Abstract: The use of psychosocial criteria to assess candidates for organ transplantation may violate the Americans with Disabilities Act (ADA). The ADA prohibits discrimination on the basis of disability or on the basis of eligibility criteria that disproportionately affect persons with disabilities. When organ programs deny access to a person because of schizophrenia, they are denying an organ on the basis of disability. When organ programs deny access to a noncompliant person, they are denying an organ on the basis of an eligibility criterion that is more common in persons with coexisting disabilities like mental illness. Accordingly, both of these denials may violate the ADA. However, the ADA recognizes that it often is appropriate to take a person’s disability into account when allocating organs for transplantation. There is a legitimate social interest in allocating organs in a way that maximizes medical benefit, and a person’s disability may compromise the benefit that the person will receive from a transplant. It is likely that courts will interpret the ADA to permit denials of organs or lower waiting list priorities for persons with disabilities as long as predictions of diminished benefit are based on scientifically valid criteria, the assessment of candidates is individualized and not based entirely on generalized predictors, and the transplant program undertakes reasonable steps like psychological counseling to compensate for an organ candidate’s coexisting disability.

The Americans with Disabilities Act

The Americans with Disabilities Act (ADA) [1] very broadly prohibits discrimination against persons with disabilities, i.e., discrimination in employment, education, housing, transportation, health care, and in access to any other public or private service or program. According to the legislative history of the ADA, it was enacted “to provide a clear and comprehensive national mandate to end discrimination against individuals with disabilities” [2, p. 22].

Definition of Disability

There are several provisions of the ADA that are relevant to my analysis. According to the ADA, a disability exists when an individual has any illness, physical or psychological, that “substantially limits” a major life activity such as walking, learning, breathing, working or participating in community activities [2, p. 52]. Persons with chronic lung disease are considered disabled because they are substantially limited in their ability to breathe [2, p. 52]. People with schizophrenia are considered disabled...
because they are substantially limited in their ability to work. Even if a person’s disabling symptoms could be alleviated with treatment, the person would still be considered disabled under the ADA [2, p. 52]. A person with chronic lung disease is disabled even if bronchodilating medications alleviate any shortness of breath; a person with arthritis is disabled even if antiinflammatory medications prevent joint pains. A person meets the legal definition of disability also if the person has a history of a disabling condition (e.g., cancer in remission) or if others regard the person as having a disability that substantially limits a major life activity (e.g., asymptomatic HIV infection) [3]. Common conditions that meet the definition of disability include diabetes [4], alcoholism [4], epilepsy [4], and morbid obesity [5].

It is important to note that everyone in need of an organ transplant is disabled by their organ failure. Both those who receive organs and those who are denied organs meet the ADA’s definition of disability. Accordingly, how might there be discrimination on the basis of disability when organs are allocated for transplantation? Discrimination on the basis of disability may occur because some patients needing an organ transplant have medical disabilities other than their organ failure, and these additional disabilities often serve as the basis for denial of an organ. For example, a person with liver failure and schizophrenia may be denied a liver transplant on account of the schizophrenia. Discrimination on the basis of disability may also occur because some patients needing an organ transplant have medical disabilities other than their organ failure, and these additional disabilities often serve as the basis for denial of an organ. For example, assume a transplant program required organ recipients to have a driver’s license to ensure that they could drive a car to keep their appointments. Denying an organ because of a lack of a driver’s license is not denial on the basis of a disability, but the requirement of a driver’s license disadvantages people who are blind and ends up screening out people who are blind from receiving organs. Accordingly, the ADA generally prohibits the use of eligibility criteria that tend to screen out persons with disabilities.

