U.S. Supreme Court to Rule on Execution of Persons with Retardation

Susan Poland

On Monday, March 26, 2001, the United States Supreme Court granted a writ of certiorari, an order that the Court will hear a case, to Ernest P. McCarver. The next day the Court heard oral argument in the case of Johnny Paul Penry. Both McCarver and Penry are death row prisoners who are mentally retarded. How their cases are linked at the highest level in the U.S. court system means going back to 1989, when the Supreme Court decided the first Penry case [Penry I].

Johnny Paul Penry was a 23-year-old white male when in 1979 he raped and murdered 22-year-old Pamela Moseley Carpenter, the sister of Washington Redskins football player Mark Moseley, in her home in Texas. With an I.Q. ranging between 51 and 63, he is considered mild to moderate mentally retarded and functions with the abilities of a 6½ to 7 year old.

In Penry I, the Supreme Court decided on June 26, 1989, two issues:

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Transplants and Mental Disability: The Meaning of Discrimination

Robert M. Veatch

In the early days of organ transplantation, mental disability was usually an automatic exclusion criterion. Often this was undoubtedly based on the crude belief that other potential recipients were more worthy of this potentially life-saving intervention.

By the 1980s, however, such prejudice was more controversial. In the United States, federal regulations prohibited discrimination against infants and children based on handicap. Decisions to forgo life-saving treatments based solely on mental handicap came under more careful scrutiny.1 Similarly, the Americans with Disabilities Act has been interpreted to prohibit discrimination against the handicapped in medical treatment decisions.2 In spite of the trend toward prohibiting explicit discrimination against those with mental disability, organ transplants pose some interesting and complex ethical problems.3

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Transplants and Mental Disability: The Meaning of Discrimination

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The Emergence of Transplants for the Mentally Disabled

Transplants are increasingly considered for persons with mental disabilities. For example, Down Syndrome often presents with correlated cardiac septal defects that potentially cause significant cardiac problems. For a period, these cardiac problems were often not corrected at birth even though such surgery was possible. Children with uncorrected septal defects developed more serious complications as they matured. After a certain point, surgical correction of the patient's heart was no longer medically feasible. These patients became potential candidates for heart transplants. Patients with the rare congenital anomaly, Kabuki Syndrome (a multiple malformation disorder that involves mild to moderate mental retardation), have been reported to develop kidney and liver problems potentially requiring transplantation. Even though they recognize that mental retardation has often been considered a contraindication for transplant, Benedetti and colleagues have located eight kidney transplant patients out of a series of 1271 with significant mental retardation.

Recently, the Loma Linda University Medical Center transplant group has been raising ethical questions about transplants in patients with mental disabilities. Assuming that the time has come to recognize that it is a prejudice to automatically exclude persons with mental handicap from access to organs for transplant, some complex and difficult questions remain about exactly what would constitute unethical or illegal discrimination.

The Practice of Counting Disability in Organ Allocation

While it is increasingly unacceptable to exclude persons from transplant waiting lists simply because of mental disability, it is a long-standing and accepted practice to decide whether persons qualify for transplant based on some general criteria such as likelihood that the organ will benefit the patient, predicted length of life of the graft and of the patient following transplant, ability of the patient to follow a complex anti-rejection drug regimen, and the availability of an intact family support network for the patient.

Transplants are increasingly considered for people with disabilities.

The problem is that some of these now-standard exclusion criteria appear with unusual frequency in persons with mental disability. For example, many transplant surgeons would hesitate to list a patient for transplant if that patient had an unusually short life-expectancy. In the standard criteria for choosing a recipient of an organ among those on the waiting list, it is generally considered acceptable to consider which candidates would have the longest predicted expected benefit from the organ. However, if persons with a condition such as Down Syndrome have a shorter-than-normal life expectancy, then giving lower priority to those who have a predicted shorter time to live will systematically give that group lower ranking on the waiting list. While forswearing explicit discrimination against the handicapped, those allocating organs might adopt general allocation criteria that seem defensible, but indirectly place those with certain diagnoses at a disadvantage. Is it discrimination against the handicapped to consider short life-expectancy a reason to rank a person lower on the list when short life-expectancy correlates with, and perhaps is caused by, a handicap?

