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research ARTICLE

## **The Wrongful-Life Concept: The Role of the Courts in Individual Morality**

—Devon Mercer

**“What we have inherited from our fathers and mothers is not all that walks in us.”**

**—Mrs. Alving in Henrik Ibsen’s *Ghosts***

Much of the cutting edge of medical science deals with the very beginnings of life: conception, gestation, and birth. We are capable of knowing with great certainty many genetic characteristics of the developing child. But what should we do when the knowledge we gain tells of disorder and defect, perhaps even of a condition so devastating as to be incompatible with life? Should there be an overarching legal and moral policy that dictates a single course of action? What selections from our society’s diverse ethical and legal history should we use to create and justify such a policy? Finally, would this policy help or hurt those most intimately connected to the decision: the parents of the developing child and, especially, the child herself?

I had a strong reaction to these questions, raised in Professor Cerullo’s “Rights Revolution” course. I decided to research them, partly with the intention of supporting my opinion that no legal or ethical policy could or should ever consider the possibility that a disabled life is worse than no life at all. Partly because of my own psychological disability, I felt that there must be a single moral answer to these questions: they must be totally untenable. However, after completing the research for the course, I find that my opinion is changing: I am now willing to believe it possible, under certain conditions, that a person may claim legal injury for an impaired life caused by serious birth defects.

### **Background of the Wrongful-Life Concept**

Today, expecting parents can choose to have tests done which will indicate the probability of serious defects in the developing fetus. Armed with this information, they can then decide how—and also whether—to proceed with the pregnancy. If a serious defect is detected, the parents must decide on the course of action best for the child, the mother, and the family. Such difficult decisions depend on the accuracy of the tests and the interpretation of the results. Sometimes the information parents receive is incorrect. This can be due to faulty methods or negligence on the part of physicians and/or laboratory technicians where the tests are processed.

Should a child be born afflicted with a severe disability that, through faulty testing, was not discovered, the parents can then consider if they and their child have been “injured” due to negligence. They may then decide to seek redress in the courts.

Legal suits where the parents of an impaired child seek to recover for their own damages are no longer uncommon. Far more complex and challenging is the suit where an impaired child (or her guardian acting on her behalf) alleges that the negligence of doctors and/or technicians resulted in her birth, which is declared to injure her in some way (1). This type of suit is known as “wrongful life,” a term coined by an Illinois appellate court in 1963. In this suit, the child declares that the provider’s negligence deprived her parents of the knowledge they needed to make an informed decision to terminate their pregnancy or avoid conceiving her at all (2). Thus, the child plaintiff states that, had it not been for the provider’s carelessness, she would not have been born at all. A child declaring “wrongful life” seeks compensation for the pain, suffering, and emotional distress, caused by the defendants’ negligence, that transforms her everyday life.

Wrongful-life suits had been brought before American courts before 1963, but with very little success. In 1967, a case was brought in front of the California Supreme Court in which a woman sued her doctors because a sterilization operation, claimed to be successful, was not, and she became pregnant. She brought suit requesting compensation for personal and punitive damages. This case, known as *Custodio v. Bauer*, was dismissed, the Court arguing that the child’s “unwanted” status did not render it or its family in any way “injured.” A second case, brought in 1976 to the First District Court of Appeals for California, involved a joint action on the part of an unmarried mother and the child (*Stills v. Gratton*). Together, they claimed cause for wrongful life because her doctor’s early abortion procedure failed, leaving her unknowingly still pregnant past the time that a second procedure could safely and effectively be done. The plaintiffs asserted that, despite the child being born healthy, he was injured by his illegitimacy and should be able to recover damages. Further, the mother requested to recover damages for her own injury: being denied the chance to abort when she still had a choice. The Court remanded the mother’s suit to a lower court. However, they dismissed the child’s petition, holding that he was not injured by his illegitimacy.