A second provision that applies to private entities addresses a different kind of discrimination. The drafters of the ADA recognized that much discrimination does not come in the form of poorer treatment directly because of a disability. In other words, it is not just that people with disabilities are systematically disfavored persons with disabilities. For example, assume a transplant program required organ recipients to have a driver’s license to ensure that they could drive a car to keep their appointments. Denying an organ because of a lack of a driver’s license is not denial on the basis of a disability, but the requirement of a driver’s license disadvantages people who are blind and ends up screening out people who are blind from receiving organs. Accordingly, the ADA generally prohibits the use of eligibility criteria that tend to screen out persons with disabilities [9]. If cigarette smoking is used as an eligibility criterion, there might be a problem since using cigarette smoking tends to screen out persons disabled by lung disease.

If this is all there was to the ADA, it would be difficult for transplant programs at private hospitals to use psychosocial criteria. Most psychosocial criteria are either disabilities or have a tendency to screen out persons with disabilities. For example, many programs exclude schizophrenics from consideration for transplantation [10], but schizophrenia is a disability, so the programs are denying transplants on the basis of a disability, and, as indicated, the ADA prohibits denials of medical services on account of disabilities. Similarly, many programs exclude people who do not comply with

Prohibitions Against Discrimination

Because there are different provisions in the ADA for public and private entities, I will assume we are dealing with a transplant program at a private hospital to simplify the analysis. This assumption does not affect the analysis; though there are different provisions in the ADA for public and private entities, the provisions essentially cover the same ground [6].

Among the provisions of the ADA that prohibit discriminatory practices, there are two that might apply to denials of organs or assignments of lower priority on the waiting list by a transplant program at a private hospital. One provision prohibits discrimination on the basis of disability “in the full and equal enjoyment of the services of any place of public accommodation” operated by a private entity [7] where hospitals and other professional offices of health care providers are explicitly defined as public accommodations [8]. This provision suggests that health care providers have to give persons with disabilities the same access to organ transplant programs as they do persons who do not have disabilities. A physician could not deny organ transplants to persons who are blind or paraplegic or give them a lower priority on the waiting list simply because of their blindness or paraplegia.

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medication regimens [10]. Noncompliance is not a disability, but since noncompliance is common in people with psychiatric disorders [11,12], the eligibility criterion of compliance has the effect of screening out persons disabled by psychiatric illness and the ADA generally prohibits the use of eligibility criteria that tend to screen out persons with disabilities. In short, the two provisions mentioned above appear to preclude the use of most psychosocial criteria.

Permissible Discriminatory Practices

There are times, however, when it is appropriate to take a person's disability into account, and the ADA permits discriminatory treatment accordingly. There are other provisions that permit denials of treatment on the basis of disability or that permit the use of eligibility criteria even though they screen out persons with disabilities.

First, the ADA allows hospitals, insurers, or similar organizations to engage in traditional risk classification practices as long as the practices are not designed as subterfuges to evade the purposes of the ADA [13]. An organ transplant program could argue that, when it denies an organ or assigns a lower waiting list priority on the basis of disability or on eligibility criteria that screen out persons with disabilities, it is doing so in accordance with traditional risk classification practices. It is standard and well-accepted practice to allocate limited resources like organs to patients who will derive a meaningful benefit from treatment. If patients have disabilities that compromise their ability to benefit from organ donation, then transplant programs could argue that it does not make sense to give the patients the same priority on the organ transplantation list as persons who would gain a greater benefit.

There is also a provision that expressly allows some use of eligibility criteria that deny services on the basis of disability or that tend to screen out persons with disabilities. The ADA permits the use of eligibility criteria that are disadvantageous to persons with disabilities as long as the criteria are "necessary" for the operation of the program [14]. Accordingly, a transplant program could argue that it has an obligation to allocate organs where they will do the most good, and its eligibility criteria are designed to serve that goal. Consequently, even though the criteria deny organs on the basis of disability or screen out persons with disabilities, the criteria may be permissible because they are necessary for the operation of the program.

