

02-7160

**IN THE UNITED STATES COURT OF APPEALS
FOR THE SECOND CIRCUIT**

**NANCY HARGRAVE on behalf of herself and all others similarly situated
and the VERMONT PROTECTION AND ADVOCACY, INC.,**

Appellees,

v.

STATE OF VERMONT *et al.*,

Appellants.

**On Appeal from the United States District Court
for the District of Vermont**

**BRIEF OF 18 FORMER STATE MENTAL HEALTH COMMISSIONERS,
THE NATIONAL MENTAL HEALTH ASSOCIATION, AND OTHERS
AS *AMICI CURIAE* IN SUPPORT OF THE APPELLEES**

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CORPORATE DISCLOSURE STATEMENT

Pursuant to Federal Rules of Appellate Procedure 26.1 and 29(c), the undersigned hereby represents that none of the *amici* organizations have parent corporations and that no publicly held company owns 10% or more stock in any *amicus*.

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INTEREST OF AMICI¹

This brief is filed on behalf of 18 former state mental health commissioners and others. Each of the former commissioners—Patrick Babcock; Joseph J. Bevilacqua, Ph.D.; James Donald Bray, M.D.; James J. Callahan, Jr., Ph.D.; Robert Constantine; King Davis; Mary Jane England, M.D.; Ivor Groves, Ph.D.; Kenneth Heinlein, Ph.D.; Donald J. Hevey; Pamela S. Hyde, J.D.; Dennis R. Jones, M.S.W., M.B.A.; Danna Mauch; John A. Morris; Frank Ochberg, M.D.; Robert Okin; Michael S. Pedneau; and Thomas D. Romeo—has run a state mental health system, including both public psychiatric hospitals and an array of outpatient services, and, in some cases, more than one. The state systems for which they have been responsible include Florida, Indiana, Massachusetts, Michigan, Missouri, North Carolina, Ohio, Oregon, Rhode Island, South Carolina, Texas, Vermont, Virginia, and Wyoming. Together, the former commissioners have over 75 years of experience operating state mental health systems.

Amici also include the National Mental Health Association (“NMHA”), the nation’s leading membership organization devoted to the proper treatment and care of individuals with mental illness; the Vermont Association for Mental Health, NMHA’s Vermont affiliate; the International Association of Psychosocial

¹ Counsel for the parties have consented to the filing of this brief.

Rehabilitation Services (“IAPSRs”), a coalition of mental health service providers; the New York Association of Psychiatric Rehabilitation Services, IAPSRs’ New York affiliate; the American Network of Community Options and Resources, an association of agencies providing support services to people with disabilities; HalfthePlanet Foundation, which provides products and services to people with disabilities; the American Association of People with Disabilities, a membership organization of people with physical or mental disabilities, their families, and friends; the Polio Society; and the National Health Law Program.

As described in more detail in the Appendix, these individuals and organizations have a strong interest in the proper care of individuals with psychiatric disabilities, and in the right of every individual to inform caregivers of his or her treatment preferences through the execution of an advance directive.

This case raises issues of great importance to the mental health and disability communities in this country. As former state mental health commissioners and mental health organizations, *amici* are uniquely positioned to speak to many of the policy issues presented in this case, including how advance directives can improve the quality of care and enhance treatment outcomes for individuals with a psychiatric disability. And by virtue of their considerable experience with individuals who have psychiatric disabilities, *amici* bring a breadth of understanding about the long-term, adverse implications of coercive medication.

Amici believe that the district court’s decision should be affirmed, and that an individual’s treatment preferences—as expressed in a validly executed advance directive—should be respected in non-emergency situations.

INTRODUCTION

Every year in this country, about one in five adults suffers from mental illness.² Coping with mental illness means confronting a wide range of treatment alternatives. For many with a psychiatric disability, anti-psychotic drugs are an excellent form of treatment. But anti-psychotic drugs do not work for everyone and are capable of producing a wide variety of side effects—whether deadly, debilitating, or merely irritating. Competent persons have a “constitutionally protected liberty interest in refusing unwanted medical treatment.” *Cruzan v. Director, Missouri Dep’t of Health*, 497 U.S. 261, 278 (1990). Where anti-psychotic drugs are administered to a patient who refuses them—a necessarily violent, invasive procedure—the risks attending these forms of treatment is increased, while the likelihood of positive treatment outcomes is diminished.

Every state has enacted some form of health care “advance directive” through which an individual may appoint an agent and specify preferences regarding treatment. Advance directives project an individual’s informed consent

² Surgeon General, *Mental Health: A Report of the Surgeon General* 16 (1999).

from periods of legal competency into periods in which legal competency may be in question.

The State of Vermont provides for the execution of an advance directive, or “Durable Power of Attorney For Healthcare,” Vt. Stat. Ann. tit. 14 §§ 3451–3467. The purpose of the Vermont advance directive law is “to enable adults to retain control over their own medical care during periods of incapacity through the prior designation of an individual to make health care decisions on their behalf.” *Id.* § 3451. The Vermont statute combines features of *instructional advance directives*, in which one sets forth specific treatment desires; and *agent-driven advance directives*, in which one appoints an agent or proxy to act for them during periods of incapacity.³

By executing an advance directive under the Vermont statute, an individual can express specific preferences about where treatment should be provided; who should treat; types of treatment (*e.g.*, electroconvulsive treatment or not); temporary care of children; who should be notified about conditions and treatments; discharge plans; and so on. By appointing an agent, an individual gains assurance that a trusted friend or family member will make appropriate treatment

³ See generally Robert D. Fleischner, *Advance Directives for Mental Health Care: An Analysis of State Statutes*, 4 Psychol. Pub. Pol’y. & L. 788, 791 (1998).

decisions and advocate the individual's interests, unhindered by the acute effects of a mental health crisis or the coercive atmosphere of confinement.

Appellee Nancy Hargrave, an individual diagnosed with the mental illness paranoid schizophrenia, had been involuntarily confined in the Vermont State Hospital on four separate occasions prior to filing suit. During her second confinement, officials of the State of Vermont administered psychiatric medication against her wishes, in a non-emergency situation. Following her third confinement, Ms. Hargrave executed an advance directive as provided by Vermont law. The State does not challenge Ms. Hargrave's competency when she signed her advance directive.⁴ As relevant here, Ms. Hargrave's advance directive stated that "in the event I become unable to make my own health care decisions, . . . [I do not authorize my] agent to consent to the administration of . . . any and all anti-

⁴ Although appellants have not challenged Ms. Hargrave's competency when she executed her advance directive, they generally question the competency of those who execute advance directives, "because they are presumably already mentally disordered at the time of execution." State Br. at 64-65. But there is no such presumption. In fact, as appellants concede, State Br. at 28, the Vermont statute presumes competency, provided two subscribing witnesses "affirm that the principal appeared to be of sound mind and free from duress" upon execution of the document. Vt. Stat. Ann. tit. 14 § 3456. In any event, a recent study found a majority of patients with mental illness competent to make treatment decisions, and concluded that a "blanket denial of the right to consent to or refuse treatment . . . cannot be based on the assumption that [individual's suffering from mental illness] uniformly lack decision-making capacity." Paul S. Appelbaum & Thomas Grisso, *The MacArthur Treatment Competence Study. I: Mental Illness and Competence to Consent to Treatment*, 19 Law & Hum. Behav. 105, 109 (Mar. 1995).

psychotic, neuroleptic, psychotropic or psychoactive medication.” JA 223, 229.

Subsequently, the State of Vermont sought to treat Ms. Hargrave with anti-psychotic medication—a form of treatment she had unambiguously rejected in her advance directive.