In these two wrongful-life cases, the courts would not agree that the healthy children were injured by the negligence that resulted in their births. While it may be possible for their parents to recover for their own actions, it could not be found that the children had suffered the injuries necessary to support rewarding damages. By the beginning of the next decade, however, the wrongful-life arena would be presented with a case of a much different sort, where the injury was as clear as it was devastating.

### **The Curlender Case: A Landmark Decision in Wrongful Life**

Brought before the Supreme Court of California in 1980, *Curlender v. Bio-Science Labs et al* established a precedent that continues to inform the wrongful-life debate a quarter century later. The plaintiff in the case, Shauna Tamar Curlender, was a minor afflicted with Tay-Sachs disease. This congenital birth defect causes “mental retardation, susceptibility to other diseases, convulsions, sluggishness, apathy, failure to fix objects with eyes, loss of motor reactions, muscle atrophy and blindness,” leaving the child with an average life expectancy of no more than four years. It is completely possible to diagnose through specialized testing, and a false negative on such a test is very rare (1).

Shauna’s parents paid Bio-Science Labs and another testing facility to administer tests to determine if they were carriers of the gene for Tay-Sachs disease. The plaintiff, Shauna, declared that the defendant parties gave her parents incorrect information; based on this information, they decided to have Shauna. The plaintiff alleged, in short, that her disabled existence is a “proximate [direct] result” of the defendants’ negligence (1).

## **The Decision of the Curlender Court : A Revolution in Damages**

In coming to their decision, the Court made three revolutionary observations: 1) there is a difference between the Curlender wrongful-life suit and the wrongful-life suits of the past; 2) monetary damages in such a case are not "impossible to calculate;" and 3) parents and afflicted children have good reasons to continue to press the courts to make these decisions. According to the Curlender Court, society's general discomfort in dealing with a wrongful-life action should not stop justice from being served (1, all quotes from this case are from this source).

The Court's first observation made a distinction between the plaintiffs in previous wrongful-life actions and Shauna Curlender. The Court declared there to be a large difference in the "injury" suffered by unwanted or illegitimate but physically healthy children and the permanently and severely disabled Shauna Curlender, who suffers both physically and psychologically from her disease. The Court declared that illegitimacy was no longer a social or legal difficulty, but that Shauna Curlender's circumstances were of a completely different nature.

The Court's second observation set a precedent still cited in the wrongful-life suits of today. Though former courts had declared that calculating the value of the "loss" in a wrongful life action was impossible, the Curlender Court stated that "public policy" was changing; that is, public perception of moral values and their role in legal and ethical issues was altering. While the idea that all life is sacred is still widely held by society, there was at the time an emerging reluctance to relegate such actions to the arenas of metaphysics or religious beliefs rather than consider them in legal terms. This public policy shift suggested to the Court that it was time to begin considering ways in which the law could benefit disabled persons, previously considered to be removed from public life.

The third observation of the Court held that parents and afflicted children continued to "seek redress for the wrongs committed" for two important reasons. First, the intensity and severity of the wrong committed is such that it cannot be ignored. Second, the "increasing sophistication" of science's methods for discovering the causes of these wrongs, "which may not with present knowledge be attributed to the fine hand of providence but rather to the lack of care," made the issue of negligence real to the wrongful life arena.

The Court then made a ten-part finding on the case. While each finding is important, findings two, four, five, and eight are the most revolutionary. They present a case where injury can be shown, fault for that injury can be proven, and damages caused by that injury can be financially addressed.

In finding two the Court stated that the defendants had a clear duty to the plaintiff and breached that duty through their negligence. In terms of the broader wrongful-life injury discussion, this was a crucial precedent. To dictate that medical providers at every level of care be equally responsible for the outcomes of their negligence is to change how medicine will be practiced.

The fourth finding of the Curlender Court would also revolutionize the wrongful- life debate in both legal and social circles. This finding declared that it would be unjust to "retreat into meditation on the mysteries of life" and chalk up Shauna Curlender's injuries to divine providence. We should not be concerned, the Court said, that without the defendants' negligence, Shauna would not have been born; rather we have simply to acknowledge that, now that she has been born, she has the legal right to recover for her injury.