Balancing the Conflicting Provisions

The preceding discussion illustrates the tension within the ADA between unjustified and justified discrimination against persons with disabilities. On the one hand, the ADA says that a transplant program cannot use psychosocial criteria that deny organs or result in lower waiting list priorities on the basis of disability, nor can a transplant program use psychosocial criteria that deny organs or result in lower waiting list priorities if the criteria tend to screen out persons with disabilities. On the other hand, the ADA says programs can use psychosocial criteria even if they disadvantage persons with disabilities as long as the criteria are reasonable risk classification measures or are necessary for the operation of the organ transplantation program.

What it sounds like then is that programs can use psychosocial criteria as long as the criteria really help distinguish among different candidates for organ transplantation in terms of their likelihood of benefiting from the transplant. If people with schizophrenia really tend to have short graft survivals, then it may be permissible to take schizophrenia into account when allocating organs.

Principle of Reasonable Accommodations

There is more to the ADA. So far, what we have found is that the ADA protects persons with disabilities from psychosocial criteria that give them less access to organs even when they would do as well with a transplantation. A program cannot deny a liver transplant because of alcoholism if, as some studies suggest [15], alcoholics have comparable graft survival to people who are not alcoholics. It is like saying that a company cannot refuse to hire a person in a wheelchair for a desk job. The paraplegia is irrelevant to the person's ability to perform a desk job. However, the ADA is also concerned with psychosocial criteria that discriminate against persons with disabilities when they would not do as well as others. The ADA is not just about preventing discrimination against persons with disabilities when the disabilities are irrelevant.

There is also a principle of reasonable accommodations which recognizes that society has developed its structures and policies on the basis of the needs of persons without disabilities. For example, people in wheelchairs have less mobility because
society tends to use stairs more than ramps or elevators. Those who use canes may have trouble crossing the street because the green light does not last long enough for them to reach the other side. Or, consider people whose psychiatric problems result in poor compliance with their medical regimen and therefore ostensibly make them poorer candidates for an organ transplant. Perhaps, these individuals would have better compliance if they had a more structured environment.

People with psychiatric problems have to rely more on external structure than on internal structure, but our society has evolved with a low level of external structure because most people can muster high levels of internal structure. We could have developed a more structured environment, and people needing external structure would be less disabled. In short, much of the disadvantage of a disability is not inherent in the disability but is a result of the interaction of the disability and the environment. If we had designed our society with the needs of persons with disabilities in mind, we would have a society in which disabilities had much less of an impact on ability to function. Accordingly, if we prohibited discrimination only when disabilities had no effect on a person’s functioning, we would do nothing to counteract the fact that our social structures are inherently biased against persons with disabilities. Treating people with disabilities equally when they start out with an unfair disadvantage simply perpetuates the original disadvantage.

Thus, the principle of reasonable accommodations says that you have to take reasonable steps to counteract the inherent biases of social structure. Specifically, for private hospitals and other public accommodations operated by private entities, there is unlawful discrimination if the entity fails “to make reasonable modifications in [its practices] when such modifications are necessary to afford [its services] to individuals with disabilities, unless making such modifications would fundamentally alter the nature of [the services]” [16]. The entity must also make auxiliary services available to ensure equal access of disabled persons to the entity’s services unless doing so would “fundamentally alter the nature” of the services or “would result in an undue burden” [17]. Thus, buildings have to have ramps as well as stairs for access.

How does the principle of reasonable accommodations apply to psychosocial criteria? Organ recipients have many responsibilities to ensure survival of their organs, and those responsibilities may not be feasible for a disabled person alone, but they may be feasible if the organ transplant program provides support services. Indeed, some transplant centers seem to be able to overcome compliance problems by having frequent contacts with their patients [18]. The principle of reasonable accommodations would likely require the provision of support services as long as it would not be unduly burdensome for the transplant program to have to provide them. Or, if a person has psychiatric problems that can be kept under control with counseling, there would probably be an obligation to include the counseling as part of the treatment program as long as the expense of the counseling was not unduly burdensome [19].

