Competence Issues in Self-Directed Care

by

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Executive Summary

> "Whatever a man may want . . . in the minutest preoccupations as well as in the greatest designs, the essence of his desire always consists in this, that he wants above all things to be able to exercise his will freely."
>
> —Simone Weil

Self-directed care holds great promise for fulfilling the goal of individualized and cost-effective services aimed at recovery for people with psychiatric disabilities. These programs will have a greater chance of success if potential issues relating to competence are addressed and resolved at the outset of the program. Concerns such as shifting levels of competence and continuity through crises can be handled through devices such as advance directives, designation of health care proxies or powers of attorney, use of fiscal intermediaries, and other similar planning tools.

Use of these tools will ensure that individual choices in self-directed care are respected, rather than questioned, by mental health or other provider agencies. If the exercise of choice triggers competence inquiries by those involved in administering the self-directed care program or approving the individual's recovery budget, self-directed care will collapse in both concept and execution.

This is not to say that any and all choices should be permissible in self-directed care. It is to be expected that choices will take place within broad, pre-negotiated and common-sense limitations dictated by concern for the responsible expenditure of public dollars. It is also crucial that individuals must have access to information, counseling, and assistance from a wide variety of sources to empower them in making decisions. Ultimately, however, an individual's choices within the framework of a self-directed care program must not precipitate a competence inquiry, whether legal or clinical in nature. This must be a core value of any self-directed care program.

In fact, this paper argues that although a number of difficult questions arise in the implementation of self-directed care programs for persons with psychiatric disabilities, the framework of competence is not a helpful way to phrase or resolve these questions. Therefore, the paper raises and rephrases questions that are likely to come up about competence and self-directed care, and proposes solutions to these questions.

Introduction and Purpose

The purpose of this paper is to examine issues that may be raised regarding competence in the context of self-directed care programs for people with psychiatric disabilities. The first portion of this paper reviews the concepts of competence in clinical and legal contexts, and how these concepts have historically been differentially applied to people with psychiatric disabilities to limit their choices with regard to marriage, voting, child-rearing, reproduction, medical care, place of residence, and other basic components of ordinary community life. The historical use of competence to limit the choices of people with psychiatric disabilities dictates caution in evaluating concerns with respect to competence in self-directed care.

This is not to say that real issues in self-directed care do not arise in the form of concerns about competence. Competence is an abstract concept that serves as an unhelpful proxy for actual, concrete problems that need to be addressed in order for self-directed care to work. Real issues associated with adapting self-directed care for people with psychiatric disabilities include how to deal with acute or short-term crises and how to adapt self-directed care for people who are ambivalent or forgetful or who change their minds. The concept of competence simply may not be the best way to either frame or solve these problems.

The second portion of the paper will examine key issues in self-directed care that may be framed in terms of competence, such as whether competence determinations should be a threshold requirement for participation in self-directed care programs, and, if so, the standard of competence to be applied; how to deal with shifting or cycling competence, and the interplay between directed care programs, Federal statutes touching on competence, and State statutory competence/guardianship provisions. The paper will reframe these questions in a way that addresses core concerns without having to involve competence determinations.

Concerns raised in the framework of competence can be analyzed by dividing them into three categories: concerns about skills vs. concerns about choices; short-term crises (shifting and unpredictable levels of competence) vs. longer-term incompetence (competence concerns that are chronic and unvarying); and concerns raised by the individual about his or her ability to participate in the program vs. concerns raised by third parties.

Finally, this paper proposes solutions to these problems and issues. In order to succeed, programs of self-directed care must include contingency and crisis planning, including the use of advance directives, health care and other forms of proxies, use of fiscal intermediaries, and other ways to ensure that a person’s choices are understood and respected. With proper planning, competence should rarely, if ever, be a concern in self-directed care for people with psychiatric disabilities.

Background

Competence is both a legal and a clinical concept with broad applications in almost every area of life. For the past 40 years, it has been the subject of numerous well-publicized studies and reports,[1] Supreme Court cases,[2] and legal symposia.[3] It is tremendously significant: that our law makes the power of individual choice legally contingent on competence.

