

Denying the Rights of the Retarded: The Phillip Becker Case George J. Annas

The Down Syndrome child in need of treatment is a medical ethics paradigm. In a film distributed by the Kennedy Foundation, for example, a Down Syndrome newborn is allowed to starve to death because his parents will not consent to surgery to correct a duodenal atresia. And it is to detect and abort fetuses affected with Down Syndrome (trisomy 21) that amniocentesis is most often used. Down Syndrome children are also better than dogs to practice surgery on, as William Nolen reminds us in his *The Making of a Surgeon*. He recounts a conversation between a pediatrician and a young surgeon about a septal defect repair—a major heart operation—the latter is going to perform the next day. The young surgeon says he's "not worried a bit," and wouldn't wear even if his patient died on the table. "Oh, now I get it," replies the pediatrician, "you're doing a mongoloid."

The Down Syndrome child in court, on the other hand, has been a rarity—most legal commentators have assumed that courts would routinely order almost any treatment withheld solely because the child's legal guardian believed that a Down Syndrome child's quality of life is low. However, there is now legal authority in California for the proposition that a Down Syndrome child need not receive heart surgery for a ventricular septal defect, even if such surgery would be routinely ordered in the case of a normal child (*In re Phillip B.*, 156 Cal. Rptr. 48, 1st App. Dist., Division 4, 1979). Since this conclusion is unprecedented and potentially dangerous to the well-being of all retarded citizens, it is important to understand both the facts and the opinion.

In July 1978, when the case first came to court, Phillip Becker was eleven years old. The petition alleged that his parents were not providing him with the "necessities of life," specifically a heart operation. He had never lived at home with his parents and had been institutionalized since birth. At the time of the petition, he was residing at Schnuhr's Nursery (a home for nineteen multi-handicapped children) and was attending the Rouleau Children's Center School in San Jose, California. He is able to write his name, has good motor and manual skills, can dress himself, is toilet-trained, can converse reasonably and take part in school and Boy Scout activities. He was described as "near the top level" for a Down Syndrome child, and there was testimony that his IQ was "around the 60 range." A school psychologist testified that he could be placed in the county's sheltered workshop following his schooling.

The Medical Testimony

In 1973 Gary Earl Gathman, a pediatric cardiologist, made a clinical diagnosis of ventricular septal defect (a hole between the two pumping chambers of the heart which elevates the pulmonary artery pressure) and recommended cardiac catheterization to define the anatomy of the problem. The parents refused. In late 1977 Phillip was again referred to Dr. Gathman because he required extensive dental surgery, and the

anesthesiologist refused to administer general anesthesia until his cardiac problem was clarified. This time the parents consented and Dr. Gathman performed the cardiac catheterization. The results confirmed his clinical impressions and indicated that Phillip had already experienced changes in his pulmonary arteries. Dr. Gathman testified that an average life expectancy for someone with Phillip's condition, left uncorrected, is thirty years; that about one-quarter of such persons would die suddenly; and that most others would slowly deteriorate. Before they are totally debilitated, they will suffer from fainting spells during which they turn blue-black because of the lack of oxygenated blood. This makes them a constant worry to their caretakers. These children also tend to be smaller, thinner, and slower than normal; they "cannot run and play and keep up with the other children."

Dr. Gathman recommended corrective surgery to the parents, putting the risk of death at 3 to 5 percent, which he considered a "low risk." The risk was related to changes in the pulmonary artery, which would continue to deteriorate. He also noted a less than 1 percent chance that a heart-block necessitating a pacemaker would result from the surgery. Dr. Gathman indicated that he did not always recommend surgery for Down Syndrome children: "For a child who has an IQ of less than 30 and is institutionalized on a permanent basis, there's very little that can be gained from surgery."

The only other physician to testify was James William French, also a pediatric cardiologist, who had been asked by Dr. Gathman if Phillip's condition was surgically correctable. He testified that he believed that it was; the pulmonary vascular disease had not progressed so far that surgery was not feasible. While he was not asked to give an opinion on this case, he indicated that he "probably would have" recommended surgery if Phillip was "otherwise normal." While confirming most of Dr. Gathman's testimony, he put the risks of death from surgery at 5 to 10 percent-----noting that in his personal opinion Down Syndrome children were "more risky" to operate on than normal children because they are "less cooperative" and "seen more subject to infection." The witness admitted that he had recommended against surgery "in cases where children were so severely damaged intellectually or the central nervous system damaged that they virtually did not function or they were virtually incapacitated."

