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Shared Decision Making: Whose Decision?

To the Editor: In the August Taking Issue commentary, Drake and Deegan (1) framed shared decision making as a moral imperative for mental health services. According to this view, traditional providers must move beyond paternalistic approaches to treatment and offer decision aids and supports to help people with mental illnesses choose among service options. It levels the field of interaction, so that mental health professionals set aside authority and partner with service consumers to decide about treatment options. We believe shared decision making does not go far enough. It does not convey to the person with mental illness that his or her decision "trumps" the preferences and choice of the provider—that is, the person with mental illness has ultimate control over life choices and treatment options.

Joint decision making is a relatively easy enterprise when patient and mental health professional agree on overall direction and activities. It is when they disagree that shared decision making is limiting. Consider times when the psychiatrist believes medication is needed but the individual wishes instead to stop.

Leaving the ultimate choice up to

the person with mental illness makes anecdotal sense, at least in terms of general medical care. Modern medicine has broadened physician roles to include those of educator and counselor, providing information patients need to decide about treatments and offering support as these treatments proceed. For example, the person treated for lymphoma is fully informed about the cancer's prognosis as well as the medical, surgical, and alternative approaches to the illness. In many cases, a single health care professional is unable to fully present the broad range of related information. The patient weighs the costs and benefits and then selects a treatment. In mental health care, self-determination is fundamental to a recovery-oriented system. Sometimes the mental health professional's role is limited to providing information and support while the person opts to move in a different direction. Professionals can be uncomfortable on the sidelines because they know that relapse and failure are not infrequent outcomes for persons with serious mental illnesses. But forestalling failure robs individuals of the dignities of risk and discovery.

Our point is by no means foreign to Drake or Deegan. Patricia Deegan has been writing eloquently about personal empowerment and recovery for more than 30 years (2). Robert Drake is a leading innovator in practices that promote recovery. Individual Placement and Support (IPS), an example of supported employment developed and championed by Becker and Drake (3), is a model of leaving the ultimate choice to the person with mental illness. The IPS participant has primary authority in deciding on vocational goals and the methods to achieve these goals. For example, when Mr. Smith opts for law school but has only a high school diploma, the IPS job coach may believe that the goal exceeds Mr. Smith's capacities but nonetheless provides comprehensive support and guidance about pursuing and obtaining a law degree. Research on IPS shows that this kind of final determi-

nation is fundamental to successful vocational rehabilitation.

At the core, we may be framing shared decision making and leaving the ultimate choice to the patient as categorically distinct when there is clear overlap. An additional moral imperative, therefore, is a research agenda that examines the intersection of the two constructs.

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Jonathon E. Larson, Ed.D.**

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In Reply: Many thanks to Drs. Corrigan and Larson for their thoughtful letter. They raise the important issue of the interface between self-determination and shared decision making. Is shared decision making a step backward in the long struggle for autonomy, choice, and self-determination for people with psychiatric diagnoses, or does it represent a step forward? We appreciate the opportunity to extend this discussion.

We view shared decision making as a critically important step forward in the struggle to make choice an option for autonomous adults who are faced with tough treatment decisions in behavioral health. Shared decision making emphasizes the process, rather than the decision itself. To make decisions that are well informed, consistent with one's values, and in one's own best interests, people need information, unbiased decision aids, support, and opportunities to ask questions and consider alternatives. An infrastructure must be created that makes this process efficient and realistic in typical clinic settings. It should

include decision support centers located in the clinic, Web-based multimedia decision aids, and decision support specialists, particularly people in recovery (1). Such an infrastructure helps to ensure that the practice of shared decision making is firmly embedded as standard operating procedure within the clinic.

The need for a formal infrastructure is further underscored by research that shows that physicians, therapists, case managers, nurses, employment counselors, and other mental health practitioners do not reliably convey accurate, up-to-date, evidenced-based information and do not always include clients in the process of making decisions (2). Thus we do not agree with the statement that "joint decision making is a relatively easy enterprise." In the absence of an infrastructure to support shared decision making, joint decision making happens at the discretion of the provider, who may or may not convey accurate information. Shared decision making promotes choice because it removes the practitioner as the arbiter of information and allows individuals to explore information in a self-directed fashion.