At the outset, it is worth stating a few core principles. First, mental illness and incompetence are not identical states, either in law[4] or as a matter of clinical judgment. As one court recently summarized, "In short, under any reasonable definition, mental illness cannot serve as a proxy for mental incapacity with regard to voting."[5] Second, all individuals, including individuals who are diagnosed with mental illness, are legally presumed to be competent to make all decisions, including medical and mental health treatment decisions.

Competence in a Clinical Context

Competence is not a global concept but is measured in terms of specific decisions or abilities: competence to enter into contracts, make medical decisions, execute a will, participate in studies or experimentation, manage finances, vote, and other individual tasks or projects. Different activities require different standards of competence. This is recognized by both clinicians and courts. "It is axiomatic that a person may be competent for one purpose, such as decision making about medical treatment, but not about others, such as the management of financial affairs." [6]

It is also well recognized that competence varies over time,[7] and judgments about competence are value laden, discretionary, and culturally bound. Research shows that judgments about competence are powerfully affected by differences in gender,[8] culture,[9] and economic status.[10] Furthermore, individuals often have been judged incompetent simply because they were given insufficient information to be able to weigh risks and benefits of a given decision, or because evaluators disbelieved information given by subjects of incompetence hearings that was, in fact, correct.[11]

There is no single accepted test for competence, even for individual and specific tasks, such as making medical decisions. As one group of researchers put it, "[a]lthough there is a clear consensus that it is essential to assess decision-making capacity . . . there is also agreement as to the lack of generally accepted, reliable, valid, and simple assessment techniques."[12] The closest approximation to this "Holy Grail"[13] came in the mid-1990s, when the MacArthur Research Project devoted years of effort by the best minds in the field and came up with three separate tests which, as initially formulated, were too long to be used in ordinary assessments. Even these tests were subject to a number of criticisms: that they equated denial of mental illness and failure to acknowledge the value of treatment too easily with incompetence,[14] that they set a higher standard of competence for those who would refuse mental health treatment than those who would refuse medical treatment,[15] and that the tests insufficiently accounted for differences in responses associated with race and culture.[16]

Ultimately, as pointed out in an article by Kapp and Mossman, even the best competence test cannot control for the subjectivity inherent in the *selection* of people whose competence will be evaluated. This selection, the authors note, is inevitably distorted by “fallible clinical judgment—along with personal variations, biases and idiosyncrasies.”[17] Outside the criminal justice context, selection of people for competence evaluation often comes because of treatment refusal or disagreements about treatment recommendations. As the MacArthur researchers note, people who comply with proposed treatment may actually be incompetent to make decisions, but their competence is rarely, if ever questioned.[18] Thus, policymakers implementing self-directed care programs need to remember that the context of challenges to competence is not actually lack of competence, but rather often occurs when an individual attempts to assert autonomy and self-direction in the face of professional recommendations to the contrary.

Competence in a Legal Context

Even within specific categories of tasks or decision making, such as medical decision making, the question of whether an individual is competent does not easily reduce to a yes/no dichotomy, despite the unavoidable artificiality of some areas of law that require such determinations. Rather, as the American Bar Association has noted, competence exists along a spectrum. The American Bar Association has replaced the nomenclature of competence with capacity, and in its canons of professional responsibility, recognizes a spectrum of capacity, rather than competence.[19]

The Supreme Court has issued numerous decisions on competence, mostly in the criminal context. These decisions set standards on the competence to stand trial,[20] competence to be executed,[21] competence to represent one’s self,[22] and competence to waive counsel and plead guilty.[23] All of these decisions are fraught with enormous implications for a person’s liberty and even life. Yet, as the Supreme Court ruled in a case upholding a defendant’s right to represent himself, the fact that a person’s decision might be mistaken and have grave consequences did not outweigh the defendant’s right to make these choices, and certainly did not impute incompetence to the defendant making the choice: Though he “may conduct his own defense ultimately to his own detriment, his choice must be honored,” 422 U.S. 806, 834 (1975). These decisions, involving life and liberty, should represent the highest standard of required competence. Yet the threshold of competence, both in the standards set and the application of these decisions is extremely low.