There is widespread support among mental health professionals, state officials, advocates, and consumers for the use of advance directives as a mechanism for coping with mental illness. Earlier this year, for instance, the National Mental Health Association declared advance directives “an underutilized tool for empowering individuals [which] offer[s] significant potential for preventing or mitigating crisis situations,” and recommended that states adopt policies to ensure that advance directives will be enforced.⁵

This brief will inform the Court of the benefit of advance directives (1) as an opportunity for patient-caregiver dialogue and a repository for critical information about individuals and their treatment preferences; (2) as a vehicle by which individuals may—when competent—refuse future administration of ineffective and harmful treatments; and (3) as a tool for the empowerment of the individual and the enhancement of the therapeutic alliance between patient and caregiver. It is the strongly held view of *amici* that respect for validly executed advance directives

⁵ News Release, National Mental Health Association, *Advance Directives Help Prevent Psychiatric Crises and Promote Recovery* (March 25, 2002), available at <http://www.nmha.org/position/advancedirectives.cfm>.

promotes long-term patient compliance with an appropriate course of treatment and increases the chances for recovery from mental illness and for reintegration into the community. Coercive treatment, by contrast, sacrifices long-term patient compliance to achieve short-term goals.

ARGUMENT

I. Advance Directives Lead to Favorable Treatment Outcomes Because They Encourage Dialogue and Provide the Caregiver with Information About the Individual

Advance directives encourage dialogue between patients and caregivers, and are a critical source of information about individual histories and treatment preferences. Because they supply caregivers with timely information, which is often not otherwise available, advance directives increase the chance that patients receive effective treatment.

A. Advance Directives Encourage Dialogue Between Patients and Caregivers.

Those who suffer from a psychiatric disability often know best what forms of treatments are likely to be effective. While the average patient with depression sees a doctor perhaps 20 minutes per month,⁶ the same patient may spend days or weeks per month living with the effects of a psychiatric disability, and

⁶ Shankar Vedantum, *Against Depression, a Sugar Pill Is Hard to Beat*, Washington Post, May 7, 2002, at A1.

experiencing the successes and failures of particular treatments. A primary virtue of the advance directive is to encourage patients to initiate a dialogue with their caregivers in which they examine these experiences and jointly consider what treatment strategies might work best.

The most likely outcome of such a dialogue is that the patient and caregiver reach consensus about appropriate forms of treatment. And consensus may be vital to recovery because successful treatment of mental illness often depends upon the patient's acceptance of and involvement in therapy. Compared with physical illnesses, certain features of mental illness make treatment particularly receptive to a patient-centered approach. It is true, as appellants assert, that psychiatric disabilities are often "cyclical." State Br. at 61. As a consequence, however, the *episodic* character of psychiatric disabilities "provide[s] a person with ample experience regarding what to expect and how best to manage the onset of symptoms that can impair decision-making capacity."⁷ Indeed, the best predictor of whether a psychotropic drug will be beneficial often lies in the patient's subjective response to the drug.⁸ Drafting an advance directive encourages

⁷ Jeffrey W. Swanson *et. al.*, *Psychiatric advance directives: An alternative to coercive treatment*, 63 *Psychiatry* 1, 3 (2000).

⁸ Theodore Van Putten & Philip R.A. May, *Subjective Response as a Predictor of Outcome in Pharmacotherapy*, 35 *Archives Gen. Psychiatry* 477 (1978); Theodore Van Putten *et al.*, *Subjective Response to Antipsychotic Drugs*, 38 *Archives Gen. Psychiatry* 187 (1981); Man Mohan Singh, *Dysphoric Response*

individuals to “reflect upon their illness and past treatment, think about early symptoms that may signal a relapse, recall treatments that have worked (or have not worked) in the past, and consider what person they might trust to carry out their wishes for treatment during a crisis.”² And by encouraging dialogue with a caregiver, the advance directive often enhances the quality of treatment strategies.

These beneficial effects of advance directives are thwarted by Vermont’s Act 114, which—to the extent it casts doubt upon the legal enforceability of an advance directive—affects a subset of those within the certified class who were or will be “deterred from executing” an advance directive (Spec. App. 27–28), and potentially deterred from this therapeutic process of dialogue and reflection.

B. Advance Directives are an Important Source of Information About Patients and Their Treatment Preferences.

Once executed, the advance directive can serve as a repository for patient histories and treatment preferences. As such, even doctors unfamiliar with a patient can learn from an advance directive which treatments are most likely to be effective for that patient.

Reactions to mental illness can be idiosyncratic and highly recognizable. Advance directives alert otherwise ill-informed caregivers to characteristic

to Neuroleptic Treatment in Schizophrenia and its Prognostic Significance, 37 *Diseases of the Nervous Sys.* 191 (1976).

symptoms—as well as how best to deal with them. Advance directives may include diagnostic and psychosocial history, concurrent medical issues, results from past medical trials, and may identify former treatment providers. These details can help doctors adjust dosage levels and manage side effects. Advance directives can likewise instruct on the kinds of actions or interventions that make the individual feel more at ease during a crisis situation. For instance, Ms. Hargrave’s advance directive expressed her “desire that people speak calmly to [her], offer [her] the opportunity to go outside, and get freash [sic] air and engage in some form of physical exercise,” and explained that “these are the things I need to do when I am upset in order to feel better.” JA 227.

C. Advance Directives Can Ensure Quick and Appropriate Treatment and May Avert Mental Health Crises.

An example illustrates these beneficial features of advance directives for individuals with psychiatric disabilities. A woman named “Mandy” has suffered for years from bipolar disorder.¹⁰ Mandy recognizes the onset of mania, a recurring manifestation of the disorder. One Friday afternoon, because she feels an adjustment in her medication dosage is necessary to avert an incipient mania,

² Swanson, *supra* note 7, at 5–6.

¹⁰ The example of “Mandy” is taken from Southend Manic Depression Fellowship Self-help Group, *Mandy's advance directive* (April 2001), available at <http://www.mdf.southend.btinternet.co.uk/page13.html>.

Mandy seeks help. Her psychiatrist is unavailable, and Mandy is told by a nurse to return on Monday. Mandy knows that by Monday, however, the mania will cause her to *feel* that she doesn't need help, even though she knows now that she clearly does need help. But Mandy has difficulty explaining this fact about her illness to the nurse, who wrongly believes that because Mandy is saying she needs help now, she could not yet have lost sufficient capacity to *actually* need that help—a common misconception about mental illness.

Mandy is fortunate to have previously executed an advance directive. By reference to her advance directive, she is able to communicate her personal history with mental illness, and in particular to show the nurse that when she has asked for help in the past, she has truly needed help. The advance directive keeps her out of the hospital—a claim made of advance directives generally. Because she is given access to the form of treatment that best suits her, Mandy's chances for a favorable treatment outcome are enhanced. And because she receives treatment *before* her condition further deteriorates, she is more likely to avert a full-blown manic episode.

It can be difficult for caregivers to ascertain information about patients with a psychiatric disability, often because the illness affects the patient's ability to articulate preferences, or causes a temporary departure from preferences he or she has long held. As Mandy's example illustrates, advance directives are often the

clearest expression or best evidence of an individual's actual wishes regarding treatment.¹¹ In sum, advance directives increase the likelihood that patients receive appropriate care.

II. Advance Directives Permit the Avoidance of Drug Treatments That Can Be Harmful and Ineffective

Respect for individual treatment preferences serves the interests of patient health and well-being.¹² The not-uncommon experience of “Jane,” who suffers from schizoaffective disorder, is instructive.¹³

During a recent hospitalization, Jane struggled to explain to her psychiatrist that certain medications, and particularly the anti-psychotic drug Haldol, exacerbated Jane's tardive dyskinesia—a neurological syndrome causing involuntary, rhythmic, and often grotesque movements of the face, lips, tongue,

¹¹ Bruce J. Winick, *Advance Directive Instruments for Those with Mental Illness*, 51 U. Miami L. Rev. 57, 84 (1996).