Certainly, it makes sense to exclude from transplant patients with very short life-expectancies. It would be cruel to expose someone with days or weeks to live to the pain and trauma of major organ transplant surgery if the patient were going to die very soon regardless. The surgery itself might shorten the life-span of a person so severely debilitated, but even if it lengthened the patient's life slightly, adding a few extra days would probably not be worth the trauma.

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Rational persons would probably decline such surgery. Even if they did not, most would consider allocating an organ to such a patient a wasteful use of a valuable resource.

But should the same reasoning apply when comparing two groups of patients in which one group will predictably have a few decades to live and the other will have a decade or two longer? If that difference is accounted for solely by the diagnosis of Down Syndrome in the group with the shorter life-expectancy, would this be discrimination against those with the mental condition, or would it be the unbiased application of utilitarian criteria designed to get as much good as possible for as long as possible from the organs?

Similar problems arise with the standard criterion of ability of the potential organ recipient to follow the complex post-surgery medical regimen. It makes no sense to provide a painful, expensive transplant and use a valuable organ if the recipient cannot follow the medical regimen necessary to increase the chance that the organ will survive. It is not in such a patient’s interest to receive the transplant and, even if he could receive it, it would be seen as an unfair depriving of others who could use the organ more efficiently.

But what if it is a mental handicap that is the reason that a surgeon believes a patient will not be able to follow the regimen? If inability to follow regimen is a legitimate general exclusion criterion in the normal population and mental handicap systematically increases the odds that person will be unable to follow regimen, this looks very much like discrimination on the basis of handicap.

Of course, assessing ability to follow regimen must take into account the specific skills of the individual who is the potential recipient. Some persons with mental disability may be fully capable of cooperating in a treatment plan. It must also take into account the availability of a support network to assist the patient in making sure that medications are taken and follow-up visits are completed on schedule.

Some persons with mental disability have effective support networks so that their mental condition would not impair adequate follow-up. In fact in some cases, it could improve the chances that the regimen would be followed. Excluding these persons on these grounds would be indefensible. But what about the practice of excluding persons with mild disability who live on their own or excluding those with more severe impairments who lack adequate support to see that the regimen is followed? If exclusion based on inability to follow regimen makes sense when applied to the general population, then does the identification of this problem in persons with mental disability count as discrimination on the basis of mental handicap?

What if mental handicap is the reason that a person cannot follow regimen?

A third example of the problem of figuring out what counts as discrimination arises in Down Syndrome patients. There are well-documented immunological abnormalities in Down Syndrome that result in serious medical problems: high incidence of infection, autoimmune disease, and malignancy.9 Leukemia, for instance, is 10-30 times more common in Down Syndrome.10

Clearly, any group of patients in the general population who had documented immunological abnormalities would have this fact considered when decisions are made to list them as transplant candidates. No patient who was at such unusual risks would want these facts ignored and many at such risk would not want to be immunosuppressed with drugs if it increased still further their risk of serious medical problems. But if a group of persons with a diagnosis involving mental disability systematically has such risks, can the entire group be excluded or given lower status on a waiting list because of these risks?

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The Meaning of Discrimination

Those working on the ethics of discrimination on the basis of handicap have struggled with these issues for many years. The usual approach is to attempt a mental exercise—a thought experiment—in which we try to imagine that the patient has some underlying medical condition needing treatment—such as the cardiac septal defect—but lacks the correlated mental handicap. We reason that if we would transplant organs into patients with septal defects who were mentally normal, then nondiscrimination requires transplanting for the handicapped with the same condition as well.

The problem with this reasoning is that for the mental exercise to be valid, we need to take into account not just the existence of the septal defect, but also of other medically relevant facts. We would need, for example, to consider a child with a septal defect who also has a shorter life-expectancy or immunological abnormalities. We would, in short, have to imagine a mentally normal patient who has exactly all the problems of persons with Down Syndrome but who lacks the Down Syndrome. The problem is that it is hard for our minds to imagine someone who lacks Down Syndrome but still has all the potential problems that those with Down Syndrome possess. If someone has all of those conditions, he or she is, in effect, someone with Down Syndrome. By the time we have taken into account all the special factors that are related to Down Syndrome we are really considering the Down Syndrome.