The law has also devised methods by which competent people can plan and direct decision making in the event that they become incompetent. Many of these instruments, such as an advance directive, durable power of attorney, and health care proxy, could be of substantial use in self-directed care programs. These are discussed more fully under “Action Items and Recommendations.”

Competence as Applied to People with Psychiatric Disabilities

Although requirements of competence theoretically apply to all persons engaged in tasks and projects regulated by law, in practice they have arisen most frequently with populations of relatively powerless people: children, elderly people, people with mental retardation, and people with psychiatric disabilities. As one commentator recently noted, "the concept of legal capacity traditionally has been an exclusionary project under which certain classes of individuals were by definition incapable of legal agency."[24] Both society and the law have until recently operated on global, irrefutable presumptions that individuals with psychiatric disabilities or mental retardation categorically lack competence to vote, make their own medical decisions, marry and have children, and dispose of their own financial resources. Until recently, people who were committed to mental institutions were deemed incompetent and lost all their rights. Discharged patients had to petition a court to "restore" their rights to vote, their abilities to procure driver's licenses and enter into contracts, and to be generally declared competent.

Civil rights cases in the 1970s began to reverse these blanket presumptions,[25] and States adopted legislation ensuring that citizens retained a presumption of competence undisturbed by treatment in psychiatric facilities,[26] or that disagreeing with one's physician regarding the use of neuroleptic medication was not, in and of itself, evidence of incompetence.[27] (The fact that legislatures considered it necessary to pass the latter statutes gives powerful evidence of the degree to which evaluations of incompetence were based simply on individuals' attempts to exercise a different choice from that recommended by their doctors).

However, significant vestiges of these presumptions of incompetence remain. In 2001, a Federal district court in Maine struck down an amendment to the Maine Constitution that permitted people under guardianship to vote, unless their guardianship was the result of mental illness.[28] Last year, the Court of Appeals for the Second Circuit invalidated a Vermont statute that excluded certain groups of people with mental illnesses from rights to enforce advance directives after being deemed incompetent.[29] Vermont still has a statute that allows people to seek voluntary guardianships to assist them in handling their financial affairs—unless they have mental illness or mental retardation.[30] In many States, statutes still presume that people who are "insane" or of "unsound mind" lack the capacity to marry, divorce, serve on juries, donate organs,[31] become licensed as dental technicians, and on and on, a litany of exclusion based on social presumptions that continue to equate mental illness with lack of capacity.

Even in States where people with mental illnesses are statutorily protected from presumptions of incompetence, it remains the case to this day that people who are clients of the public mental health system have their competence challenged more frequently than people who are not, and on a much more attenuated basis (often, still, disagreement with the recommendations of their physicians or psychiatrists). Even people who receive their psychiatric treatment from private providers and facilities face more stringent inquiries into competence than people who do not.

Having one's competence questioned, or being determined incompetent, has devastating personal, emotional, and social consequences.[32] The concept that a program specifically designed to enhance autonomy and promote empowerment would challenge the competence of a person who took those program goals seriously, is paradoxical at best. In fact, interviews with individuals who are operating or developing self-directed care programs reflect that competence concerns turn out to be negligible in programs that are client centered and dedicated to self-determination.

Key Issues and Values

Avoiding Competence Inquiries Altogether

As suggested above, competence inquiries and determinations are problematic in a variety of respects. This country has a troubling history of using assumptions about incompetence to deprive people with mental disabilities of basic rights in much the same way that literacy tests were used in the Deep South to deny African Americans their basic rights. In both cases, tests were imposed on one group in the population that were not imposed on other groups, and artificially high standards were imposed on that group for participation in fundamental aspects of social and political life. Because of the subjectivity of competence, the history of the use of competency inquiries, and innate assumptions that are still a part of competence doctrine today, competence is not the best framework in which to analyze the real concerns raised by extending programs of self-directed care to people with psychiatric disabilities.

In fact, a conscious effort should be made to structure self-directed care programs in a way that precludes competence inquiries, especially competence inquiries by the agency administering the self-directed care program, the mental health authority, or its case managers. To do this, program creators can anticipate the instances in which competence inquiries are likely to be raised, and structure the program to obviate a need to determine competence.

