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Carl A. Anderson

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The Role of Government in Protecting Children with Disabilities

Carl A. Anderson

The author is a member of the United States Commission on Civil Rights. This paper was presented to the Bioethics Section of the American Academy of Pediatrics.

My subject is the role of government in the supervision of life-saving therapy in the nursery. As you know, the United States Commission on Civil Rights released not long ago an important report on discriminatory treatment of handicapped newborns.¹ The Commission concluded that evidence supports a finding that discriminatory denial of medical treatment is and has been a significant civil rights problem for infants with disabilities.² As a member of the Commission, my remarks focus upon the unique problems of those with disabilities, but most of what I have to say will be applicable *a fortiori* to life-saving therapy for infants *without* long-term disabilities.

Let me start by stating my overall approach to the subject. My general view of government is that it attempts to do far too much. The complexity of the modern world gives rise to many demands for government action; yet it is precisely this complexity that often makes it impossible for a governmental decision-maker to possess adequate information for a sound decision.

Furthermore, the danger of a government that intrudes too deeply into private matters is ever-present, and must be borne in mind. The generally accepted doctrine of *parens patriae* — that government can and must invade parental autonomy when the safety of children is threatened — must not be transformed into a general mandate for governmental snooping into child-rearing practices. Against this sort of abuse, a strong doctrine of parental rights must be asserted.

Role of Government

In the words of noted children's rights scholars Goldstein, Freud and Solnit: "As *parens patriae* the state is too crude an instrument to become an adequate substitute for flesh and blood parents. The legal system has neither

the resources nor the sensitivity to respond to a growing child's ever-changing needs and demands."³ I join their conclusion that "A policy of minimum coercive intervention by the state thus accords . . . with our firm belief as citizens in individual freedom and human dignity . . ." ⁴ If the state is "too crude an instrument" to substitute for parents' judgment, it certainly is also "too crude an instrument" to substitute for physicians' judgment. The state should not constantly second guess medical decision-making, impose futile therapies or hopelessly prolong the dying process.

These views are part of the general framework that I bring to the issues before us today. I also bring to them the realization that when we deal with issues involving the care and well-being of children, we often confront profoundly difficult policy questions. For example, although we frequently say that policies affecting children should be in their best interest, our ability to predict what is in the best interest of children is often tenuous and highly speculative. Furthermore, as a society we often lack a consensus on precisely what is the best interest of children. Those who view themselves as advocates for children bear a heavy burden of persuasion that they do indeed know what is best for children rather than simply pursuing their own value judgments, especially when the decision is to offer less than maximum therapeutic effort.⁵

In the 1979 case of *Parham v. J.R.*, the Supreme Court got it just right: "The statist notion that governmental power should supersede parental authority in *all* cases because *some* parents abuse and neglect children is repugnant to American tradition."⁶ That case involved whether the Constitution requires that parents who seek state administered institutional mental health care for their child must undergo a formal adversary judicial proceeding prior to commitment. The Court found that when "a neutral physician . . . make[s] a careful review of the parents' decision in order to make sure it is proper from a medical standpoint . . . [it is unnecessary] to employ an adversary contest to ascertain whether the parents' motivation is consistent with the child's interests."⁷ Let me, for now, emphasize the Court's two criteria: that the parents' decision be reviewed by "a neutral physician," and that the decision be "proper from a medical standpoint."

That said, let me add that government has an irreducible role to play in vindicating and protecting elementary rights, including the civil rights of children. In this regard, no individual's decision authority, whether parent or physician, can always be regarded as absolute. This belief is a foundational one for the Civil Rights Commission, since that body is specifically empowered by Congress to recommend legislative action for the enforcement of civil rights.

Etymologically, the term "civil rights" means the rights that every citizen has simply by being a citizen. But in standard usage today, the meaning of "civil rights" is that people in our country — even non-citizens — are not to have extraordinary burdens placed on them on the basis of prejudice or irrelevant factors. The factors of prejudice, irrelevance, and extraordinary burdens are important to understanding the role of government. Govern-

ment should not invade a privately made decision where the factors are absent. You might say that a basic doctrine of the civil rights movement is that people must not be injured or burdened because of irrelevancies.