Individualized Assessments

There is an additional requirement of the ADA that affects the use of psychosocial criteria. The ADA requires that there be an individualized assessment [20] of whether a person with a disability is an appropriate candidate for a transplant. Organ transplant programs cannot judge prospective organ recipients simply on the basis of their inclusion in a group or class of similar persons. Hence, even if the person has a disability that generally makes people a poor candidate for organ transplantation, the issue is whether it makes this particular person a poor candidate.

Potential Legal Challenges Under the Americans with Disabilities Act

The foregoing discussion suggests a few avenues by which a person could challenge denial of an organ or assignment of a lower priority on the waiting list when the denial or lower assignment results from the use of a psychosocial criterion that is based on disability (e.g., schizophrenia) or tends to screen out persons with disabilities (e.g., noncompliance). First, the person could argue that the basis for the denial or assignment of lower priority has not been demonstrated to be scientifically valid. For many psychosocial criteria, there really are no empirical data demonstrating the reliability or validity of the criteria. If invalid criteria are being used, then there is no evidence that the disabled person would gain less of a benefit from an organ transplant than would other persons. Even if valid criteria are used, they might be applied improperly to deny an organ. In such a case, the person could argue that, al-
though valid and reliable criteria were used, the criteria were not used correctly when the transplant program made its psychosocial assessment. In making these two arguments, the person could cite a survey of transplant programs by Levenson and Olibrisch [10] that examined the use of psychosocial criteria. They found wide a variability among programs in the extent to which they used the different psychosocial criteria, suggesting that many of the criteria are of uncertain value. They also found that many of the programs did not have formal processes for making psychosocial assessments or that the programs used evaluators who may not have had sufficient expertise to make psychosocial evaluations. The first line of attack then is to challenge the psychosocial assessments as being based on invalid criteria or as having not been carried out with reliable procedures.

Second, even if the criteria used are generally meaningful predictors of graft survival and there is a sufficiently rigorous evaluation process, a person denied an organ on the basis of a psychosocial contraindication may not be affected by the contraindication in the usual way. If in that person’s case, the presence of the contraindication does not in fact mean that graft survival would be compromised, then denial of an organ would presumably be unlawful.

Third, in cases where there really are psychosocial reasons to disfavor a person with a disability, the person would have a claim under the ADA if the program did not undertake all reasonable accommodations to help overcome the negative effects of the disability on graft survival. If support services could compensate for the person’s psychosocial problems, and it would not be unduly burdensome for the center to provide those support services, then the ADA would require provision of the services.

A More Expansive View of the ADA

So far I have discussed my sense of how the ADA will be interpreted by the courts. I suggest a more expansive view of the ADA that I think the courts should adopt, although I suspect they will not. As indicated, the ADA includes a principle of reasonable accommodations that says we need to take into account the fact that we have structured our social organization with the needs and abilities of persons without disabilities in mind. As a result, people with disabilities do not function as well, not because it is inevitable that they will be hampered by their disabilities but because our social structure is not designed to accommodate their needs. In other words, the extent to which a particular condition is disabling is a function not only of the condition itself but also of social factors.

There is a second important aspect to this social or environmental side of disability. It is not only true that social factors can magnify the impact that a disabling condition has on a person’s ability to function, it is also true that the very existence of a disabling condition may be a consequence of social factors. Whether a person actually develops a disabling condition may be a consequence of the commissions or omissions of society.

For example, social forces cause disability by commission when environmental pollution leads to lung diseases or cancers, when lead-based paint damages the neurologic systems of children, and when unchecked violence results in traumatic injury. An important way in which social organization causes disability by omission occurs when priorities are established for medical research. Some illnesses, like heart disease and cancer, are the subject of vast research expenditures; other illnesses receive little attention from federal research funds. As a result, preventive and curative measures are developed unequally. People with coronary artery disease are saved by surgery from disability while people with multiple sclerosis cannot be helped very much by medical care. In part, this disparity may exist because it may be easier to treat coronary artery disease than multiple sclerosis. But at least part of the difference in responsiveness to treatment likely results from the fact that many more resources have been poured into research for coronary artery disease than for multiple sclerosis.