Shared decision making recognizes and honors the autonomy of both the practitioner and the person with a diagnosis. In this model, there is a dynamic tension between the two parties. The practitioner is a gatekeeper with the legal power to give or deny access to treatment. On the other hand, the individual can exercise personal autonomy by refusing or consenting to treatment. For instance, a physician can recommend ECT, but a client can refuse it. Conversely, a client with a substance abuse history can request a benzodiazepine, but the physician can refuse that request. Shared decision making is a platform that invites and empowers both autonomous parties to form an alliance, exchange information, and find common ground regarding what, if any, treatment might help and what desirable treatment outcomes might be. Of course, watchful waiting, or postponing treatment in favor of monitoring events over time, has always been

an integral component of shared decision making.

Finally, shared decision making is not indicated in situations when decisional capacity is clearly compromised according to the law. Examples include PCP intoxication, advanced Alzheimer's disease, and delirium. In such situations the spirit of self-determination and shared decision making can be honored through the use of psychiatric advance directives.

A cartoon published in 2003 in the *British Medical Journal* shows a group of physicians hovering about a bed-ridden patient. The attending physician pronounces to the patient, "When we want your opinion, we'll give it to you." Shared decision making heralds the end of the monologue and the beginning of the dialogue.

Robert E. Drake, M.D., Ph.D.

Patricia E. Deegan, Ph.D.

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A Staging Model to Guide Psychological Interventions in Psychosis

To the Editor: Several key lines of evidence support the utility of a clinical staging model to guide early interventions for patients with psychotic disorders (1,2). Such an approach defines the progression of disease in time and identifies the patient's position along this continuum of the course of illness (2). This approach integrates a variety of neurobiological, social, and personal risk factors, providing a clinical decision framework for person-tailored early intervention.

Although use of low-dose antipsychotics has shown clear-cut advantages in the treatment of fully fledged psychosis (3), there is insufficient evidence to support this pharmacologi-

cally based intervention for help-seeking patients who are in the prodromal phase or at ultra-high risk of psychotic illness but who are still below the threshold of frank psychosis. In this context, psychological interventions that address phase-specific components of the prodromal phase of psychosis are of primary importance, both as a way to control subjective distress and as an opportunity to add to the knowledge base on early intervention in psychosis in mental health services.

According to recent modeling of the progression to schizophrenia and related disorders (1,2), at least four stages along a continuum can be identified: a premorbid phase, without gross psychosocial impairment but with detectable endophenotypic vulnerability traits and risk factors; an early prodromal phase, with mostly anomalous subjective experiences (such as basic symptoms), initial psychosocial impairment, and deterioration of the quality of life and of relationships with peers; a late prodromal phase, consisting of subthreshold psychotic symptoms—that is, attenuated psychotic symptoms or brief and limited intermittent psychosis; and an overt psychotic phase that is liable to develop into schizophrenia.

Such staging indicates a continuum of increasing risk, where initially unspecific conditions that phenotypically overlap with the early stages of other disorders gradually progress to more defined clinical-diagnostic profiles. Given the heterogeneity and multidimensionality of the mental states that might indicate a risk of psychosis, psychological interventions should be individually tailored to address salient clinical and biopsychosocial features and would be better conceived as a spectrum of problem-focused techniques.

Indeed, patient and family psychoeducation, self-help (including online resources), and supportive counseling might be better suited for the initial phase, whereas other interventions, such as symptom-focused coping training, enhancement of problem-solving skills, cognitive-behavioral therapy, and interpersonal

psychotherapy would become progressively more pertinent according to the incremental level of psychopathology, personal suffering, and caregivers' burden. Thus the clinical staging model can promote increasing integration of psychotherapeutic techniques, ranging from context-oriented skills training that supports specific domains of behavioral functioning to more sophisticated sociocognitive interventions (4) and even to the reestablishment of a coherent self-narrative during recovery from psychosis (5).

Mapping the "taxonomy of risk"—as reflected in the clinical staging model of psychosis—to a coherent spectrum of psychotherapeutic techniques offers clinicians a unique opportunity to move beyond the rigid geography of traditional psychotherapy "brand names" toward a more person-centered approach focused on early intervention.

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Acknowledgments and disclosures

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An Early Example of Culturally Competent Services

To the Editor: In their article in the August issue, Hernandez and colleagues (1) stated that "cultural competence occurs when there is compatibility among four important factors: community context, cultural characteristics of local populations, organizational infrastructure, and direct service support." In their otherwise comprehensive literature review, it is astonishing that they failed to find, in their own state, an early research-based model that exemplified all of these characteristics.