¹² Act 114 directs the State of Vermont to honor treatment preferences in an advance directive for 45 days, after which time the involuntary treatment of a patient who remains incompetent may be ordered upon a finding of no “significant clinical improvement.” Vt. Stat. Ann. tit. 18 § 7626(c)(1). *Amici* are unaware of any evidence to support the 45-day duration, which, in any event, preempts alternative courses of treatment taking longer than 45 days to produce positive results.

¹³ The example of “Jane” is taken from Ronald S. Honberg (General Counsel, National Alliance for the Mentally Ill), *Advance Directives*, 11 J. NAMI Cal. 63 (2000), available at <http://www.nami.org/legal/advanced.html>.

fingers, hands, legs, and pelvis.¹⁴ Perhaps because he dismissed Jane as incapable of speaking in her own behalf on account of her illness, Jane's psychiatrist prescribed Haldol over her protest. The unwanted treatment and associated loss of control left Jane opting for homelessness over the prospect of another confinement.

Jane's case is like Nancy Hargrave's in at least one respect—both involved the refusal of anti-psychotic drug treatments. Jane's is a cautionary tale, however, because—unlike Ms. Hargrave—Jane had not planned for a future loss of capacity by executing an advance directive, which may have shown Jane's psychiatrist that Haldol was an ineffective and potentially dangerous treatment for her. As we demonstrate below, many anti-psychotic drugs present such dangers.

A. Anti-Psychotic Drugs Can Be Harmful And Ineffective.

Although they are helpful in some cases, there are many practical reasons for wishing to avoid anti-psychotic medications. Indeed, studies indicate that patient drug refusals correlate with the severity of the side effects exhibited by the drug refused.¹⁵ As recognized in the scientific literature¹⁶ and in the courts,¹⁷

¹⁴ Robert M. Levy & Leonard S. Rubenstein, *The Rights of People with Mental Disabilities* 112 (1996).

¹⁵ See Theodore Van Putten *et al.*, *Subjective Response to Antipsychotic Drugs*, 38 *Archives Gen. Psychiatry* 187 (1981).

¹⁶ As discussed in this Part II.B.

psychotropic drugs are capable of producing a wide variety of side effects—some deadly, some debilitating, and some merely irritating. These side effects can occur even when the drugs are prescribed and administered correctly.¹⁸

“Psychotropic drugs intervene in the deepest functions of personhood. They are mind altering.” *Steinkruger v. Miller*, 612 N.W.2d 591, 597 (S.D. 2000) (citation omitted). They affect the patient’s ability to regulate thought, emotion, emotional expression and the patient’s response to external stimuli.¹⁹ The drugs tend to induce psychomotor slowing, emotional quieting, reduction of initiative, and indifference to external stimuli.²⁰ “[T]he psychological syndrome that is induced by these drugs is not usually considered to be particularly pleasant,”²¹ and is seen by many patients as an unnerving assault on their personality.

In addition to these effects, psychotropic drugs can produce certain extrapyramidal, or involuntary-movement disorders: (1) parkinsonian-like

¹⁷ See, e.g., *Riggins v. Nevada*, 504 U.S. 127, 134, 142–44 (1992); *Washington v. Harper*, 494 U.S. 210, 229-30 (1990); *Mills v. Rogers*, 457 U.S. 291, 293 n.1 (1982); *United States v. Weston*, 255 F.3d 873, 877 n.3 (D.C. Cir. 2001); *Kulas v. Valdez*, 159 F.3d 453, 455-56 (9th Cir. 1998), *cert. denied*, 528 U.S. 1167 (2000); *United States v. Brandon*, 158 F.3d 947, 954 (6th Cir. 1998).

¹⁸ Dennis E. Cichon, *The Right to “Just Say No”: A History and Analysis of the Right to Refuse Anti-psychotic Drugs*, 53 La. L. Rev. 283, 297 (1992).

¹⁹ Robert M. Julien, *A Primer of Drug Action* 229, 229-30 (6th ed. 1992).

²⁰ *Id.* at 230.

²¹ *Id.*

symptoms, and (2) tardive dyskinesia. Parkinsonian-like symptoms include hand tremors, drooling, cogwheel rigidity, loss of spontaneous and associated movements, blank stare, dulled facial expressions, and stooped posture.²² These symptoms can be extremely unpleasant, and they occur in a substantial proportion of patients on psychotropics.²³

One of the most common parkinsonian-like side effects is akathisia, affecting twenty percent of patients on psychotropic medication. Symptoms range from “a subjective feeling of muscular discomfort to an agitated, desperate, markedly dysphoric pacing with hand-wringing and weeping,”²⁴ and may include “feelings of fright, rage, terror, or sexual torment.”²⁵ These distressing symptoms of akathisia have caused patients to attempt suicide.²⁶ Tragically, hospital staff often mistake the symptoms of akathisia for symptoms of the patient’s disorder and

²² *Id.* at 230-31.

²³ *Id.* at 231.

²⁴ Alan F. Schatzberg & Jonathan O. Cole, *Manual of Clinical Psychopharmacology* 95 (1986).

²⁵ Marcus A. Krupp *et al.*, *Current Medical Diagnosis & Treatment 1987* 628 (1987).

²⁶ Robert E. Drake & Joshua Ehrlich, *Suicide Attempts Associated with Akathisia*, 142 *Am. J. Psychiatry* 499 (1985).

increase the patient's dose of medication in response, which only exacerbates the akathisia.²⁷

A second major type of motor disturbance neuroleptic patients may experience is tardive dyskinesia, “a neurological syndrome characterized by involuntary, rhythmic, and often grotesque movements of the face, lips, tongue, fingers, hands, legs, and pelvis.”²⁸ These symptoms can be severely disabling.²⁹ Tardive dyskinesia is usually irreversible, even after the patient stops taking neuroleptic medication.³⁰ Separate studies indicate that psychiatrists fail to notice symptoms of tardive dyskinesia in an overwhelming majority of cases—75 percent³¹ and 90 percent,³² respectively—placing patients at a severe risk of contracting this incurable and debilitating disease.

²⁷ Peter J. Weiden *et al.*, *Clinical Nonrecognition of Neuroleptic-Induced Movement Disorders: A Cautionary Study*, 144 *Am. J. Psychiatry* 1148, 1150-51 (1987) (finding a 65% nonrecognition rate by clinical psychiatrists).

²⁸ Levy, *supra* note 14, at 112.

²⁹ Robert M. Julien, *A Primer of Drug Action* 229, 231 (6th ed. 1992).

³⁰ Dilip V. Jeste *et al.*, *The Biology and Experimental Treatment of Tardive Dyskinesia and Other Related Movement Disorders*, in 8 *American Handbook of Psychiatry* 536 (Philip A. Berger & Keith H. Brodie eds., 2d ed. 1986).

³¹ Cichon, *supra* note 18, at 307 (citing T. E. Hansen *et al.*, *TD Prevalence: Research and Clinical Differences*, in *New Research Abstracts*, 139th Ann. Meeting of the Am. Psychiatric Assoc. (1986)).

³² Weiden, *supra* note 27, at 1150.

In a small percentage of cases, psychotropic drugs cause neuroleptic malignant syndrome, which can lead to permanent neurological damage or death.³³ It appears in between 1.2 and 2.4 percent of cases,³⁴ although it “continues to be underdiagnosed by clinicians, even in sophisticated hospital settings. Due to the explosive course of this condition, lack of early recognition can prove fatal.”³⁵

Psychotropic drugs may also cause a variety of blood disorders, the most serious of which provokes a precipitous decrease in the white blood cell count. Called agranulocytosis, this condition places the patient in danger of contracting life-threatening infections, and it must be detected within one to two weeks of onset in order to be effectively cured.³⁶

Other side effects of anti-psychotic drugs are less severe, but still bothersome, and include dizziness, drowsiness, dry mouth and throat, stuffy nose, urinary retention, constipation and blurred vision.³⁷ The drugs may also cause sexual dysfunction, menstrual irregularities in females, skin disorders, and various

³³ Barry H. Guzé & Lewis R. Baxter, *Neuroleptic Malignant Syndrome*, 313 *New Eng. J. Med.* 163 (1985).