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One possibility is to try in our minds to separate the physical problems that correlate with Down Syndrome from the mental problems exactly the way we would treat someone who had a short life-expectancy and immunological problems but was mentally normal.

That may work when we consider the impact of certain physical problems of organ transplant, but what if the problem is mental disability itself? That may well be the case if the mentally disabled have a harder than usual time following a regimen after transplant. The thought experiment would then require that we imagine someone who is as incapacitated mentally as the patient with Down Syndrome and treat the Down Syndrome patient exactly the same way. But someone who has a mental incapacity that exactly mimics the Down Syndrome is, in effect, someone with Down Syndrome. We could well end up concluding that both patients should get lower priority in the allocation of organs because of increased difficulty in following regimen. This, of course, is exclusion solely based on mental handicap. It, however, relies on mental handicap solely as a basis for predicting organ graft survival—a criterion normally considered morally legitimate in excluding patients from transplant or giving them lower priority.

On the other hand, if we say that these factors related to mental handicaps must be excluded from consideration if we are to avoid discriminating, we would end up saying that inability to follow regimen is irrelevant in deciding whether a person should receive an organ. But that would end up inflicting a potentially useless procedure on a person who could not benefit. It is hard to see how these factors could be ignored in those who do have some underlying diagnosable mental disability.

Some of these problems are potentially open to correction in an ideal world in which there are enough resources to attack the complications of transplant. For example, if all persons with mental handicap had an adequate support network the problems with inability to follow regimen might be reduced or even disappear.

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If differences in life-expectancy measured in decades are not morally relevant to the allocation of organs the systematic lower life-expectancy in Down Syndrome might no longer be an issue. (Or alternatively we could devote resources to figuring out why the life expectancy is lower and fix the problem. If lower life-expectancy were entirely attributed to mortality from organ failure amenable to transplant, an admittedly unlikely possibility, then exclusion from transplant would turn out to be exactly the wrong strategy.)

Unfortunately, we do not live in an ideal world. It is likely there will always be medical and social factors that correlate with various diagnoses of mental disability that are perceived as legitimate factors in writing organ allocation rules. Short patient survival, inability to follow regimen, and immunological problems are all seen as legitimately relevant allocation criteria. That they become illegitimate when they are correlated with some underlying diagnosis of mental disability seems unlikely.

Treating persons with retardation plus physical problems adversely affecting transplant exactly the same way we treat those persons who have the same physical problems but lack retardation seems reasonable, but what do we do when the mental incapacity itself is the cause of some factor like inability to follow regimen that accounts for the tendency to exclude?

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10. Ibid.

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U.S. Supreme Court to Rule on Execution of Persons with Retardation

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one, that the execution of persons with mental retardation did not violate of the Eighth Amendment, and two, that mental retardation should be a mitigating factor for jury consideration during sentencing. The issue to be decided in the new Penry case [Penry II] is, when has a trial court adequately informed a sentencing jury of a defendant's mental retardation?

After becoming a prisoner on death row, Johnny Paul Penry began exhibiting signs of mental illness, whereas at the time of the offense, during trial, and afterwards during sentencing, no evidence of incompetency was found. Exactly three years earlier, on June 26, 1986, the Court, in the case of Ford v. Wainwright, Secretary of Florida Department of Corrections, concluded that the Eighth Amendment prohibits the death penalty for insane prisoners, because based on English common law roots, the punishment of execution, whether for retribution or deterrence, was clearly not to be administered to a person who had lost sanity, be it prior to the offense, or at any time during subsequent legal proceedings (such as arraignment, pleading, trial, judgment, sentencing, or execution), despite differing rationales concerning the humaneness and moral quality of the law. Justice Thurgood Marshall wrote that the Court takes into account "objective evidence of contemporary values before determining whether a particular punishment comports with the fundamental human dignity that the Amendment protects."

The Eighth Amendment of the U.S. Constitution (which prohibits "cruel and unusual punishments"), as one of the first ten amendments, is part of the Bill of Rights. Effective on December 15, 1791, the language of the Eighth Amendment is derived from that in the 1789 English Bill of Rights. The principle behind the Eighth Amendment goes back further to the Magna Carta, and that principle is a basic underlying concept of dignity. The State may have the power to punish, but the Eighth Amendment limits the power to "civilized standards" to quote Chief Justice Earl Warren in the March 31, 1958, decision of Trop v. Dulles, Secretary of State. Chief Justice Warren noted, "The Amendment must draw its meaning from the evolving standards of decency that mark the progress of a maturing society."