In the 1970s and 1980s the University of Miami–Jackson Memorial Community Mental Health Center (CMHC) developed a model based on prior community research and community outreach techniques similar to those in the applied example used by Hernandez and colleagues, the African-American Family Services of Minneapolis. The Miami CMHC served a multiethnic inner-city catchment area with five ethnic community teams that were based on the demographic characteristics of the center's neighborhoods and an assessment of their needs. The teams, African American, Bahamian, Cuban, Haitian, and Puerto Rican, were composed of clinical and social scientist staff matched to the ethnicity and language of the neighborhoods.

In addition to providing outreach and helping the communities access needed resources, the center offered crisis, inpatient, consultation, and referral services and developed nine neighborhood mini-clinics that served outpatient and aftercare clients in their own localities. Extensive case management was also provided, because research had demonstrated that environmental interventions can improve therapeutic outcome (2). At a time when dropout rates as high as 75% were reported for African-American and Hispanic clients, this CMHC had a mean dropout rate of 4%, with a high of 12%. With respect to keeping appointments, normative evaluation data indicated no-show rates ranging

from 40% to 56% for African-American and Hispanic clients. This CMHC had a mean no-show rate of 9.7% (3).

The program went on to develop a national cross-cultural training institute for mental health professionals, which trained nearly 200 clinical and administrative staff and produced its own research data on organizational changes in culturally competent care (4). The program eventually became freestanding as New Horizons CMHC; however, despite its success, it has had to vastly reduce its services. We may develop many ideal models, but unfortunately, programs rich in cultural competence cannot persist without adequate funding and zeitgeist support.

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In Reply: We thank Dr. Lefley for her letter. Between 1979 and 1991 she and her colleagues (1–3) developed and documented an exemplary mental health services approach reflecting the organizational cultural competence features that we identified in the literature published between 1994 and 2004—both in our August article and elsewhere (4). The first two of these features involve accounting for community context and cultural characteristics of service populations, which Lefley and colleagues accomplished by deliberately and clearly grounding services in the ecological contexts of their community

(including cultural perspectives on mental health and its treatment).

We identified a third broad cultural competence feature, organizational infrastructure, which includes organizational functions such as communication, governance and planning, evaluation, human resources, and service array. Employing communication practices that stressed learning and direct exchanges of information both within the organization and between the organization and the community, Lefley and colleagues facilitated community participation in evaluation, planning, and governance. These efforts, along with a human resources infrastructure that procured culturally competent staff, facilitated a service array responsive to the needs of the population served.

Lefley and colleagues' approach reflected three important characteristics that make up the final organizational cultural competence factor we identified—direct service support. First, the range and capacity of available services reflected the needs of the service population (service availability). Second, policies and procedures facilitated individuals' ability to successfully enter, navigate, and exit needed services and supports (service accessibility). Finally, organizational practices directly promoted service use in the community and facilitated organizational accountability by tracking service use patterns (service utilization).

Lefley and colleagues' approach reflected nearly all of the cultural competence features identified in our literature review and summarized in our organizational cultural competence model. Consistent with the tenets of our model, this culturally competent approach led to service parity in their community.

In her comments on our model, Dr. Lefley underscored that "programs rich in cultural competence cannot persist without adequate funding and zeitgeist support." We wholeheartedly agree. In presenting our model, we argued that its focus on the ability of mental health service organizations to understand and respond to local communities' cultural-

ly influenced values, needs, and attitudes toward service emphasizes that cultural competence is an aspect inherent to all mental health services and not only those serving racial and ethnic minority groups. We believe that the dissemination of this important perspective is an integral part of ensuring the zeitgeist that Dr. Lefley highlights as integral to the sustainability of culturally competent services that—like the model she developed with her colleagues—reflect the factors identified in our review.

In the context of mental health services, culture is a dynamic set of factors that have a pervasive influence on the experience of all individuals. As such, recognizing culture and incorporating it into organizational functioning are essential to the development of approaches that lead to service parity. We hope the findings summarized in our model help foster the day when service approaches such as that developed by Lefley and colleagues are the norm rather than the exception.

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Linda M. Callejas, M.A.