Reframing Competence Questions as Program Issues

Rather than spotlighting the individual with psychiatric disabilities in what is sure to be a disempowering and discouraging inquiry into competence, questions can be focused on the program the individual is participating in. A different set of questions, framed programmatically, can be asked:

- Should there be any prerequisites to participation in a self-directed care program for people with psychiatric disabilities?
- What limitations on choice should the program impose, a priori, and on what basis?
- How will the program deal with crises?
- How will the program deal with different perspectives on symptomatology and functioning?

- How do self-directed care programs intersect with Federal and State statutory programs and requirements? For example, if an individual in a self-directed care program funded by Medicaid is involuntarily committed under a State commitment statute, how does the Medicaid Institutions for Mental Disease (IMD) exclusion, which bars the use of Medicaid funds for treatment in a psychiatric hospital, affect the person's participation in the self-directed care program?

Many of these questions are better ways of framing issues that might otherwise be framed as questions of competence, and all should be anticipated and answered in the structuring of a self-directed care program. These questions are discussed further in the sections below.

Should there be any prerequisites to participation in a self-directed care program? What limitations on choice should be imposed? Instead of "What is the standard of competence, if any, for participation in self-directed care programs for people with psychiatric disabilities?"

Two issues have arisen in regard to participation: (1) should there be any threshold prerequisites for participation in a self-directed care program, and (2) should there be any circumstances under which a person's participation is discontinued? There is already disagreement in the field on the first question. Some experts, such as Thomas Nerney of the Center for Self-Determination, strongly believe that self-directed care is linked to basic citizenship rights, which can and should be exercised by all persons without exception. On the other hand, when New Hampshire convened a group of stakeholders to develop a self-directed care program, the resulting model excluded people on conditional release from the State hospital.

This paper generally agrees with Nerney's perspective that anyone who desires to participate in a self-directed care program should be admitted to the program. In some self-directed care programs, individuals drop out because they are not ready or do not wish to assume responsibility for directing their own recovery. Interestingly, self-directed care programs report that a considerable length of time is needed to work with people to help them emerge from the role of dependency and compliance into a more autonomous and responsible position with regard to their recovery.

However, even in programs that do not exclude anyone based on symptomatology or functioning, some potential obstacles exist under the current legal system. Programs often fail to consider people who are under guardianship as potential participants in self-directed care. At least one program excludes people under guardianship because of the contradiction between self-directed care and guardian-directed care. This exclusion may be unnecessary. First, the guardian might consent to direction by the ward. Second, if a guardian refuses to assent to a ward's desire to participate in self-directed care, this may violate the ward's rights in some States. There are court decisions that prohibit a guardian from interfering with a ward's participation in treatment planning, or seeking assistance from an advocate.[33] Other court decisions affirm the right of wards to challenge certain kinds of treatment decisions by guardians, such as the decision that they should remain institutionalized.[34] People who are under guardianship participate in self-directed care programs for persons with mental retardation and developmental disabilities, and it may be a harmful precedent to exclude people with psychiatric disabilities who are under guardianship from self-directed care programs.

Concerns about the ability of people with psychiatric disabilities to participate in self-directed care programs that are articulated within a competence framework primarily relate to two very different areas: the choices people make to advance their recovery and the skills they need to manage a program involving those choices. For example, if a person with a psychiatric disability determines that he or she needs a personal care assistant to help in recovery, questions could be raised about the individual's choice in a variety of ways. First, it is possible that those administering the program could believe that, in general, personal care assistance cannot advance recovery from psychiatric disability. Second, they could believe that this individual's psychiatric disability makes him or her very dependent, and thus that personal care assistance would exacerbate the disability rather than assist in recovery. Third, they could raise concerns about the specific personal care assistant selected (the person chosen could be considered unreliable or a bad influence).

All of these questions would be quite different from concerns relating to the individual's skill to implement the program (the person cannot understand or follow the Internal Revenue Service and Social Security rules about hiring the personal care attendant, keep time records, balance a checkbook, etc). In fact, concerns about skills far more basic than understanding Social Security regulations rank high as obstacles to self-directed care. At least one program reports that almost half of participants have serious literacy problems. Concerns about skills and choices are discussed separately below.