One of Phillip's teachers, a school psychologist, a program coordinator, and a probation officer gave additional testimony. This established, among other things, that Phillip's parents visit him about twice a year (although they testified they saw him five to six times a year) and that he is a lovable child who "refers to lots of men as Dad." There was no further medical testimony, although the parents placed into evidence a letter from Dr. Harry E. Hartsel, who predicted that Phillip would not learn to read, write, or take care of himself; he leads "a life I consider devoid of those qualities which give it human dignity."

The Parents

The only other witnesses were Phillip's parents, who testified that although Phillip had never lived with them, they considered themselves responsible for him as part of their family. They monitor his care and once transferred him to another institution when they thought he wasn't getting proper care. They thought about the proposed heart surgery for a long time, and consulted with a number of physicians and a Jesuit priest (they are both Catholics). Their primary reason for refusing consent was that they do not want Phillip to outlive them. They believe that geriatric care in this country is terrible and that Phillip will not be well cared for after they die. "His quality of life would be poor in such a place" and "life in and of itself is not what it's all about." They also did not want him to be a burden on their other children. When asked who would be better off if Phillip were dead, Mr. Becker replied: "I think it would be best for everyone, including Phillip and the survivors." And later he said, "There is no useful point in extending his life beyond the natural, by means of this operation." Mrs. Becker testified similarly, saying: "Geriatric care in this country at its best is not good. And I really don't want Phillip to have to be extended into geriatric care. As it is, Phillip will be with us our whole life. We are looking into them living thirty or forty years. Well be seventy or eighty."

The Judge's Opinion

The testimony took a day-and-a-half with Judge Eugene M. Premo of the juvenile court presiding. The court ruled immediately after the closing arguments. In a statement that can be charitably characterized as rambling, the judge decided not to order the surgery. He found the proposed surgery "elective" and not "a life-saving emergency." He determined that there were inherent risks of the surgery which no one could control, "such as a slip of the knife, malpractice, negligence" all of which would "make this entire case moot." He described the parents as articulate, intelligent, caring, loving, and thoughtful. He spoke of two of his judicial colleagues who had Down Syndrome children-one cares for the child and "the other one can't literally face the fact that the child exists." He said he didn't think he personally could handle it "if it happened to me."

The judge condemned the physician who testified that he would not recommend surgery if the child's IQ were 30 or less, denoting the IQ test as a "vehicle of terrible abuse" that could be wrong and is always arbitrary. Given what he regarded as a subjective medical opinion, the judge was kindly disposed to the Beckers. He concluded that their decision was "in the range of debatable actions." He did not want the government interfering with parental choice; he was worried "by the fact that 1984 is coming upon us." The legal conclusion: "There is no clear and convincing evidence to sustain this petition (to operate)."

The Appeal

At the urging of the Pro Life Council of California, which had been instrumental in bringing suit, the California Attorney General's office agreed to appeal. The opinion of the appeals court, written by Judge P. J. Caldecott and concurred in by Judges J. Rattigan

and J. Christian, is, if anything, less well-reasoned than Judge Premo's. The appeals court considered three questions: (1) was there any substantial evidence to support the judge's decision; (2) should the judge have required clear and convincing proof (or should the evidentiary standard have been preponderance of the evidence), and (3) should Phillip have been advised of his right to have counsel appointed for him at the proceeding? All three questions were quickly disposed of, the latter two on technical points.

On the first point, the appeals court noted that one physician testified that the operation on Phillip was more risky than average because of pulmonary vascular changes and because he was a Down Syndrome child. In addition there was risk of nerve damage that could necessitate a pacemaker. This evidence alone showed that the court "had before it a child suffering not only from a ventricular septal defect but also from Down Syndrome, with its higher than average morbidity, and the presence of pulmonary vascular changes." This was all the appeals court needed to conclude that the lower decision was based on substantial evidence.

The Precedent

The case stands for the proposition that Down Syndrome children do not have to be given treatment, if it can be demonstrated that the risks of the treatment are slightly higher than they would be in a normal child. How did this remarkable eugenic policy come to be articulated by an American court? Let me suggest some possible reasons.

First, nowhere in the lower court proceedings, is there any articulated standard for decision. Courts have recently been choosing among three: the best interests of the child, substituted judgment (usually considered the same standard when a child is involved), and reviewing the parental decision to see if it is "fair and reasonable." The lower court did not cite any of these; instead it decided that the parents can make the treatment decision as long as it is "in the range of debatable actions." This standard is reasonable if it means that the proposed medical care is debatable in the medical community and that there is no medical consensus on treatment for this child.'

However, as applied by the trial judge, the standard seems to be, as long as the parents sincerely believe in what they are doing (and are willing to debate it?), courts should not "second guess" them.