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Satisfaction as an Outcome Measure

To the Editor: We would like to take issue with Dr. Norquist's (1) July Taking Issue commentary, "Contented

but Not Better: Problems With Satisfaction." His comments about the study by McCrone and colleagues (2), which used satisfaction as a primary outcome measure in a cost analysis of assertive community treatment teams in London, raised two important issues: the precision of satisfaction as a concept and its utility for policy decisions. His comments ignore an extensive literature that has refined the concept of satisfaction and has demonstrated the role of satisfaction as an indicator of health care quality (3). Recently, satisfaction has been successfully used as a primary outcome in clinical antipsychotic trials (Canuso C, Grinspan A, Merriman C, et al., unpublished manuscript, 2009). Satisfaction as a multidimensional construct captures the essence of what patients, clinicians, policy makers, and taxpayers hope to achieve (4).

Thus we disagree with the thrust of Dr. Norquist's comments, which for some readers will raise doubts about such subjective constructs. We do agree that it would have been more informative if McCrone and colleagues had taken a multidimensional approach in addition to using a global measure of satisfaction. Several studies in the oncology field, as well as our studies of quality of life, have demonstrated the reliability of global measures. Although global measures capture patients' preferences, we agree that they do not provide information about factors that contribute to the genesis of the construct of satisfaction. Measures assessing satisfaction must be specifically focused.

We have demonstrated that most psychiatric patients are able to focus on questions about satisfaction with the care they receive and are reliably and consistently able to express their inner feelings and their level of satisfaction (4). Uncritical acceptance of the notion that psychiatric patients are unreliable in expressing their inner feelings can set the field back 30 years. The paradox is that when psychiatric patients report their hallucinations and delusional experiences, which are subjective in nature, they are believed and their reports are taken to be valid in making a diagnosis.

When we submitted our first paper in the mid-1970s, which presented data about negative subjective responses to antipsychotics, the editor returned the manuscript with a polite comment that the reviewers considered the subject as “soft science.” It took several years for the concept of measuring subjective responses to antipsychotics to become well-established, mainstream clinical practice, and the practice has been further supported by dopamine neuroimaging studies.

We agree that satisfaction as a construct requires continued refinement and more understanding of its components. However, administrators and policy makers who pay no attention to patients’ dissatisfaction with therapeutic interventions should not be surprised when these interventions fail. We are afraid that Dr. Norquist’s comments could discourage research and once more relegate subjective experiences such as satisfaction to the realm of “soft science.” We do not doubt that many of our patients will never be contented unless they feel better.

A. George Awad, M.D., Ph.D.
Lakshmi N. P. Voruganti, M.D., Ph.D.

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In Reply: I appreciate the comments of Drs. Awad and Voruganti. They appear to agree with the two points I tried to make in the brief commentary: use of a single outcome indicator

alone (such as a global score of patient satisfaction) can lead to misguided policy decisions and a global measure of satisfaction fails to capture the complexity of the concept. Such short commentaries without references preclude extensive elaboration on a topic. Unfortunately, Drs. Awad and Voruganti read more into the commentary than was intended. I did not indicate that people with mental illness are incapable of expressing their “inner feelings.” In fact, I stated that measures of satisfaction are “essential to understanding clients’ preferences and providing feedback to professionals and managers.” I’ve been involved in quality-of-care research for more than 20 years and have advocated since the beginning for broader measures of quality of care, especially those that go beyond measures of clinical symptoms alone and incorporate client perspectives (1).

Although Drs. Awad and Voruganti agree that more work is needed to improve satisfaction measures, they seem to believe that there is enough existing research to convince us that we can use the measures without concern. Perhaps I have misread their letter, but if they do believe this then they are mistaken. Much progress has been made in the area of satisfaction measures but much more work needs to be done before we can feel confident using them as outcome measures (especially alone) to indicate where to intervene in improving quality of care. This is true not only in mental health but across the rest of health care, including oncology. In fact, given the problems with satisfaction ratings, the Institute of Medicine chose not to include them in its influential report on quality (2). Others have provided very thoughtful assessments of the current state of such measures in the mental health area and have concluded that more research is needed (3). This doesn’t mean that satisfaction can’t be determined; it means we need better ways of measuring the concept than exist currently. This includes going beyond traditional survey methods and incorporating better qualitative techniques.

The goal is to improve the quality of the care we deliver so that the lives

of people with mental illness will be better. To do so, we must have reliable and valid measures of the various components of quality to know where to make strategic changes in the delivery of care (4). To assume that we have enough information to use current measures of satisfaction alone as adequate outcome indicators of quality would not only set us back far more than 30 years but delay any further improvement in health care. This could result in the worst outcome—people who are neither contented nor better.