Skills. A number of different skills or abilities may be involved in self-directed care. Skills may, for example, include entering into contracts, choosing providers, hiring caretakers, directing care, and authorizing payment. Although concerns about a person's skills to fulfill these responsibilities could theoretically be articulated in the framework of competence, this rarely happens. Rather, in all the self-determination programs surveyed for this paper, it is simply assumed that people need some assistance in carrying out their programs, and the assistance is provided in the form of "cash counseling" or "fiscal intermediaries." People are, to the extent possible, taught these skills, but the lack of skills does not preclude them from participation in the program.

Choices. Choices about recovery obviously raise more difficult questions, and disagreement about those choices have often been articulated using the framework of competence. If self-directed care is to have any meaning, the choices that people make about what will help them recover must be respected.

Obviously, choices are not unlimited and infinite. Public dollars must be used responsibly. But limitations should be considered and articulated at the outset of the program, and within those limitations, the individual's choice should be respected and supported. The limitations should not narrow the possibilities available to the individual to such an extent that they effectively replicate the existing mental health program. A core value of self-determination programs must be that they expand the options available for recovery, allowing the individual to design and choose the services needed to the maximum extent possible. Furthermore, within the predetermined limits of the program, informed autonomy must take precedence over clinical judgments of appropriateness. The exercise of autonomy is a prerequisite to recovery, and it must be recognized that, as a practical matter, autonomy will not proceed in lockstep with clinical judgment. Even if the exercise of autonomy takes longer to lead to recovery, it may well be a longer-lasting recovery in the end.

There are a number of ways to maximize the chance that autonomous choices will lead to recovery. First, the individual clearly must have access to a great deal of information from a wide variety of sources. Second, it is helpful to articulate what the individual's idea of recovery would look like—the individual's own home or apartment, mainstream employment, satisfying personal relationships—and then ask how the services selected by the individual will lead to accomplishing those goals. Third, the individual should have trusted friends, family, or peers to serve as sounding boards and help with crafting a plan or program. Tom Nerney has referred to this kind of supportive community as "assisted competence." Finally, a successful self-directed care program will be run with flexibility, patience, humor, humility, and common sense by the people administering the program, who will understand that decisions that show a lack of judgment do not necessarily signal an incompetent decisionmaker.

Although self-directed care programs for people with psychiatric disabilities are relatively new, the idea of self-directed care programs is not new at all. These programs have been used with great success in populations that include people with physical and developmental disabilities. Self-directed care programs have been developed for people with serious and continuing cognitive and emotional problems, including an individual who was autistic and completely mute. These programs took as their primary goal the painstaking identification of the individual's true preferences, likes and dislikes, through intense listening, observation, and trial-and-error. These programs worked astonishingly well with people who would clearly have been judged "incompetent" to take part in them.

In addition, self-directed care programs can be compared to Ticket to Work voucher programs. In the latter instance, people who are disabled enough to be receiving Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI) are granted vouchers to help them seek vocational training.

How will the program deal with crises? Instead of "How can people with shifting competence succeed in self-directed care programs?"

Although self-directed care programs have succeeded with people with physical disabilities and mental retardation, one of the key differences between these groups and people with psychiatric disabilities is that the latter are often subject to short-term acute crises in which the person's decision making and future thinking abilities may be compromised for a brief period, after which they resume a level of functioning that once again permits thoughtful planning and decision making.

People with psychiatric disabilities interviewed for this paper readily acknowledged that at certain points for short periods of time they would not be capable of direction or control, and they were concerned that if this happened, they would be excluded from the self-directed care program altogether. The fact that the New Hampshire steering committee chose to exclude people on conditional release from hospitalization from its self-directed care model shows that these fears are not entirely baseless. It is clear that self-directed care programs must provide for and continue through acute crises, or, as one project terms it, "increased symptoms," or else these programs would exclude a substantial portion of people with psychiatric disabilities, including those who might benefit most from self-directed care programs. Past a certain point, hospitalization may create difficulties for self-directed care programs that are funded by Medicaid rather than by direct State agency mental health dollars, but creative solutions, such as writing Medicaid waiver applications to take this contingency into account, are available.