³⁴ Levy, *supra* note 14, at 113 (internal citations omitted).

³⁵ *Id.* (footnote omitted).

³⁶ Cichon, *supra* note 18, at 298–99.

³⁷ Julien, *supra* note 29, at 229.

other endocrine and hormonal disorders.³⁸ Even these side effects “can be a source of acute distress to patients who are struggling to feel wide awake and think more clearly”³⁹ in order to work through their disorders.

B. The New Class of “Atypical” Anti-Psychotic Drugs Exhibits Many of the Limitations of Conventional Anti-Psychotic Drugs.

The *amici* joining this brief recognize the increasing use of a new class of drugs called atypical anti-psychotics (“atypicals”). *Amici* share the hope that because they exhibit a more favorable side effect profile in some individuals than do conventional anti-psychotic drugs, atypicals may bring greater relief to a wider population. As we now show, however, atypicals leave unresolved the most significant problems associated with forcible administration of the older, conventional drugs.

First, because atypical drugs are not yet available in injectable form,⁴⁰ they are not among the drug treatment options available to the State of Vermont for the involuntary treatment of patients pursuant to Act 114. Rather, conventional anti-psychotic drugs—with the consequent risks discussed above—continue to be forcibly administered. And, indeed, even if an injectable atypical is ultimately

³⁸ Cichon, *supra* note 18, at 298.

³⁹ Levy, *supra* note 14, at 112.

⁴⁰ *United States v. Gomes*, 289 F.3d 71, 83 (2d Cir. Apr. 24, 2002).

approved, hospitals will likely continue to rely on conventional drugs given the higher cost of atypicals.⁴¹

Second, as with any drug, atypicals pose risks and cause side effects,⁴² some of which are substantial. These include the extrapyramidal or involuntary-movement disorders—*e.g.*, Parkinsonism, acute dystonia, tardive dyskinesia, and neuroleptic malignant syndrome—discussed more fully above in connection with the conventional anti-psychotics.⁴³ One of the most widely prescribed atypical drugs, clozapine, presents a serious risk of agranulocytosis, a potentially fatal disappearance of white blood cells associated as well with conventional anti-psychotics.⁴⁴ Clozapine has also been linked to hyperglycemia, as has the atypical drug olanzapine.⁴⁵ Less severe side effects of these and other atypicals may

⁴¹ John Geddes *et al.*, *Atypical Antipsychotics in the Treatment of Schizophrenia: Systematic Overview and Meta-Regression Analysis*, 321 *Brit. Med. J.* 1371, 1375 (2000).

⁴² In fact, a meta-analysis concluded that many of the perceived benefits of atypicals derive from the excessive doses of conventional drugs used in the comparative trials. See *id.* at 1374.

⁴³ Jan Volavka *et al.*, *Clozapine, Olanzapine, Risperidone, and Haloperidol in the Treatment of Patients with Chronic Schizophrenia and Schizoaffective Disorder*, 159 *Am. J. Psychiatry* 255 (Feb. 2002).

⁴⁴ Philip Janicak *et al.*, *Principles and Practice of Psychopharmacotherapy* 206-07 (2d ed. 1997).

⁴⁵ Elizabeth Koller *et al.*, *Atypical Antipsychotic Drugs and Hyperglycemia in Adolescents*, 286 *JAMA* 2547 (Nov. 2001).

include sedation and weight gain.⁴⁶ Given the comparatively short history of the widespread use of atypicals, many late-onset side effects may yet be identified; in fact, a study just released in April, 2002, concluded that atypicals were significantly associated with diabetes mellitus.⁴⁷ Thus, atypicals are not without serious risks and side effects which will continue to justify refusals in particular cases.

Third, while the risk of side effects from psychotropic drugs is significant and severe, the benefits of the drugs—even the atypicals—are not at all clear. Psychotropic drugs are not the “antibiotics” of mental illness. Unlike antibiotics, these drugs do not cure the underlying illness.⁴⁸ At best, they control the symptoms of mental illness, and they do not always do that. Although psychotropic drugs benefit a majority of patients, they provide no symptomatic relief for a substantial number of people, and they may actually aggravate the underlying condition of other patients.

⁴⁶ Rafael A. Rivas-Vasquez *et al.*, *Atypical Antipsychotic Medications: Pharmacological Profiles and Psychological Implications*, 31 *Prof. Psychol.: Res. & Prac.* 628, 633–35 (2000).

⁴⁷ Michael J. Sernyak *et al.*, *Association of Diabetes Mellitus with Use of Atypical Neuroleptics in the Treatment of Schizophrenia*, 159 *Am. J. Psychiatry* 561 (Apr. 2002).

⁴⁸ Levy, *supra* note 14, at 110.

Even in those cases where psychotropic drugs produce initial benefits, controversy remains about the long-term efficacy of drug treatment. “[S]ymptom reduction by itself is not synonymous with successful treatment.”⁴⁹ Successful treatment ultimately means living independently outside the hospital, and drugs—especially when they are involuntarily administered—can make this goal more daunting and unmanageable. Psychotropics can “inhibit a patient’s ability to learn social skills needed to fully recover from psychosis.”⁵⁰ And there is evidence that reliance on psychotropic drugs for therapy fosters patient dependency on the hospital and tends to increase the likelihood of rehospitalization.⁵¹

The basic point here is that while anti-psychotic drugs can be effective in addressing some symptoms in some individuals, their therapeutic efficacy is often overestimated. And, as we show in Part III below, coercive administration of these drugs may compromise the patient’s long-term health and readjustment to the community.

⁴⁹ Samuel J. Keith, *Drugs: Not the Only Treatment*, 33 *Hosp. & Community Psychiatry* 793 (Oct. 1982).

⁵⁰ Michael L. Perlin, *Competency, Deinstitutionalization, and Homelessness: A Story of Marginalization*, 28 *Hous. L. Rev.* 63, 104 (1991) (quoting *Rennie v. Klein*, 476 F. Supp. 1294, 1299 (D.N.J. 1979)) (internal citations omitted).

⁵¹ J. Sanbourne Bockoven & Harry C. Solomon, *Comparison of Two Five-Year Follow-Up Studies: 1947 to 1952 and 1967 to 1972*, 132 *Am. J. Psychiatry* 796 (Aug. 1975).

III. Advance Directives Have Therapeutic Effects Which Promote Long-Term Patient Independence

Animating this appeal is a tension between, on the one hand, a patient's interest in controlling her treatment through the execution of an advance directive, and, on the other, the State of Vermont's interest in forcibly injecting her with the anti-psychotic drug of its choosing. But there is a danger in so narrowly construing these two, seemingly opposed interests, because the long-term goal of all sides is—or at least should be—the betterment of the patient's mental health and her eventual independence from the institution. As we now show, the coercive administration of anti-psychotic drugs, whether conventional or atypical, undermines this long-term treatment goal. At the same time, evidence suggests that advance directives promote mental health and patient reintegration into the community.

A. The Coercive Administration of Anti-Psychotics, Whether Conventional or Atypical, Undermines Long-Term Therapy Goals.

The “forcible injection of medication into a nonconsenting person's body . . . represents a substantial interference with that person's liberty.” *Riggins*, 504 U.S. at 134 (quoting *Harper*, 494 U.S. at 229). As Ms. Hargrave is aware from her experience at the Vermont State Hospital, forcible injection can be a violent, invasive procedure. Coercive treatment—whether by injection or otherwise, and

whether of conventional or atypical drugs—sacrifices long-term patient compliance to achieve short-term goals. It is, therefore, inconsistent with long-term mental health and patient independence from the institution.