When Congress passed the Rehabilitation act of 1973,⁸ it made a decision on behalf of the nation that disabilities belong in the category of irrelevancies. Prejudice against those with disabilities, especially mental ones, runs very deep in a culture that values physical and mental perfection the way ours does. This prejudice runs — or at least, it ran — among the most as well as the least educated. The written record is long and sad.

There was, for instance, the book *Heredity and Human Progress*, published in 1900, in which one D. McKim advocated the gassing of persons with mental deficiencies.⁹ In 1941, a physician speaking at a meeting of the American Psychiatric Association made the same proposal, complete with a “competent medical board” whose powers of life and death would be invoked by the so-called “guardians of the child.”¹⁰

Lest we think this was a fringe view at the time, the APA’s journal reprinted this speech, together with an editorial arguing that the reluctance of parents to let their mentally deficient children be killed constitutes a “psychiatric problem.” The editorial urged that this “problem” be studied, so as to determine “whether it can be assessed as healthy or morbid, and whether in the latter case it is modifiable by exposure to mental hygiene principles.”¹¹

Now, these recommendations of killing for eugenic purposes were made at a time when such ideas were actually being put into practice in central Europe.¹² Likewise, behavior modification through “exposure to mental hygiene principles” was also being tried, in the form of large-scale manipulation of public sentiment through propaganda. The rejection of genocide and totalitarianism that supposedly characterized the post-War period put the brakes on the more horrific proposals, but the prejudice that motivated those proposals was and is harder to deter.

Attitudes and Values

The Rehabilitation Act was supposed to deter such attitudes — or rather, to deter their harmful effects. As you know, Section 504 of the Rehabilitation Act gives to every “otherwise qualified individual in the United States” a right not to be discriminated against in any program receiving federal money. The statute is phrased in broad and general terms, and does not make specific mention of various categories of intended beneficiaries.

However, one of the bill’s sponsors, the late Senator Hubert Humphrey, inserted material in the record discussing the problem of discrimination against handicapped children. A frequent theme in these materials is that medical professionals, for all their specialized knowledge, frequently underestimate the real potential of children who, when born, appear severely disabled. Another theme is that the professionals tended to estimate

potential solely in terms of future economic productivity — which, of course, is not a medical judgment, but a value judgment.¹³

This brings to mind Baby Jane Doe, the handicapped infant girl born at University Hospital at Stony Brook, New York, in 1983. In this extraordinary case, the parents reversed their original decision not to seek surgery. As a result, this little girl, named Keri-Lynn, today smiles at the mother whom supposedly she would never be able to recognize, holds toys with the hand she would supposedly never be able to open and close.

According to a story from Associated Press, the child “likes to throw a ball to the family’s golden retriever, cruise around in a walker and try to sing ‘Row, Row, Row Your Boat.’ ”¹⁴ As the Commission’s report aptly comments, “it is hard to recognize the pain-wracked, unaware, bedridden creature of the doctors’ confident prediction.”¹⁵

Keri-Lynn had a predecessor who was not as fortunate: the so-called Bloomington Baby, who was born with both Down’s Syndrome, and trachea-esophageal fistula, a congenital abnormality incompatible with life but fully correctable in 90 percent of cases. However, the ordinarily indicated surgery was withheld, *because* the child had Down’s as well. This was, in effect, a death sentence — a very slow and painful one, fully carried out.

The reaction to the Bloomington Baby case led to the regulations under Section 504 which were sought to be applied in Keri-Lynn’s case. That case led to a succession of legal attacks, both procedural and substantive, in one of which the American Academy of Pediatrics was a party. When the legal dust settled, we were left with an inconclusive plurality opinion from the United States Supreme Court, upholding the overturning of the regulations, and an ongoing problem of ordinary care being denied to neonates with disabilities.¹⁶

The view of the Civil Rights Commission is this:

[A] recipient of Federal financial assistance should not be able to escape the requirements of section 504 simply by persuading or encouraging a nonrecipient to authorize what, but for the nonrecipient’s involvement, would be prohibited discrimination

. . . [T]he Commission recommends that the Executive branch give careful consideration to resuming investigation of allegations that children with disabilities are discriminatorily denied medical treatment based on handicap and initiate enforcement of section 504 in cases in which allegations are found to be justified.¹⁷

In addition to the short-lived regulations under Section 504, Congress in 1984 passed the Child Abuse Amendments.¹⁸ This legislation emerged from the crucible of a negotiating process that, in part, pitted the medical community against the disability rights community.