The preference is, of course, to manage these increased symptoms in the community, with reassurance and assistance. The self-directed care program in Florida has not had a single involuntary commitment since the inception of the program, although two participants were briefly in jail. These participants were not disenrolled from the program, and it is not anticipated that participants would be disenrolled from the program during any period of hospitalization.

Times of crisis or increased symptoms might be a good subject for advance planning of the kind discussed in the "Action Items and Recommendations'" section of this paper. A person can choose the kind of assistance that will help him or her weather the crisis best and designate trusted surrogate decisionmakers to act on his or her behalf if necessary.

How will the program deal with different perspectives on symptomatology and functioning? Instead of "What if program personnel believe that the participant is incompetent to direct his or her own care?"

There are two very different situations in which the competence of an individual with a psychiatric disability is questioned. The first situation is when an individual questions his or her own competence. Most people with psychiatric disabilities have experienced times in their lives when they identify themselves as being in crisis, unable to make decisions without assistance, or unable to make decisions under the weight of severe depression. These situations are usually acute and short-term and result from the pressure of intolerable feelings, or the biological effects of withdrawal from or changes in medication. Sometimes they are predictable (an anniversary or proximity to a traumatic event) and sometimes they are entirely unpredictable.

The second situation is when an outside party or agency questions an individual's competence. This latter situation usually results from an individual making choices that the agency believes are not in his or her best interest. Raising these concerns reflects an imbalance of power between the individual or agency raising the competence issue and the person whose competence is being questioned. Questioning competence is the antithesis of promoting self-determination. On the other hand, it is clear that program directors cannot refuse to act in the face of imminent harm to self or others.

Thus, an extremely important variable is whether the concerns about capacity, competence, or ability are expressed by the individual participating in the self-directed care program or by an outside agency or third party. People who have tried to initiate programs of self-directed care report that consumers of mental health services can be skeptical of any program or project that claims to honor consumer autonomy. Issues of trust will be core to the success of any self-directed care program. If these programs are truly self-directed, it will mean that, like all autonomous decisions made by every citizen in this country who chooses service providers and makes housing and medical decisions, choices will be made that appear in hindsight to be grave mistakes, from the point of view of others and sometimes from the perspective of the individual him or herself. The program must be prepared to live with this eventuality and plan around it—not try to prevent every possible mistake. Furthermore, the people who are running the program and the mental health professionals affiliated with it must be committed to autonomy in a real way. Thus, they cannot be the agents of an inquiry into competence, whether legal or clinical.

Distinctions must be made between behavior and choices. If a program participant's behavior is threatening or dangerous to others, then in extreme cases the program may have to respond by calling for an involuntary evaluation. Carolyn Russell indicates that this has never happened in the Florida program. The distinction this paper is trying to make is between choices, which ought never to be the catalyst for coercion or competence challenges, and conduct, which cannot be consequence-free if it threatens to endanger others.

How do self-directed care programs intersect with Federal and State statutory programs and requirements?

Although it is beyond the scope of this paper, a program that is as totally transformative of an entrenched culture as self-directed care is, is bound to come into conflict not only with social structures but with the laws that have arisen to enforce them. The assumption that people with psychiatric disabilities are unable to control and direct their treatment has resulted in the popularity of treatment modalities that people with psychiatric disabilities would rarely choose for themselves, ranging from day programs to sheltered workshops to Haldol. Attendance at or compliance with these modalities has been ensured by a lack of options and choices, the accustomed role of treatment providers in directing care, and negative consequences for the noncompliant patient. These structures are supported by a variety of laws as diverse as those regulating reimbursement for services, establishing representative payee systems, overriding treatment refusal, guardianship, and even mandatory reporting.

Action Items and Recommendations

One of the ways to avoid difficulties is to plan ahead. This is true for both the self-directed care program and its participants. The legal system has devised many forms and instruments to effectuate advance planning for an individual’s anticipated (and, perhaps even more important, unanticipated) periods of incompetence. These instruments include execution of advance directives and designation of health care proxies and fiscal intermediaries. In addition, the mental health field has devised various forms of crisis plans over the years.