Patient acceptance of treatment is an important determinant of treatment success.⁵² Consequently, and not surprisingly, anti-psychotic drugs are least effective when administered against a patient's will.⁵³ This widely accepted proposition has important implications in the administration of psychotropic drugs, because there is no reliable method for doctors to predict who will be helped by such medication and who will not. As mentioned, the patient's own subjective response to a given psychotropic drug is usually the best predictor of whether that drug will be an effective form of treatment.⁵⁴ In one typical study, patients were asked to report their reaction to a regimen of a designated psychotropic drug. Patients who expressed an initial negative reaction to the medication had substantially worse treatment outcomes than patients who expressed an initial positive response to the medication: only *fourteen percent* of negative responders showed unequivocal improvement on medication, in contrast with *seventy-four*

⁵² See *infra* notes 53 to 56 and accompanying text.

⁵³ See generally Bruce J. Winick, *The Right to Refuse Mental Health Treatment: A Therapeutic Jurisprudence Analysis*, 17 Int'l J.L. & Psychiatry 99, 101-02 (1994); Harris Dienstfrey, *Where the Mind Meets the Body: Type A, the Relaxation Response, Psychoneuroimmunology, Biofeedback, Neuropeptides, Hypnosis, Imagery and the Search for the Mind's Effect on Physical Health* (1991).

⁵⁴ Theodore Van Putten & Philip R.A. May, *Subjective Response as a Predictor of Outcome in Pharmacotherapy*, 35 Archives Gen. Psychiatry 477 (Apr. 1978); Van Putten, *supra* note 15, at 187; Man Mohan Singh, *Dysphoric Response*

percent of positive responders.⁵⁵ Some negative responders, “although cooperative and calm to start with, became acutely panicked and objectively more disorganized several hours after the first dose.”⁵⁶

It is axiomatic that the coercive administration of anti-psychotic drugs is inconsistent with patient treatment acceptance. Forcible medication can create extremely negative associations that discourage individuals from voluntarily complying with their treatment regimens. Compliance may be assured while the individual is under a forcible medication order, whether in the hospital, or in the community under an order of nonhospitalization; however, forcible medication prevents the formation of patterns of behavior that will lead the patient eventually to take the medication voluntarily.

The degrading experience of being forcibly medicated coupled with the powerful effects of the drugs can be so traumatic that some patients may reject further treatment altogether. For example, research has shown that many homeless individuals with mental illness have “opted out” of the mental health system after being forcibly medicated. Jane’s experience with Haldol, recounted above, is but one example of this common phenomenon. These individuals choose life in the

to Neuroleptic Treatment in Schizophrenia and its Prognostic Significance, 37 *Diseases of the Nervous Sys.* 191 (1976).

⁵⁵ Van Putten, *supra* note 15, at 189.

streets in part to avoid the compulsory administration of psychotropic medications⁵⁷—the very risk posed by Act 114.

Appellants assert on the basis of a single affidavit that forcible medication—in derogation of an individual’s competently expressed choices regarding treatment—“may” reduce the duration of an individual’s hospitalization. State Br. at 30–31. *Amici* submit that precisely the opposite is true—*i.e.*, that forcible medication is inconsistent with long-term independence from the hospital. Indeed, forcible medication trades long-term improvement and independence for short-term, short-sighted treatment goals.

B. Advance Directives Promote Individual Goal-Setting and Achievement, Which Are Critical to Recovery From Mental Illness.

Advance directives help to reverse the feelings of helplessness and disenfranchisement experienced by many with a psychiatric disability. A participant in a recent study expressed a “sense of control, empowerment, strength, and safety” in having completed an advance directive.⁵⁸ Another described the

⁵⁶ *Id.*

⁵⁷ Pamela J. Fischer & William R. Breakey, *Homelessness and Mental Health: An Overview*, 14 *Int’l J. Mental Health* 6, 29 (1986).

⁵⁸ Swanson, *supra* note 7, at 8.

advance directive as “a document that is my voice when I am not able to be.”⁵⁹

Although anecdotal, these comments tend to corroborate the findings of a Presidential commission which concluded that the honoring of advance directives promotes individual self-determination by giving effect to “[a] patient’s subjective, individual evaluation of well-being.”⁶⁰

In addition, the very process of considering, drafting, and executing an advance directive exerts powerful therapeutic effects of its own. As mentioned, psychotropic drugs, whether conventional or atypical, are least effective when they are administered against the will of the patient. But the opposite is also true—the ability of the individual to determine appropriate treatments can itself produce positive outcomes. Indeed, principles of cognitive and social psychology may best explain why the empowerment of individual choice leads to better treatment outcomes.⁶¹ Individual choice can bring “a degree of commitment which mobilizes the self-evaluative and self-reinforcing mechanisms that facilitate goal achievement.”⁶² In particular, the setting of treatment goals through the drafting of

⁵⁹ *Id.*

⁶⁰ Lester J. Perling, *Health Care Advance Directives: Implications for Florida Mental Health Patients*, 48 U. Miami L. Rev. 193, 203 (Sept. 1993).

⁶¹ See Bruce J. Winick, *Therapeutic Jurisprudence Applied: Essays on Mental Health Law* 69 (1997).

⁶² *Id.* at 69-70.

an advance directive encourages self-monitoring and self-reactive processes; helps one structure behavior over often-lengthy courses of treatment; and focuses interest, attention, and personal involvement in the treatment.⁶³ This “goal-setting effect” has been identified as “one of the most robust findings in the psychological literature.”⁶⁴

As a general proposition, when we allow people to exercise choice, they are more likely to act as mature, self-determining individuals. These therapeutic effects can be particularly powerful for individuals like Nancy Hargrave, who have experienced a loss of autonomy. Various terms “infantilization,” “learned helplessness,” or “law related psychological dysfunction,” the denial of choice can produce feelings of failure and depression.⁶⁵ Thus, “[a] persistent criticism of mental hospitals is that, by taking over virtually all aspects of patients’ lives, they foster dependency, incompetency, learned helplessness, and a form of institutional personality”⁶⁶ The same can be said for the compulsory treatment of individuals under orders of nonhospitalization. On the other hand, the exercise of individual choice promotes the development of decision-making skills and

⁶³ *Id.* at 73.

⁶⁴ Donald J. Campbell, *The Effects of Goal-Contingent Payment on the Performance of a Complex Task*, 37 *Personnel Psychol.* 23 (1984).

⁶⁵ See Winick, *supra* note 61, at 79-81.

functional capacities essential to community readjustment—all of which furthers the goal of patient independence from the institution.⁶⁷

As in the example of Mandy (discussed above), advance directives may move people to seek treatment earlier than they otherwise would, in an effort to avoid the circumstances under which the advance directive would become operative. In fact, because the execution of an advance directive can motivate a patient to carry through with outpatient treatment, advance directives can be an effective form of therapy even if the patient never loses capacity and the instrument is never formally invoked.⁶⁸ And even where one declines to execute an advance directive, the *right* to have exercised a choice of treatment may mitigate the potential for resentment to “a course of treatment later imposed through surrogate decisionmaking.”⁶⁹

C. By Enabling the Patient To Refuse Unwanted Treatments, Advance Directives Promote a Healthy Therapeutic Alliance Between Doctor and Patient.

“Therapeutic alliance” describes an ideal, cooperative relationship between the mental health professional and the patient as both are allied against the

⁶⁶ Winick, *supra* note 11, at 81 n.88.

⁶⁷ See Winick, *supra* note 61, at 68.

⁶⁸ Swanson, *supra* note 7, at 3.

patient's illness. A healthy therapeutic alliance is increasingly seen as playing a central role in the treatment of those with psychiatric disabilities.⁷⁰ Because advance directives encourage the conditions for an effective therapeutic alliance, they can play an important role in mental health therapy.