The appeals court did no better. It bowed to the "best interests" standard, but nowhere applies it. Of course, it cannot. It makes no sense to argue that non-treatment is in Phillip's best interest-unless one is willing to argue that the quality of life of even high-level Down Syndrome children is so low that they are better off dead-even if death will come slowly with pain and discomfort. Alternatively, the parents argued that institutional life is so poor that it would be cruel to subject Phillip to it in later life. This argument would let us justify not treating any senior citizen in an institution or nursing home because the care they receive is so poor. Likewise, the argument that the parents do not want their son to outlive them cannot prevail. It is, in fact, statistically more likely that

one or both parents will die before he does than that he would suffer harm because of the surgery. And even if this were not so, we do not (yet) permit parents upon their deaths to have their children executed.

Second, the decision was made in a judicial vacuum, with no consideration of similar cases from other jurisdictions. Two cases that could have been discussed were *Quinlan* and *Saikewicz*. The first decision permitted a parental decision to withhold or withdraw treatment, but only if the patient had "no reasonable possibility of returning to a cognitive, sapient state." The second decision found that Joseph Saikewicz, a sixty-seven-year-old institutionalized individual with an IQ of 10, was "cognitive and sapient" and that any decision not to give him chemotherapy for cancer (arguably an "elective" treatment for a non-emergency condition) could only be made by determining what decision he himself would make if he could make the decision. On the basis of either of those decisions, treatment for Phillip Becker would have been ordered in New Jersey and Massachusetts. Ironically, the appeals court, in citing a *Stanford Law Review* article by Professor John Robertson (who argues in support of such a child's right to treatment), uses only his definition of Down Syndrome.³

Third, the medical evidence could have been better presented. Only one physician was prepared to testify that the operation be done on Phillip-, the other was not ready to commit himself. Both were pediatric cardiologists-and the judge seemed to need a surgeon to assure him that the operation could be done and was in the range of the routine. Even though neither court ever used the adjectives "ordinary" or "extraordinary," both opinions clearly assume the recommended surgery is extraordinary; that risks of 5 to 10 percent mortality and 1 percent of needing a pacemaker are major risks on which one can reasonably decide against treatment. Incredibly, neither court balanced the surgical risks against the certainty of prolonged debilitation and death.

Conclusion

Parents have a right to their moral convictions. But the law places some limits on their actions. When a parental decision is challenged, courts have an obligation to transcend emotional considerations. Courts must make principled decisions based on clearly articulated standards. The Becker decision is an arbitrary decision based on a vague standard. It devalues human life in the name of family autonomy; it particularly attacks the mentally retarded.

Phillip Becker was denied his right to live because he is a member of an oppressed minority group: the mentally retarded. We cannot take rights seriously for ourselves, if we do not respect them in our weakest citizens.' Taking rights seriously is not a painless or cost-free measure; it is the only way our values can survive. Given all this, it is extremely disturbing that the California Supreme Court decided not to review the case. On narrow, legalistic grounds involving standards of review, the case may appear uninteresting. However, it was not decided on these grounds

and has a symbolic value far beyond its petty prose. It stands as a beacon cautioning us that courts too make mistakes: but the mistake is made in the open. It must be openly acknowledged, reversed if possible, and challenged by other courts confronted with similar decisions.

REFERENCES

¹See, e.g., *In re Hofbauer*, 56 A. D. 2d 108, 411 N. Y. S. 2d 416 (App. Div. 1978). *affd*, N. Y. S. 2d. (1979) (parents' treatment of son with metabolic therapy and laetrile for Hodgkin's disease upheld because condition was not deteriorating, they would resort to conventional therapy if it was, and child *was* under the care of a licensed New York physician who believed that their treatment course was reasonable). In contrast *is Custody of a Minor*, 379 N. E. 2d 1053 (Mass. 1978) reviewed and *affd*, Mass. Adv. Sh 2124 (1979) (parental supplement of chemotherapy with laetrile was ordered terminated on the basis that the child, Chad Green, was being seriously harmed by the treatment and that unanimous medical testimony opposed it).

²See George J. Annas, "*Reconciling Quinlan and Saikewicz: Decision Making for the Terminally III Incompetent*," *American Journal of Law de Medicine* 4 (1979), 367.

³John Robertson, "Involuntary Euthanasia of Defective Newborns: A Legal Analysis," *Stanford Law Review* 27 (1975), 213, n. 5.

⁴See Ronald Dworkin, *Taking Rights Seriously*, (Cambridge; Harvard University Press, 1978), pp. 264-205.