CSB, Highlands CSB, Mt. Rogers CSB.

APPENDIX D

ACRONYMS

ACT	Assertive Community Treatment
BHA	Behavioral Health Authority
CCJB	Community Criminal Justice Board
CSA	Comprehensive Services Act
CSBs	Community Service Board
CIT	Crisis Intervention Teams
CLE	Continuing Legal Education
CRP	Community Resource Pharmacy
DCJS	Department of Criminal Justice Services
DOC	Department of Corrections
DMAS	Department of Medical Assistance Services
DMHMRSAS	Department of Mental Health, Mental Retardation, and Substance Abuse Services
ECO	Emergency Custody Order
FPS	Forensic Peer
FERPA	Family Educational Rights and Privacy Act
HIPAA	Health Insurance Portability and Accountability Act
IE	Independent Examiner
ICAAC	The Interagency Civil Admissions Advisory Council
JIRC	Judicial Inquiry Review Commission
JLARC	Joint Legislative Audit and Review Commission
MCES	Montgomery County Emergency Services
MCT	Mobile Crisis Team
MOT	Mandatory Outpatient Treatment
NAMI	National Alliance on Mental Illness
NGRIS	Not Guilty by Reason of Insanity
NIMH	National Institute of Mental Health
OIG	Office of the Attorney General
ORTS	Offender Re-entry and Transition Services
PACT	Program of Assertive Community Treatment
PMI	Person with Mental Illness
SAMHSA	Substance Abuse and Mental Health Services Administration
SED	Serious Emotional Disturbance
SIM	Sequential Intercept Model
SSI	Supplemental Security Income
SSDI	Social Security Disability Insurance
SMI	Severe Mental Illness
TDO	Temporary Detention Order
VACSB	Virginia Association of Community Service Boards
VOCAL	Virginia Organization of Consumers Asserting Leadership
WRAP	Wellness Recovery Action Plans

PAGE INTENTIONALLY LEFT BLANK

APPENDIX E

EMPOWERMENT AND SELF DETERMINATION TASK FORCE RECOMMENDATIONS

CHAPTER I. EMPHASIZING INDIVIDUAL CHOICE

Recommendation I.1. Various sections of Title 37.2 of the Code of Virginia and the Rules and Regulations to Assure the Rights of Individuals Receiving Services from Providers Licensed, Funded or Operated by the Department of Mental Health, Mental Retardations and Substance Abuse Services, 12 VAC 35-115 et seq. (“Human Rights Regulations”), should be re-worded to emphasize individual choice and decrease stigmatization.

Recommendation I.2. Assurance of the rights of the individual involved in the commitment process should be guaranteed through vigorous advocacy of the person’s wishes, conscientious and ongoing notification of their rights throughout the process, and thorough presentation of evidence and argument before the special justice.

Recommendation I.3. Family and close associates whom the individual wants to be present should be notified of the hearing, and opportunities for their participation should be arranged.

Recommendation I.4. Attorneys appointed to represent individuals in civil commitment proceedings should first complete a certification process similar to that enacted for *guardian ad litem* attorneys. The Office of the Executive Secretary should develop this certification process.

Recommendation I.5. Certification of emergency services clinicians as Preadmission Screening Evaluators should be awarded based upon a written examination covering essential knowledge, skills and abilities. Regular and documented completion of continuing education and training should also be implemented.

Recommendation I.6. The Uniform Preadmission Screening Form (“UPSF”) should be revised to emphasize the individual’s involvement in treatment planning and his or her personal preferences and to avoid stigmatization.

Recommendation I.7. The rights of the individual involved in the commitment process should be assured through vigorous advocacy of the person’s wishes, conscientious and ongoing notification of their rights throughout the process, and thorough presentation of evidence and argument before the special justice.

Recommendation I.8. Individuals involved in the civil commitment process should have the right to have family and close associates notified of the hearing and have their participation in the process either in person or by other means.

Recommendation I.9. Certification of emergency services clinicians, as Preadmission Screening Evaluators should be awarded based on a written examination covering essential knowledge, skills and abilities. Regular and documented completion of continuing education and training should also be implemented.

CHAPTER II. ADVANCE DIRECTIVES

Recommendation II.1. The General Assembly should amend the Health Care Decisions Act to authorize and govern the use of instructional directives in connection with all health care decisions to supplement the current provisions that pertain only to end-of-life care. This recommendation has 5 parts.

Recommendation II.1 (A). There should *not* be a separate statute for a *psychiatric* advance directive.

Recommendation II.1 (B). The General Assembly should amend the Code of Virginia to add a “stand-alone” (agent optional) instructional advance directive for all types of health care to supplement the existing provisions of the Virginia Health Care Decisions Act governing care at the end of life. This is to supplement, and not to replace, living wills and health care powers of attorney already permitted under Virginia law.

Recommendation II.1(C). Any legally competent person who has capacity should be able to make a non-end-of-life advance directive at any time.

Recommendation II.1(D). An individual should be able to revoke all or portions of his advance directive at any time, unless he has clearly expressed in that directive his or her intention that he not be able to do so at times when he is determined to lack capacity.

Recommendation II.1(E). The legislation governing advance directives outside the context of end-of-life care should include an “override” section to address the particular circumstances under which advance directives of this kind should not be binding.

Recommendation II.2. Virginia Code 37.2-1101, Judicial Authorization of Treatment should be amended to replace the “best interests” standard with the “substituted judgment/best interests” standard used elsewhere in the Code.

Recommendation II.3. The Secretary of Health and Human Resources should establish an effective program for informing stakeholders about advance directives for health care, including peer-provided advance directive facilitation services for individuals with mental illness who wish to complete the documents. The programs should regularly offer and provide free facilitation services to, at a minimum, all public sector consumers of mental health services who are willing and able to make an advance directive.

Recommendation II.4. The Commonwealth should create or support a single, secure electronic repository for advance directives. This would enable health care providers to identify quickly patients with advance directives and to access these documents in an emergency. Individuals would be able to choose whether to have their advance directives stored in the repository.

CHAPTER III. INCENTIVES.

No Recommendations.

CHAPTER IV. FAMILY/CLOSE ASSOCIATE INVOLVEMENT

Recommendation IV.1. All public and private facilities and providers should facilitate opportunities for families and other close associates to be involved in the treatment of an individual with mental illness to the maximum extent desired by that individual. These opportunities should include education, training and support groups.

Recommendation IV.2. The DMHMRSAS should establish policies requiring the education of staff on the benefits and appropriate procedures for having discussion with consumers about the benefits of supports of others and offer them an opportunity to identify which individual(s) they give permission to be informed and involved regarding their treatment.

CHAPTER V. PEER SUPPORT.

Recommendation V.1. DMAS and DMHMRSAS should review the recent ruling by the Center for Medicare and Medicaid Services allowing services provided by qualified peer support providers to be billed as a distinct service and should prescribe the necessary criteria for billing peer support as a stand-alone service.

Recommendation V.2. DMHMRSAS should encourage and provide financial support for widespread use of peer support services throughout the mental health system, should obtain specific data on peer specialists and other peer providers and the peer support services they provide, and should establish a peer specialist training program in Virginia, with clear qualification guidelines for enrollment. The General Assembly should provide sufficient funding for such training to assure that the Commonwealth has an adequate workforce of peer support providers.

Recommendation V.3. Peer support specialists should be available to serve as advocates for respondents during the commitment process upon request.