In the first instance, an effective therapeutic alliance requires communication between patient and caregiver. Advance directives present a “concrete opportunity and focus for discussing the patient’s preferences and intentions regarding future treatment.”⁷¹ Advance directives persuade patients to carefully consider and articulate personal values and acceptable tradeoffs. Faced with multiple contingencies and treatment options, patients considering advance directives are naturally encouraged to establish a dialogue with their caregivers, and, ideally, to form a therapeutic alliance. After a discussion with their caregiver about the merits and disadvantages of treatment options, patients typically elect some forms of treatment, decline others, and reach consensus with the caregiver about the best treatment strategy.

An advance directive structures the patient-caregiver relationship in ways that can be beneficial to the formation of a therapeutic alliance. An effective

⁶⁹ Winick, *supra* note 11, at 84.

⁷⁰ Thomas G. Gutheil *et al.*, *Legal Guardianship in Drug Refusal: An Illusory Solution*, 137 Am. J. Psychiatry 347, 349 (Mar. 1980).

therapeutic alliance demands that the patient retain autonomy over treatment decision-making—and that is best accomplished through an advance directive. Knowing “that patients have the power to direct the future course of their treatment,” caregivers are more likely to “negotiate with patients about treatment, increasing the likelihood that the patients will be treated with dignity and respect, rather than paternalistically.”⁷² And by protecting the patient’s right to determine their future course of treatment, the patient is assured that her strongly held treatment preferences will be observed—even when she has been committed to the care of a mental hospital, where distrust can be the most acute.

Once patients are assured that they control their treatment, and can refuse undesirable medications, they often feel safer in complying with the course of treatment they have selected.⁷³ As one psychiatrist noted, “[i]t is surprising how much ‘compliance’ is produced when the patient is convinced that you are really on his side rather than just looking out for his ‘best interests’ as you, the

⁷¹ Swanson, *supra* note 7, at 8.

⁷² Winick, *supra* note 11, at 83.

⁷³ Ronald J. Diamond, *Enhancing Medication Use in Schizophrenic Patients*, 44 *J. Clinical Psychiatry* 7, 13 (June 1983).

psychiatrist, see them.”⁷⁴ In fact, most refusers do not persist in their treatment refusal, and communicating with patients about the risks and benefits of drug therapy usually persuades them to undergo it voluntarily.⁷⁵ Thus, open dialogue and negotiation—both of which are promoted by advance directives—are frequently the preconditions for a healthy therapeutic alliance.

CONCLUSION

Advance directives are an important tool for the treatment of mental illness. By providing timely access to patient treatment preferences, advance directives help to assure that patients receive appropriate treatments and avoid those which may be ineffective or harmful. By promoting self-reliant behavior and a healthy therapeutic alliance between patient and caregiver, advance directives generally further the long-term goal of mental wellbeing, patient independence, and reintegration into the community. And by involving patients in their therapy *before* a crisis erupts, advance directives reverse the cycle of “learned helplessness” which has long plagued institutionalized mental health care.

⁷⁴ Donald T. Conley, *A Szaszian Approach to the Right to Refuse Treatment*, in *The Right to Refuse Antipsychotic Medication* 58, 62 (David Rapoport and John Parry eds., 1986).

⁷⁵ Paul S. Appelbaum & Thomas G. Gutheil, *Drug Refusal: A Study of Psychiatric Inpatients*, 137 *Am. J. Psychiatry* 340, 345 (Mar. 1980).

The competent execution of a legally-enforceable advance directive should be an option available to every individual in the State of Vermont—including, and perhaps especially, to those individuals with a psychiatric disability.

Respectfully submitted,

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CERTIFICATE OF COMPLIANCE

I hereby certify that, in compliance with Federal Rules of Appellate Procedure 29(d) and 32(a)(7)(B), the foregoing brief of *amici curiae* contains 6,728 words (fewer than the 7,000 permitted for this brief).

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APPENDIX

Identification of *Amici* Former State Mental Health Commissioners

Patrick Babcock

For more than five years, Patrick Babcock served as the Director for the Michigan Department of Mental Health before becoming the Director of the Department of Social Services. As the state official responsible for the delivery of mental health services, Babcock oversaw community mental health services that included 55 community mental health boards serving all 83 Michigan counties. He also was responsible for community residential services for former residents of state facilities for persons with mental illness and developmental disabilities. Babcock is the Director of Public Policy for the W.K. Kellogg Foundation, where his duties include serving as Project Director of a health reform project in three Michigan counties and a national initiative to monitor the impact of devolution of federal policies to state governments.

Joseph J. Bevilacqua, Ph.D.

Joseph Bevilacqua has twenty-one years experience as State Commissioner of Mental Health Services in Rhode Island, Virginia, and South Carolina. He also served as Assistant Commissioner for Community Services for four years in Virginia. Prior to state services, Bevilacqua served in the United States Army as a social work officer working in psychiatric hospitals and Mental Health Clinics both in the states and overseas. Throughout Bevilacqua's career he has been actively affiliated with a number of academic institutions, including appointments at the University of Virginia, Brown University, Medical College of Virginia, University of South Carolina, and Medical University of South Carolina. He used his state role to encourage collaboration between the universities and departments of mental health. This collaboration included research projects, student placements in state programs and faculty consultation in major state initiatives such as community development and hospital downsizing. He has also written a number of publications in the field of mental health.

A priority of Bevilacqua's commissionerships has been active and strong support of consumers of mental health services. Bevilacqua served two terms as President of the National Association of State Mental Health Program Directors and currently serves on the Board of Directors of the Human Services Research Institute, Boston; the Center for Health Resources, Lincoln, Rhode Island; The Green Door, a psychosocial rehabilitation program in Washington, DC; and the National Alliance for the Mentally Ill-Rhode Island.

James Donald Bray, M.D.

Donald Bray oversaw the Oregon Mental Health Division from 1971 to 1979. After retiring from Oregon state government in 1989, he was a Visiting Scholar with the South Carolina Department of Mental Health. He has served as a mental health consultant to the National Institute of Mental Health and to the following states: Illinois, Utah, Alabama, Idaho, and Kentucky. Bray currently works as a consultant to the South Carolina Public-Academic Mental Health Consortium and the Department of Mental Health. Bray's career has been primarily focused on developing community-based services for people with severe mental disorders and developmental disabilities.

James J. Callahan, Jr., Ph.D.

James Callahan has had extensive experience working in mental health in Massachusetts state government, having served as Commissioner of the Department of Mental Health, Medicaid Director and superintendent of two state hospitals, in addition to being the former Secretary of the Department of Elder Affairs. Callahan also directs a National Institutes for Mental Health funded training program in mental health services research, and is Professor and Director of the Policy Center on Aging at the Heller School, Brandeis University in Waltham, MA.

Callahan is the principle investigator for the Brandeis component of a National Institute for Mental health managed care research program of Harvard Pilgrim Health Care. He serves on the Board of the Center for Mental Health Research at the University of Massachusetts Medical School. He is a member of the Advisory Council to the Massachusetts Mental Health Partnership that operates the Medicaid managed mental health/substance abuse program.

Callahan has written extensively in the fields of mental health, long term care and aging. He is a Fellow of the Gerontological Society of America and recipient of its Maxwell Pollack Award for excellence in bridging the worlds of research and practice. He received the Louis Lowy Award of the Massachusetts Gerontological Association and the American Public Health Association's Key Award for excellence in policy, research education and service. Callahan served as the founding Chair of the National Academy on an Aging Society, is a former board member of the American Society on Aging, and has been a national program director for three national programs of the Robert Wood Johnson Foundation concerned with supportive services and housing.

Robert Constantine

Robert Constantine spent many years working in mental health for the Florida state government. He served as the State Mental Health Program Director in the early 1980's, was the chief administrator for several psychiatric facilities, and later returned to state government to serve as the State Director of Alcohol, Drug Abuse and Mental Health Programs. Constantine is the President and Chief Executive Officer for the Florida Council for Behavioral Healthcare.