Consider another example in which research efforts may have led to better success rates in treating some patients than others. Persons with chronic lung disease (a disabling condition) who also suffer from coronary artery disease (a second disabling condition) do not do as well with bypass surgery for their coronary artery disease as persons with normal lung function and coronary artery disease. Consequently, they are less likely to be viewed as appropriate candidates for bypass surgery. Yet, the difference in likelihood of success may reflect not simply the fact that chronic lung disease inevitably complicates treatment of coronary artery disease but also the fact that techniques for bypass surgery were developed around the prototype of a patient with normal lung function. If treatment for bypass surgery had been developed on the assumption that
patients with coronary artery disease also have chronic lung disease, then different surgical techniques or altogether different treatments would have been developed, techniques or treatments that would be more successful than current treatments for patients with chronic lung disease (although perhaps less effective than current treatments for patients with normal lung function). For example, there might have been a greater emphasis on nonsurgical therapies than on surgical therapies since persons with chronic lung disease are much better able to tolerate nonsurgical than surgical therapies.

The way social organization can affect disability is demonstrated by the experience with heart transplantation as a treatment for end-stage heart disease. There are many patients who have such severely compromised cardiac function that heart transplant appears to be the only treatment left, but the patients do not have high enough priority on the waiting list to receive a transplant. Recent research on these patients has shown that unusually aggressive medical therapy is more effective than previously used regimens of medical therapy and that the newly aggressive approach often obviates the need for transplantation [21]. Had fewer resources been devoted to surgical approaches that can benefit only certain patients and more resources devoted to medical therapies that can be offered to all patients with severe heart disease, effective treatment likely would have become available sooner to a much broader range of patients who are more severely disabled by their illness. This phenomenon is analogous to the phenomenon of medical treatments often being more effective for men than women. Because research studies have typically used only men as subjects, the treatments developed are based on a male model and are often not as effective for treating women [22].

How does all of this fit in with eligibility criteria for organ transplantation? For many of the disabilities that compromise a person's ability to benefit from a transplant, there have not been the kinds of efforts devoted to understanding and treating the disabilities as for other medical problems. Psychiatric illnesses have suffered when research dollars are allocated; obesity has gotten little attention as well. If there had been more aggressive efforts in the past to treat these conditions and other disabling conditions targeted by eligibility criteria for transplantation, they would not now have the effect they do on organ transplant success. If we had better treatment for schizophrenia, schizophrenics would be viewed as better candidates for organ transplantation.

Moreover, much of the neglect of certain kinds of diseases reflects invidious prejudices people have about those diseases. Psychiatric illnesses have often not been viewed as real illnesses; other diseases, like obesity, have been ignored because they have been viewed as self-inflicted. Indeed, only in recent years has there been recognition of the fact that obesity results not simply from poor dietary self-control but also from genetic factors, which may be the major determinant of a person's body weight [23].

Accordingly, if we took the principle of reasonable accommodations really seriously, we would say that even meaningful medical differences among organ transplant candidates are not necessarily a basis for preferring one person over another, that these differences may have resulted from unfair biases in social structure. To compensate for these biases, physicians arguably should discount the significance of medical differences among patients when allocating organs for transplantation.

The difficult question is how much physicians should discount medical differences among patients. It is impossible to measure the effects of unfair biases or to know what the world would look like if society had evolved with fairer policies and structures. Nevertheless, we must make some efforts to overcome the biases of social structure. That we cannot tailor our remedy to the problem exactly should not prevent us from trying to remedy the problem as best we can.