Advance Directives

Almost all States have laws enabling their citizens to execute advance directives. Many States, such as Alaska, Arizona, Hawaii, Idaho, Illinois, Maine, Minnesota, North Carolina, Oklahoma, Oregon, South Dakota, Texas, Utah, Vermont, and Wyoming, have separate advance directive laws for mental health treatment, often granting fewer rights or imposing more restrictions. An advance directive permits an individual to plan for health care in the event that he or she should be deemed incompetent. Thus, a competent individual can ensure that he or she will not be given a drug involuntarily in the event of incompetence. More controversially, an individual can consent in advance to involuntary treatment in the event that he or she is incompetent and refuses medication. This latter version of an advance directive is often called a “Ulysses Contract.”

Self-directed care programs may want to consider encouraging participants to fill out advance directives and to review them every six months, or every year. One of the great potential benefits of self-directed care is the opportunity for the individual to grow, and advance directives should be reviewed and revised to reflect changing perspectives and directions, as people experiment with different approaches to recovery.

Health Care Proxies

Since many studies have shown that medical professionals often ignore advance directives if there is no one besides the incompetent patient to enforce them, a crucial component of advance planning is the appointment of a trusted other or others to act in the individual’s stead and ensure that his or her preferences continue to be carried out. In fact, the clearest message from both self-directed care program directors and people with psychiatric disabilities with whom I spoke was the need for a supportive community of others as a prerequisite for success of the self-directed care program.

Crisis Plans

While advance directives and health care proxies are limited to health care decisions, both medical and psychiatric, general planning for coping with periods of difficulty, including planning about housing, employment, child care, and possible hospitalization, should be part of the self-directed care program. In fact, planning for respite or refuge or additional support could help avoid hospitalization.

Fiscal Intermediaries

Virtually all self-directed care programs use fiscal intermediaries to pay the bills for the recovery budget devised by the program participant. These intermediaries must be completely separate from the mental health system and the provider system, and accountable to the individual. They cannot exercise clinical judgment over the appropriateness of choices.

Notes

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[1] President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Making health care decisions: The ethical and legal implications of informed consent in the patient practitioner relationship* (Washington, DC: Government Printing Office, 1982);

Paul S. Appelbaum & Thomas Grisso, The MacArthur Treatment Competence Study: I. Mental illness and competence to consent to treatment, *Law and Human Behavior, 105 (*1995),

Thomas Grisso et al., The MacArthur Treatment Competence Study : II Measures of abilities related to competence to consent to treatment, *Law and Human Behavior,* 127 (1995), and

Thomas Grisso & Paul Appelbaum, The MacArthur Treatment Competence Study: III Abilities of patients to consent to psychiatric and medical treatments, *Law and Human Behavior*,149 (1995).

[2] See cases listed in notes below.

[3] *University of Miami Law Review,* No. 3, The Law of Competence, Symposium Issue (January 1993);

Psychology, Public Policy, and Law, No. 1, A Critical Examination of the MacArthur Treatment Competence Study: Methodological Issues, Legal Implications, and Future Directions, Symposium Issue (March 1996).

[4] In re LaBelle, 728 P.2d 138, 146 (Wash. 1986); Rivers v. Katz, 495 N.E.2d 337, 342 (N.Y. 1986).

[5] Doe v. Rowe, 156 F.Supp2d 35, 55 (D.Me. 2001).

[6] Drope v. Missouri, 420 U.S. at 176.

[7] Roesch, Hart, & Zapf, 96, 109 (noting that a person might be competent to consent to treatment one week but not the next).

[8] Susan Stefan, Silencing the different voice: Competence, feminist theory and law, *University of Miami Law Review,* 763, 768 (1993). (Women are dramatically overrepresented as subjects of challenges to competence, even when controlled for larger proportion of older women in the population.)

[9] Daniel W. Fitzgerald, Cecile Marotte, Rose Irene Verdier, et al., Comprehension during informed consent in a less-developed country, *Lancet*,1301 (Oct. 26, 2002) and

Paul Farmer, Can transnational research be ethical in the developing world? *Lancet*, 1266 (Oct. 26, 2002) (discussing problems with competent consent to experimental HIV research by extremely poor and illiterate Haitians).