King Davis

King Davis served as Commissioner of the Virginia Department of Mental Health, Mental Retardation and Substance Abuse Services from 1990 through 1994. During that period, a priority of the department was the placement of individuals with disabilities in the community. A number of initiatives were developed to increase the success of community placements. The Commonwealth of Virginia's commitment to community placements extends as far back as 1968 with the development of the Community Services Act. Additionally, in response to efforts by the U.S. Justice Department to ensure compliance with the Civil Rights of Institutionalized Persons Act, the Governor, Attorneys General, and the legislature supported the Department of Mental Health's efforts to decrease its reliance on institutions in favor of community-based strategies of care. This strategy included specific placement in local communities of a fixed number of institutionalized residents with mental retardation at the Northern Virginia Training Center. This community-based strategy became the accepted

policy direction of the Commonwealth of Virginia. Davis is the William & Camille Hanks Cosby Professor at Howard University. King currently occupies the Robert Lee Sutherland Chair in Mental Health and Social Policy at the University of Texas at Austin.

Mary Jane England, M.D.

As the first commissioner of the Massachusetts Department of Social Service (“DSS”) from 1979 to 1983, Mary Jane England helped establish and administer a new state agency for children and their families. Before her appointment at DSS, she served as the Associate Commissioner of the Massachusetts Department of Mental Health and Mental Retardation.

In 1995, England served as president of the American Psychiatric Association, and she is a past president of the American Medical Women’s Association. She serves as the Vice President of the National Academy of Public Administration, the American College of Psychiatry, the American College of Mental Health Administration, and the Group for the Advancement of Psychiatry.

England also served on the Board of Overseers for the U.S. Department of Commerce, Malcolm Baldrige National Quality Award. She currently serves on the U.S. Department of Health and Human Services Substance Abuse and Mental Health Services Administration National Advisory Council; the National Institute of Mental Health Advisory Council; and the President’s Quality Forum Planning Committee.

England was also associate dean and director of the Lucius N. Littauer Master in Public Administration Program at the John F. Kennedy School of Government, Harvard University. Dr. England is the chair of the Board of Visitors of Boston University School of Public Health and a member of the Board of Visitors of Boston University School of Medicine. England is president of the Washington Business Group on Health, a nonprofit national health policy and research organization whose membership includes many of the nation’s major employers.

Ivor Groves, Ph.D.

Ivor D. Groves, Ph.D., is Director of Human Systems and Outcomes, Inc., located in Tallahassee, Florida. He has over 30 years experience in

managing and measuring performance in public and private human service programs. Since 1993, Dr. Groves has served as the federal court monitor for the reform of the child welfare system in Alabama. Since 1994, he also has served as the federal court monitor in the reform of the children's mental health and special education programs in Hawaii. Previously, Dr. Groves served as District Administrator, Florida Department of Health and Rehabilitative Services ("HRS"), and as the Assistant Secretary for Alcohol, Drug Abuse and Mental Health, HRS.

Dr. Groves provides consultation, training, technical assistance, and system and organizational development planning to public and private organizations in human services and education. As a result of his experiences in management, performance assessment, and outcome measurement, he has increasingly focused on identifying and developing the most effective methods for developing consistent quality practice by the frontline care providers and their supervisors.

Kenneth Heinlein, Ph.D.

Ken Heinlein has more than 20 years experience in the field of developmental disabilities, including direct services to adults with developmental disabilities in community-based vocational and residential settings and eight years in the administration of Wyoming's developmental disabilities system serving infants, toddlers, and preschool aged children and adults with disabilities. In Wyoming, he served as Director of the Department of Health and Social Services and Director of Department of Health, both of which oversaw the Department of Developmental Disabilities. Heinlein is the Director of the Outcome Resource Center for the Wyoming Institute for Disabilities/University Affiliated Program at the University of Wyoming where he conducts research in post-institutional placements, including research into the cost and quality of community-based supports and services for persons with developmental disabilities.

Donald J. Hevey

From 1982 to 1985, Donald Hevey served as the Director of the Alcohol, Drug Abuse and Mental Health Program Office for the State of Florida. In this position, he was responsible for directing, regulating and contracting for the statewide administration of all community alcohol, drug abuse and mental health programs and institutional mental health, substance abuse and

forensic programs. He also served as the Assistant Director of this office in 1981 to 1982. Prior to his service in state government, Hevey served as the Chief Executive Officer of the Manatee County Community Mental Health Center in Bradenton, Florida, where he was responsible to a community board of directors for the management and administration of a comprehensive mental health and substance abuse center. Hevey presently serves as President and Chief Executive Officer of Mental Health Corporations of America.

Pamela S. Hyde, J.D.

Pamela Hyde was appointed by Governor Richard F. Celeste as the Director of the Ohio Department of Mental Health, and later the Ohio Department of Human Services, the state's Medicaid and child welfare agency. She served as the Director of the Seattle Department of Housing and Human Services, and then was recruited as President and Chief Executive Officer of ComCare, a Phoenix-based behavioral health managed care company. She currently consults with state and local governments, foundations, federal agencies, and non-profit organizations nationwide on a variety of human services and organizational issues. Hyde is trained as an attorney and also spent several years as an advocate and executive director of a statewide protection and advocacy agency.

Dennis R. Jones, M.S.W., M.B.A.

Dennis Jones was Commissioner of Mental Health in Indiana from 1981 until 1988. He was then Commissioner for the Texas Department of Mental Health and Mental Retardation for six years. Both of these positions included institutional and community responsibility for mental retardation as well as mental health.

Danna Mauch

Danna Mauch served as Director of Mental Health for the State of Rhode Island, Assistant Commissioner of Mental Health for Massachusetts, and Executive Director of an ambulatory and long-term care provider. In the Commonwealth of Massachusetts, she directed the Divisions of Forensic Medicine, Mental Health and Substance Abuse. Until recently, she served as the Special Master for the United States District Court for the District of Columbia, evaluating the implementation of reforms to the publicly-

financed mental health system in the nation's capital. In her government roles, Mauch effected major systems changes in the provision of psychiatric care. As a result, Rhode Island's Mental Health System was rated number one in the nation by the Public Citizen Health Research Group.

Mauch served as member of the National Advisory Board of the U.S. Center for Mental Health Services and co-chaired a health care reform task force on behavioral health for the Labor and Human Resources Committee of the U.S. Senate. She was also Principal Investigator on a number of federal and foundation-funded research and demonstration projects in the mental health and long-term care fields. She has published several key articles and book chapters on the management of care and public-private partnerships in services delivery and systems management for the behavioral health care industry. Mauch is currently the Chief Executive Officer of Magellan Public Solutions, Inc., a health care organization with the capacity to deliver specialty care management solutions to the public sector.

John A. Morris

John Morris served an interim appointment as Director of Mental Health for South Carolina from 1995 to 1997; he also served as Deputy State Director. Before 1990, he held numerous clinical and administrative positions in the Department of Mental Health, having begun his career as a ward attendant at the South Carolina State Hospital in 1969. Morris became a program director for the Missouri Department of Mental Health in the mid-1970's.

Morris is Professor of Clinical Neuropsychiatry and Behavioral Sciences at the University of South Carolina School of Medicine and the founding Director of the SC Center for Innovation in Public Mental Health, a partnership between the School of Medicine and the SC Department of Mental Health. In addition, Morris is Visiting Professor of Mental Health Policy at the George Warren Brown School of Social Work at Washington University in St. Louis, where he was named a Distinguished Alumnus in 1996. He is currently principal investigator on a federal grant to replicate a supported employment model for persons with serious mental illnesses, and has been PI on two grants to replicate rural assertive case management models. Morris is immediate past president of the American College of Mental Health Administration, and serves on the Board of Directors for the Technical Assistance Collaborative, Inc., as well as for the National Advisory Council to the Georgetown Technical Assistance Center for

Children's Mental Health and the Kentucky Center for Mental Health Studies. He is serving a three-year term on the Standing Review Committee on Knowledge Application for the Center for Mental Health Services, and has just been invited to serve a one year term on the Public Policy Committee of the National Mental Health Association.