The regulations that these amendments put in place are skeletal indeed.¹⁹ Furthermore, the only penalty for a state that fails to enforce them is loss of federal funds under the Child Abuse Prevention and Treatment Act. This act provides no more than \$35,000 annually to most states, and none at all

to California, Ohio, Indiana, and Pennsylvania. As a vehicle for preventing something that the Civil Rights Commission views as a violation of fundamental rights, the regulations under the Child Abuse Amendments are something less than Olympian.

For the time being, the issue is left for the most part where many people think it should remain — in the field of medical ethics. But there is a problem with that. To leave it there is to beg the question. Withholding ordinary care from newborns with disabilities is an issue of medical ethics and nothing more if, but only if, it does not constitute invidious discrimination.

Quality of Life

Earlier, I quoted from the journal of the American Psychiatric Association. Now, I would like to quote from a guest editorial in the journal of the American Academy of Pediatrics entitled, "Sanctity or Quality of Life?" by Peter Singer.²⁰ It is particularly interesting because it was published by the Academy precisely during the time the Academy and other medical organizations were engaged in a series of meetings with officials of the Department of Health and Human Services to explore attitudes and practices in the medical community regarding treatment of disabled infants in light of the Department's Section 504 regulations. In his article, Singer concluded:

Once the religious mumbo-jumbo surrounding the term "human" has been stripped away, we may continue to see normal members of our species as possessing greater capacities of rationality, self-consciousness, communication, and so on, than members of any other species; but we will not regard as sacrosanct the life of each If we compare a severely defective human infant with a nonhuman animal, a dog or a pig, for example, we will often find the nonhuman to have superior capacities, both actual and potential, for rationality, self-consciousness, communication, and anything else that can plausibly be considered morally significant. Only the fact that the defective infant is a member of the species *Homo sapiens* leads it to be treated differently from the dog or pig. Species membership alone, however, is not morally relevant.²¹

Contrary to Prof. Singer's allegation, species membership is not only morally relevant, it is the very point upon which rests the moral foundation of the American form of government and the moral consensus which makes it possible. It is precisely this moral insight of Thomas Jefferson in the Declaration of Independence, that all human beings are endowed with the inalienable right to life and liberty, which is the linchpin of all our civil rights. This recognition is also the precondition of any enduring appreciation of human dignity. And as Jefferson recognized, the dignity of the human person is inalienable, which is to say that it cannot be made dependent upon a third party's determination of capability or quality.

More than 20 years ago the journal of the California Medical Association editorialized that "The traditional Western ethic has always placed great emphasis on the intrinsic worth and equal value of every human life

regardless of its stage or condition [and that this] reverence for each and every human life has also been a keystone of Western medicine and is the ethic which has caused physicians to try to preserve, protect, repair, prolong, and enhance every human life which comes under their surveillance."²² The editorial continued approvingly that this traditional ethic was being replaced by a new ethic of the quality of life, an ethic which unlike its predecessor would for the first time sanction killing.

These two ethics are commonly described respectively as sanctity of life or quality of life.²³ However, I believe, they are better appreciated in terms of their positing an absolute or conditional dignity of the human person. It is ultimately the new ethic's conditionality of human dignity which opens to us the prospect of extraordinary violations of basic human and civil rights. At the same time, I believe it is the absoluteness of the dignity of the human person which provides the firmest ground to protect against the dangers posed by both arbitrary individuals and overreaching government.