[10] Ibid.

[11] Jonathan Rabinowitz, Evaluating the competency of the neediest, *Journal of Mind and Behavior*,157, 169 (1994) (A woman was found incompetent on the basis of saying that she possessed 35 patents and that her landlord was taping her; in fact, the woman did possess 35 patents, and "an officer of the court subsequently found that her landlord was secretly taping Ms. Weitzner.")

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[12] Rachel A. Pruchno et al., Competence of long-term care residents to participate in decisions about their medical care: A brief, objective assessment, *Gerontologist,* 622, 624 (1995).

[13] Loren Roth et al., Tests of competency to consent to treatment, *American Journal of Psychiatry, 297*, 283 (1977) (comparing the search for a single competency test to a search for the Holy Grail).

[14] Christopher Slobogin, “Appreciation” as a measure of competency: Some thoughts about the MacArthur Group’s approach, *Psychology, Public Policy, and Law*, 18, 22 (1996).

[15] Trudi Kirk & Donald Bersoff, How many procedural safeguards does it take to get a psychiatrist to leave the lightbulb unchanged? *Psychology, Public Policy. and Law*, 45 (1996).

[16] Susan Stefan, Race, competence testing, and disability law: A review of the MacArthur competence research, *Psychology, Public Policy, and Law*, 31 (1996).

[17] Marshall Kapp & Douglas Mossman, Measuring decisional capacity: Cautions on the construction of a “capacimeter,” *Psychology, Public Policy, and Law*, 73, 82 (1996).

[18] Thomas Grisso & Paul Appelbaum, The MacArthur Treatment Competence Study III: Ability of patients to consent to psychiatric and medical treatments, *Law and Human Behavior,* 149, 172 (1995).

[19] Model Rules of Professional Responsibility, Rule 1.14, and Commentary (American Bar Association, 2003).

[20] Dusky v. United States, 362 U.S. 402 (1960) (per curiam), Pate v. Robinson, 383 U.S. 375 (1966); Drope v. Missouri, 420 U.S. 162 (1975). In order to be judged competent, the individual must have “a rational as well as factual understanding of the proceedings against him” and have “sufficient present ability to consult with his attorney with a reasonable degree of rational understanding,” Dusky at 402.

[21] Ford v. Wainwright, 477 U.S. 399 (1986). In order to be competent to be executed, an individual must understand the nature of the death penalty, and why it is being imposed on him.

[22] Faretta v. California, 422 U.S. 806 (1975).

[23] Godinez v. Moran, 509 U.S. 389 (1993). The standard for pleading guilty and waiving the right to counsel is identical to the standard for competence to stand trial.

[24] Nancy Knauer, *Temple Policy and Civil Rights Law Review, 321*, 324 (200)

[25] Lessard v. Schmidt, 349 F.Supp. 1078 (E.D.Wisc. 1972)

[26] See, e.g., Fla.Stat.Rev. ; 20 Pa. Consol. Stat. 5511.2(f)

[27] Minn.Stat. 253B.092, subd.5(b) (2002).

[28] *Doe v. Rowe*, 156 F.Supp.2d 35 (D.Me. 2001).

[29] *Hargrave v. Vermont*, 340 F.3d 27 (2nd Cir. 2003).

[30] 14 Vt.St.Ann. 2671(b)(1) and (d)(1) (2002).

[31] Michael T. Morley, Proxy consent to organ donations by incompetents, *Yale Law Journal* , 1215 (2002).

[32] Bruce Winick, Presumptions and burdens of proof in determining incompetency to stand trial: An analysis of *Medina v. California* and the Supreme Court’s new due

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process methodology in criminal cases, *University of Miami Law Review,* 817, 859-62 (1993).

[33] *In re Phoebe G.*, Conn Supreme Court 2002

[34] *Bonnie S. v. Altman*, 683 F.Supp. 100 (D.N.J. 1989); *Heichelbech v. Evans*, 798 F.Supp. 708 (M.D. Ga. 1992); *Doe v. Austin*, 848 F.2d 1386, 1392 (6th Cir. 1988).