To some extent, the statutory language provides an answer. The ADA does not require that transplant programs undertake unlimited measures to accommodate persons with disabilities. The obligation to accommodate ceases when the accommodations would become unduly burdensome or would result in a fundamental alteration of the program [24]. This limitation on the obligation to accommodate likely reflects a tension between the egalitarian spirit of antidiscrimination law and utilitarian concerns. Using medical resources where they will do the most good is an important value even if it is not the only important social value at stake with resource allocation. The limitation on the obligation to accommodate also undoubtedly reflects the fact that not all effects of disability are a consequence of biased social structures, and that in some cases, the debilitating effects of a disability result primarily from its inherent nature.1

1 An anencephalic infant's lack of cerebral cortical tissue, for example, would be a devastating disability under any social structure.
These considerations suggest the following standard for the obligation to provide reasonable accommodations. If a disabling illness seriously compromises a person’s ability to benefit from an organ transplant, the person could be denied an organ. Otherwise the person should be given the same opportunity as other candidates to benefit from a transplant. In other words, if the patient’s illness prevents the patient from realizing a reasonable minimum level of benefit from the treatment, it would be permissible for physicians to deny the treatment to the patient on account of the illness. Thus, if a person’s schizophrenia prevents the person from gaining a reasonable minimum level of benefit from a liver transplant, the person could be denied a new liver.

What would constitute a reasonable minimum level of benefit, like other legal standards, is not easily reduced to a precise formula. Courts would still have to rely to some extent on the exercise of discretion by transplant programs, but it also would be important that courts set the threshold low enough to ensure that it provides meaningful protection for persons with disabilities. Thus, if an organ transplant program excluded persons whose coexisting illnesses prevented them from gaining more than a few months of benefit from an organ, there should be no problem with the exclusion. If, however, a person gave lower priority to persons who would gain a few years of benefit on the ground that other persons would gain more benefit, that kind of prioritizing should not be permitted.

Clearly, such an approach would prevent society from maximizing the benefit to recipients of organ transplantation, but welfare maximization is not the only goal of a just society. Indeed, when we require employers to accommodate persons with disabilities in the workplace, we are saying that they must do so even though it will diminish the company’s economic efficiency and therefore society’s overall economic welfare. It costs money to accommodate persons with disabilities, but it is only fair to spend the money to compensate for the biases of social structure.

As I have indicated, while I think this view is the most appropriate way to realize the goals of the ADA, it is not likely to be adopted by the courts. Rather, the standards that I discussed are probably a much better predictor of where the courts will end up.

**Conclusion**

The ADA may have a profound effect on the way psychosocial criteria are used to allocate organs for transplantation. Because psychosocial criteria commonly are based on disability or have the effect of disadvantaging persons with disabilities, they are subject to scrutiny under the ADA. To ensure that psychosocial criteria do not unfairly and unlawfully discriminate against persons with disabilities, organ transplant programs should follow the following principles:

1. The application of psychosocial criteria must reliably distinguish different candidates for organ transplantation by finding meaningful differences among the candidates in the extent to which they will benefit from a transplant.
2. There must be a reliable process for undertaking psychosocial assessments.
3. Psychosocial assessments must be individualized such that they are based on the particular patient’s likelihood of benefiting from a transplant. Assessments that reflect generalizations about the patient and ignore more specific data are unacceptable.
4. Reasonable support services must be provided and other reasonable steps must be undertaken to help overcome the effects of a person’s disability on the person’s ability to benefit from an organ transplant.

**References**

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3. 42 U.S.C. § 12102(2)
4. 28 C.F.R. § 36.104
5. Cook v. Rhode Island, 10 F.3d 17 (1st Cir. 1993)
7. 42 U.S.C. § 12182(a)
8. 42 U.S.C. § 12181(7)(F)
13. 42 U.S.C. § 12201(c)
19. New Mexico Association for Retarded Citizens, 678 F.2d 847, 854–55 (10th Cir. 1982)