A civil rights issue is not transformed into an issue solely of "medical ethics" merely because it has a hospital for its locale. To take an extreme case for illustration, a political assassination does not become solely an issue of "medical ethics" because the perpetrator happens to be a doctor and the victim a patient. Now, the question of what duty of care a doctor owes to a handicapped newborn is not nearly so clear a case. Clearly there *are* pure issues of medical ethics involved. But at the point where a doctor says, "I owed this patient a diminished duty of care solely because he is handicapped," then the issue ceases to be purely one of medical ethics, and becomes one of civil rights. In the words of the Supreme Court, he has ceased to be a "neutral physician" making "a proper medical judgment."

According to the declaratory judgment entered in the Bloomington Baby case,²⁴ the doctor who delivered the baby recommended against surgery with the full knowledge that death would result, because, "even if surgery were successful, the possibility of a minimally adequate quality of life was non-existent due to the child's severe and irreversible mental retardation." The father of the child testified that he had previous experience with children with Down's syndrome and that "he and his wife felt that a minimally acceptable quality of life was never present for a child suffering from such a condition." Of course, as we all know, the judge then approved, what he termed "a medically recommended course of treatment," a course of treatment which was intended to result in the death of that child. I think it is clear that the Bloomington Baby was denied treatment not on the basis of a neutral and proper medical judgment, but because he was a member of an historically despised and vulnerable minority — persons with mental retardation.

Regarding the treatment of newborn infants with spina bifida, the Commission during its deliberations heard the following testimony from Dr. David McLone: "Since I have been at Children's Memorial Hospital [we have] operated on all children and have not used any form of selection . . . 85 percent of them survived and 15 percent of the children have died

from complications . . . of the 85 survivors, 73 percent of them have normal intelligence. Approximately 85 percent of them have a shunt for their hydrocephalus . . . 89 percent of the survivors are community ambulators . . . someone who can walk from the school bus to the classrooms, between classrooms and can walk in their neighborhoods. We would, therefore estimate," Dr. McLone continued, that "based on these numbers, that something like three-fourths of the children who survive will be competitive and independent as adults. There will be another 10 percent . . . who will require some kind of sheltered care, and about 10 percent of the survivors will be impaired to the point that they will require some kind of nursing care throughout their life."²⁵ Now, if Dr. McLone's experience is normative, what neutral medical principles can support the decision to provide only "supportive" care until death for these children, as was initially the case with Keri-Lynn?

In these circumstances, decisions to withhold care from the disabled, whether made by doctors or by anyone else, are usually based on rationales about the costs of maintaining such persons, about their relative lack of economic productivity, and about their lesser potential for leading a fulfilled life — that is, a life that the person making the judgment would subjectively call fulfilled. One thinks immediately of the fateful treatment formula apparently utilized by doctors at Children's Hospital of Oklahoma where the infant's quality of life equals its natural endowment multiplied by the contribution to its care provided by its family and the large society [QL = NE x (H plus S)].²⁶

There are two problems with such a rationale: it is often factually wrong as regards the predicted outcome, and it is invariably wrong as regards the moral presuppositions regarding the value of human life.

On the first problem, the factual issue, the Commission noted:

A substantial body of evidence shows that time and time again predictions of a poor quality of life made at birth for a child with a disability are subsequently proven wrong. Too many examples have been adduced to be dismissed as isolated instances.²⁷

And as to the second issue, the moral one, I can do no better than to quote again from the Commission's report:

A country committed to the civil rights of all should address the very real problems people with disabilities and their families face through fostering supportive services and social acceptance, and through defending their rights to accessible and integrated transportation, housing, education, health care, and employment — not by eliminating those with disabilities.²⁸

Perhaps one of the most persuasive arguments made on behalf of apportioning life-saving care in a manner that disadvantages those with disabilities is the argument that resources for such care are scarce, and therefore, apportioning it is a matter of triage. In making the necessary determinations, one can proceed at random, or one can do it on a first-come, first-served basis, or one can do it on the basis of likelihood of

recovery. As yet another alternative, according to some, one can do it on the basis of anticipated quality of life.