Frank Ochberg, M.D.

Frank Ochberg was Director of the Michigan Department of Mental Health from 1979 to 1981. Prior to serving in that position, he spent ten years at the National Institute of Mental Health, the last two as Associate Director. He has published over 100 titles, many on community mental health services, in scientific and lay publications, and has served as a consultant to the Federal Bureau of Investigation, the U.S. Secret Service, and the London Metropolitan Police (Scotland Yard). At Michigan State University, he is a Clinical Professor of Psychiatry and an Adjunct Professor of Criminal Justice. Ochberg is a psychiatrist in private practice in Michigan.

Robert Okin

Robert Okin is the former Commissioner of Mental Health for both the state of Vermont and the state of Massachusetts. He is a consultant with Mental Disabilities Rights International and is a nationally and internationally known expert on human rights for people with mental disabilities.

As Chief of Service of the San Francisco General Hospital ("SFGH") Department of Psychiatry, Professor of Clinical Psychiatry, and Vice Chair of the University of California at San Francisco ("UCSF") School of Medicine's Department of Psychiatry, Okin's major role is to provide leadership to and administration of the SFGH site of the UCSF Department of Psychiatry. Since he joined the Department in 1990, his major effort has been focused on the development and expansion of both mental health/substance abuse services and the academic mission at this site. He has overseen the development of crucial services for San Francisco's most critically mentally ill, including the SFGH Department of Psychiatry's Case Management Program for High Users of the Emergency Department (which received this year's National Association of Public Hospital's Safety Net Award), the Crisis Resolution Team for psychiatric patients in crisis, a Partial Hospitalization Program for patients transitioning from acute inpatient care, a variety of outpatient and inpatient Substance Abuse

Programs, the establishment of the Division of Psychosocial Medicine, and the Department of Public Health's capitate contract for comprehensive mental health services for 200 of San Francisco's most expensive users of the mental health system.

Michael S. Pedneau

As the North Carolina State Director of Mental Health, Developmental Disabilities and Substance Abuse, Mike Pedneau brought federal class action lawsuits to closure by complying with the settlement agreement in *Willie M. v. Hunt* and by achieving compliance in the Court Order in *Thomas S. v. Hunt*. The latter case involved a class of 2,000 individuals with mental retardation who spent more than 30 days in state psychiatric hospitals. By treating and habilitating people with mental retardation in community settings, North Carolina was able to continue downsizing its state hospitals and shift nearly 60% of the cost of this care to federal Medicaid funds. Since compliance, North Carolina has continued to divert people with mental retardation from care in state hospitals unless extreme circumstances are involved. During his six years as State Director, each of the four state psychiatric hospitals decreased the use of seclusion and restraint and North Carolina adopted legislation for mental health advance directives as well as state law provisions authorizing appointment of guardians for mental health decisions.

Thomas D. Romeo

Thomas Romeo was Director of Rhode Island's statewide agency for mental health for 12 years. With the support of four Governors, the Rhode Island State Legislature, and many citizens, he established a system of services based upon individual needs and with the ultimate goal being return to one's home community. In Rhode Island, institutional settings continue to be considered a "last resort."

Identification of *Amici* Organizations

National Mental Health Association

The National Mental Health Association ("NMHA"), is the country's oldest and largest nonprofit organization addressing all aspects of mental health and mental illness. With its more than 340 affiliates, NMHA works to

improve the mental health of all Americans—especially the 54 million individuals with mental disorders—through advocacy, education, research and service. NMHA envisions a just, humane and healthy society in which all people are accorded respect, dignity and the opportunity to achieve their full potential free from stigma and prejudice. NMHA has educated millions about mental illnesses and reduced barriers to treatment and services. Its programs include Campaign for America’s Mental Health; Partners in Care; the Children’s Mental Health Matters Campaign; Consumer Support and Voter Empowerment Project; the Mental Health Information Center; Justice Programs and the Safe Schools/Healthy Students Action Center.

Vermont Association for Mental Health

The Vermont Association for Mental Health (“VAMH”) is a citizen’s organization working to promote mental health and mental health services. VAMH’s members represent a broad spectrum of Vermonters, including concerned citizens, consumers, parents, family members, small businesses, large corporations, mental health organizations and individual practitioners in both public and private sectors.

International Association of Psychosocial Rehabilitation Services

International Association of Psychosocial Rehabilitation Services (“IAPSRS”) is an international coalition of agencies, practitioners, families, and persons with psychiatric disabilities. The purpose of IAPSRS is to help advance the role, scope, and quality of services designed to facilitate the community readjustment of people with psychiatric disabilities. IAPSRS seeks to improve the quality of psychosocial rehabilitation services and resources, to strengthen the role of community-oriented psychosocial rehabilitation within the mental health services delivery systems, and to facilitate the coordination and continuity of programs.

New York Association of Psychiatric Rehabilitation Services

The New York Association of Psychiatric Rehabilitation Services (“NYAPRS”) is a diverse, grassroots, statewide coalition of New Yorkers who provide and/or use community-based mental health services. It is dedicated to improving services and social conditions for people with psychiatric and trauma-related disabilities by promoting their recovery, rehabilitation and rights. In doing so, NYAPRS brings together thousands

of New Yorkers with psychiatric disabilities and the professionals who support them. NYAPRS is associated with over 130 community mental health organizations located throughout the state to engage in a variety of training, technical assistance, and new service development initiatives, as well as advocacy.

American Network of Community Options and Resources

American Network of Community Options and Resources (“ANCOR”) is a nationwide association of 700 private, non-profit, for-profit and family care agencies that provide support and services to more than 150,000 people with disabilities. ANCOR has more than thirty years of proven leadership representing private providers at the federal level. The membership services persons of all ages, income levels, sexes, and races in urban, rural, and suburban areas—supporting people wherever they live and work. Most member agencies support group homes, apartments, and other supported living arrangements in typical, stable family neighborhoods in order to best meet the needs of the people they support. Some members provide vocational and employment services through supported employment, community rehabilitation programs, and extended employment arrangements.

HalfthePlanet Foundation

HalfthePlanet Foundation is a nonprofit organization that offers comprehensive, reliable information, products and services to people with disabilities, their families and friends. The Foundation administers the well-known website—halftheplanet.com—the most comprehensive disability resource on the Web, created by people with disabilities for people whose lives are touched by disability. Under the leadership of renowned disability rights leader, John Kemp, HalfthePlanet Foundation supports the application of technology to promote the values of the ADA—independent living, social inclusion, equality of opportunity, economic self-sufficiency and empowerment.

The American Association of People with Disabilities

The American Association of People with Disabilities (“AAPD”) is a nonprofit, nonpartisan membership organization of people with disabilities, their family members and supporters. AAPD was founded on the fifth

anniversary of the ADA and works to promote policies and programs that further the ADA's goals of equality of opportunity, full participation, independent living and economic self-sufficiency for the more than 56 million children and adults with disabilities in the U.S.

The Polio Society

The Polio Society serves its nationwide membership with information and referral services, training in self-advocacy to enforce the civil rights of persons with disabilities, and support for legislation of benefit to polio survivors and the disability community at large. The Americans with Disabilities Act is a key element of the Polio Society's advocacy. The members are persons with disabilities as a result of polio and post-polio syndrome.

National Health Law Program

National Health Law Program ("NHeLP") is a public interest law firm that engages in legal and policy advocacy on behalf of low income and working poor people, people with disabilities, people of color, and children. In its work, NHeLP represents individuals who are experiencing disabling conditions affecting a wide range of activities. The Program also sponsors research and writing on laws which have been enacted to benefit our client groups.

CERTIFICATE OF SERVICE

I hereby certify that, on the 3rd day of July, 2002, I served the foregoing brief by causing two copies thereof to be sent by first-class mail, postage prepaid, to counsel for the parties, as follows:

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