The issue of sentencing in McCarver is much broader than the issue in the new Penry case. In McCarver, the question goes back to the first issue in Penry I: whether under society’s current standards the Constitution's ban on cruel and unusual punishments bans the execution of mentally handicapped people. The legal definition of insanity, as used in the insanity defense, derives from the common law prohibition against execution of "lunatics" and "idiots"; it encompasses both mental defect and mental deficiency. However, in Penry I, Justice O'Connor distinguished those persons diagnosed as being profoundly or severely mentally retarded as corresponding to the ancestral concepts of lunatics and idiots. Thus Johnny Paul Penry’s level of mental retardation did not meet the legal level required for a successful insanity defense.

Ernest McCarver has an I.Q. of 67. Because the Court follows the AAMR (American Association on Mental Retardation) definition of mentally retarded, meaning with an I.Q. of 70 or below, Mr. McCarver is considered retarded. He functions at the level of a child 10-12 years old. In 1987, at age 26, he murdered a 71-year-old man in a cafeteria in North Carolina. Mental illness played no role in his case. So why is the United States Supreme Court reexamining under McCarver the question from Penry I of Eighth Amendment constitutionality of capital punishment of the mentally retarded?

Justice Sandra Day O’Connor wrote in Penry I that "in absence of better evidence of a national consensus, mental age should not be adopted as a line-drawing principle" in Eighth Amendment jurisprudence when deciding whether punishment is cruel or unusual. Justice O’Connor

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observed, "While a national consensus against execution of the mentally retarded may someday emerge reflecting the 'evolving standards of decency that mark the progress of a maturing society' (Trop), there is insufficient evidence of such a consensus today."

The Justice reasoned, "The cleanest and most reliable objective evidence of contemporary values is the legislation enacted by the country's legislatures." In 1989, when Penry I was decided, of the 38 states allowing capital punishment, only Georgia prohibited capital punishment of the mentally retarded and days later Maryland became the second state. Today, of the 38 states (along with federal and military law) allowing capital punishment, 13 states prohibit capital punishment of the mentally retarded. When one considers that 12 states (along with the District of Columbia) prohibit any capital punishment, the nation is split on this question. Half now prohibit capital punishment of persons with retardation. The Court's "national consensus" may have emerged, and thus the issue of execution of a mentally retarded person under the Eighth Amendment of the U.S. Constitution comes before the U.S. Supreme Court.

LATE DEVELOPMENT: On June 4, the U.S. Supreme Court ordered a new trial for Johnny Penry because the jury must be instructed to consider the mitigating circumstances.

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Follow-up:

District of Columbia Reaches $29 Million Settlement in CaseCharging Poor Care of Persons with Retardation

In an ongoing controversy over the poor quality of care for persons with retardation in the United States capital city, the District of Columbia, has, since the last issue of the Newsletter of the Network on Ethics and Intellectual Disability, reached a settlement with advocates for its mentally retarded residents. The agreement establishes a $29 million "protection fund" to create a monitoring system to help assure adequate care.

The case is the latest chapter in a long history of controversy over inadequate care that has included a series of 116 uninvestigated deaths and a court-ordered shutdown of the city's Forest Haven asylum, an archaic facility that at one time housed over 1100 residents. The closing of the asylum was supposed to lead to creation of city-financed group homes that would include adequate monitoring of the quality of care.

The problems with the group homes, including reports of problems including deaths and abuses, led to interventions on behalf of the residents.

The agreement, while welcomed by the advocates for the residents, has been criticized because it focuses exclusively on monitoring and fails to provide any additional resources for training or any wage increases for care givers.

The agreement is the latest development in a very tragic controversy that has existed in the city for over 20 years. It led to the firing last year of five of the top managers in the city's agency that deals with those with mental retardation and eventually the resignation of Dale J. Dangremond, the recently-hired top administrator of the city's mental retardation agency. She left after serving only five months on the job complaining that she had all the responsibility, but none of the authority, to fix the system.

It remains to be seen whether the influx of monitoring funds will be sufficient to resolve the problems.

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