Thus, it is argued that even if one should save the life of a handicapped newborn rather than let life-saving equipment sit idle, one should prefer to save someone with the capacities to make a greater economic or social contribution to society. Now, triage is as old as battlefield medicine, which is to say as old as war. I do not intend to address desperate hypotheticals based on acute, local shortage of equipment. I do, however, want to address a larger point: we live in what some economists call "the affluent society," and in a society as wealthy as ours, there is simply no excuse for allowing triage situations to arise in ordinary medical practice. It is *de facto* discriminatory to allow triage situations to develop, such as that people are left to die as a direct result of being disabled. Shortages that create such situations should be dealt with by appropriate private and public means.

We must be careful not to let "triage ethics" spill over into ordinary situations. It is one thing when there is only one respirator in a five-hundred mile area, and three patients in the hospital who need it. It is another for the individual physician to allow or recommend death for a patient solely because of the notion that it is inefficient to allocate society's resources to preserving that patient's life.

It may seem to many that full recognition of the civil rights of disabled newborns would involve some undue governmental intrusion. That objection to civil rights has been raised in many other legal environments as well. I do not consider it a trivial objection. But the very concept of the rule of law, rather than the rule of the jungle, means that some people, some of the time, are going to have to do something other than what they want to do, all because someone else has an inalienable right.

A tremendous amount rides on the distinction between a legitimate medical judgment and a judgment that incorporates social factors, especially eugenic ones. If the latter, we are in the realm of discrimination. To dramatize the distinction, suppose that a doctor, claiming to be judging a matter of medical ethics, announced that so-called "crack babies" in danger of death are not to be given life-saving treatment. The outcry that would instantaneously follow (especially in minority communities) would be entirely justified. That doctor would have made a grossly discriminatory decision, notwithstanding the invocation of medical ethics. We can be reasonably certain that no doctor or medical ethicist would make such a decision. But, twenty years ago, one would have been reasonably certain that no doctor or medical ethicist would say that human beings may be less valuable than pigs. Obvious truths aren't so obvious any more.

In closing, I would like to relate a story that appeared several days ago in the *Washington Post*.²⁹ It begins like this: "On Oct. 24, 1951, Rita Greene was supposed to go home from the hospital. That morning during a routine test she suffered a drug reaction that stopped her heart." Within minutes a surgeon had run down four flights of stairs, opened Rita's chest with a razor blade he had used earlier that morning to shave, and performed direct

open-heart massage. But nearly 40 years later, Rita remains unconscious, still in the same hospital in what now is described as a persistent vegetative state.

Rita had come to D.C. General two years before her injury as a young operating room nurse; she remains there now as a patient. The article continues that her fellow "nurses bathe her every day and do her silvery hair up once a week. It is a point of great pride among her nurses that despite her years of inactivity, there's not a bedsore on her body." One nurse, Claire Norton, knows Rita very well. She has been her private-duty nurse for 35 years. Claire Norton works the midnight to 8 a.m. shift and often stays overtime to do extra services for Rita. "To me," she says, "Rita [is an example of the] inherent dignity of every person no matter what their limitations . . . [S]he has a life. As a nurse, I will sustain it, I will protect it, I will defend it to the end."

My point in recounting Rita's story is not that there is no difference between Keri-Lynn and Rita Greene or between the Bloomington Baby and Nancy Cruzan. Of course, important differences exist. Rather, my point is that the dignity of the human person exists equally and inalienably at the edges of life as well as at its center. Human dignity can never be measured by a quality of life standard, especially when such standards have been historically linked with a profound prejudice against certain classes of persons. It is the role of government to ensure a legal framework in which such prejudice will not dominate neutral medical decision-making.

In Hebrew, the word for justice — "saddiq" — conveys the notion that to be just, one must honor the integrity of one's relationship or covenant with others.³⁰ I would suggest to you that it is this concept of justice which underlies our fundamental approach to civil rights. It is a concept which I think Claire Norton knows well because she has lived it for 35 years. It is a concept which I would also suggest to you is a fundamental premise of medical ethics and that therefore there should be no necessary contradiction between our national commitment to civil rights and the practice of medicine.

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