Grayson S. Norquist, M.D., M.S.P.H.

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Psychosocial Distress in Cancer Patients’ Families

To the Editor: In the August issue Muriel and colleagues (1) reported results from a study that surveyed oncologists about how they managed their patients’ psychosocial distress. The high screening and referral rates are encouraging. Yet I was struck by the lack of attention to family members’ psychosocial distress, which can often have profound effects on a patient’s psychosocial needs. Failure to engage a patient’s family in the screening and referral process can render futile all the patient interventions—from support groups to referrals to social workers and psychiatrists.

Treating the family of a cancer patient is not part of usual care. Even at tertiary care cancer hospitals, where

the threshold for initiating psychosocial interventions is low, implementing family involvement remains a challenge. I read Muriel and colleagues' report while caring for a profoundly depressed patient with metastatic gastric carcinoma. Our attending oncologist addressed psychosocial distress early on in the management of the patient, and the primary team planned to obtain an official psychiatry consult to help manage the patient's depression. However, we stalled—not because the resources were not available at our institution, not because the team was insensitive to the psychosocial issues in the case, and not because the patient, who had capacity, was resistant to receiving psychosocial interventions. Instead, it was the patient's family that presented the barrier to optimal psychosocial care.

Their resistance began with the psychosocial screening process. They demanded that no mental status exams be performed because the questions were "belittling" to the patient, but every time they themselves detected a change in mental status, they demanded STAT head CTs and neurosurgical consults before psychiatric consults were "permitted." Under medicolegal pressure from the hospital's administration and from the Patient Services Department, who were embroiled in impending litigation with the family, the primary team scurried about mollifying the family's demands, gathering consults from neurology, hematology, neurosurgery, and even general medicine but unable to obtain the raw data (a mental status exam and depression screen) to intervene psychiatrically.

This family's suspicious and threatening attitude toward medical care in general and psychiatric care in particular was an extreme but understandable reaction to the stress of their loved one's illness. Though extreme, it provides an example of how a patient's family can become the barrier to psychosocial care even in settings where screening is regularly performed and interventions are readily available. Although oncology patients can be deemed "without capacity to make medical decisions" or "a danger

to themselves," their families cannot. The family cannot be referred for a psychiatry consult, and the family cannot be collectively prescribed anxiolytic and antidepressant medications or sent to therapy under duress to help manage their reactions to their loved one's terminal illness.

It is heart-wrenching to stand helplessly by as a family inadvertently ruins the opportunity for their loved one to enjoy his or her final days. Finding ways to involve "difficult" families in psychosocial interventions without violating the trust and autonomy of the patient and the family is essential to developing more effective psychosocial care in cancer medicine.

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In Reply: Dr. Gulliver's letter raises important concerns about the delivery of psychosocial and psychiatric care to patients with cancer. Her case description highlights complex clinical issues about the social context of oncology practice and the importance of involving family at many levels. In clinical practice, it behooves medical and psychosocial teams to include family caregivers in communication and medical decision making, as well as in assessments of coping and the need for psychosocial intervention.

In fact, 44% of oncologists in our study reported that "talking with family" was one of their methods of screening for distress (1). Caregivers and other persons in the patient's social network can be an asset to patients' coping and to their receipt of psychosocial care, but these individuals can also be liabilities depending on their own beliefs and past experiences with medical and psychiatric care. There is increasing attention to caregivers of patients with cancer and

to the potential for enhancing outcomes for both patients and caregivers (2–4).

The case also raises questions about the role of patient autonomy and the responsibility of physicians to treat adult patients according to their own wishes, especially in difficult medicolegal situations. This is in contrast to pediatrics (the first author has worked in both adult and pediatric settings), where parents and guardians make medical decisions for children under 18 but are also held accountable by child protection laws for making decisions that are in the best interest of their child. Adult oncology settings are not organized to account for complex family systems, and clinicians are therefore left to use clinical skill and judgment in assessing and treating a patient's comorbid medical and psychiatric conditions, either in collaboration with the family or despite their involvement.

Although there are particular systemic challenges with difficult families, clinicians must continue to strive for appropriate screening and delivery of psychosocial and psychiatric care to patients with cancer. Psychiatrists working in oncology settings are well positioned to enhance oncology providers' awareness of reliable methods of identifying and treating psychosocial distress, as well as to advocate for increased availability of mental health services in oncology treatment settings.

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William Pirl, M.D.

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