The Court, in finding five, sought to answer a question raised by many opponents of the wrongful life concept: If parents are fully informed of a serious birth defect in their developing child and they still choose to deliver that child at term, would the child have the right to bring a wrongful life action against her own parents? The Court argued that this exact scenario could happen, and that it would not be unjust or illegal for the child to take such an action. In this scenario, the "conscious choice" of the parents becomes an "intervening act of proximate cause," absolving the doctors of responsibility. The Court held that "we see no sound public policy which should protect those parents from being answerable for the pain, suffering, and misery which they have wrought upon their offspring."

These actions of the Court, finding eight declared, do not imply that the child has a right not to be born, but rather that she has a right to compensation for the pain, suffering and medical expenses incurred as a result of the defendants' negligence. Significantly, the Court refused to say that there is a value to be attached to life and that the value of a "normal" life is greater than that of an impaired life, but it did declare that if the birth and its associated defects are the direct results of negligence, then the plaintiff has a right to sue for the damages caused by that negligence. In this case and cases like it, birth brings with it the injury, and, like any injury caused by malpractice, it entails the right to compensation.

The Curlender case ended in a decision to reverse the order of a lower court which had dismissed the case. In terms of damages, it declined to award medical costs because the parents were already seeking to recover for those same costs in a separate suit. However, it did say that the plaintiff, Shauna, had pleaded sufficient cause for punitive damages. The Court allowed that she could bring a separate suit before a judge and jury to press for these damages. Further, they saw no reason, either in public policy or legal precedent, to make the defendants in future wrongful life cases exempt from punitive damages.

Despite the Curlender decision and findings, the wrongful-life concept is still a point of legal disagreement. Many courts consider wrongful-life actions using differing criteria and, most importantly, they do not all agree that being born is a "legally cognizable injury" (3). That is, they do not agree that being born alive and disabled can be construed as being worse than not being born. In fact, only three states recognize a wrongful-life action as valid based on precedent. Further, twenty-seven states actively refuse, through judicial opinion or statute, to recognize wrongful-life actions. Maine is the only state to recognize wrongful life in statute (3).

### **"Disability as Difference": Modern Wrongful-Life Ethics**

The wrongful life concept is a subject of dispute among medical ethicists as well as lawyers and judges. While the legal system may be able to separate the wrongful-life concept from the evaluation of disabled lives, evaluation is exactly what some ethicists feel is happening. Maria Michela Marzano-Parisoli, a registered nurse with the Center for Health, Ethics, and Social Research in Paris, is among those opposed to the concept. In her article "Disability, Wrongful-Life Lawsuits, and Human Difference: An Exercise in Ethical Perplexity," she lists four main implications of a wrongful-life concept. She asserts that any one of these implications alone is frightening enough to dismiss the concept (4).

First, Marzano-Parisoli contends that babies born disabled cannot necessarily be said to be worse off than had they never been born at all. As there is no single "fixed and immutable model of normality and health," there can be no absolute way to distinguish between the "normal and healthy people whose life is worth living and

abnormal and disabled people whose life is, on the contrary, wrongful." Second, she draws frightening parallels between the concepts of wrongful life and eugenics. If we accept that there are some lives that "should not have been created," Marzano-Parisoli claims, then we might be tacitly accepting that it is morally acceptable to "extinguish" those lives. Marzano-Parisoli's third premise argues that there are other cases apart from disability where it may be considered unethical to bring a child into life. Drawing from the philosophies of John Stuart Mill, she asserts in her article that he too would have found that "bringing children into being without the prospect of adequate physical and psychological support is nothing short of a moral crime." According to this logic, if giving birth to a child whose life will be difficult due to disability is morally wrong, shouldn't we also claim that giving birth to a child who will suffer difficulty in life because of poverty or emotional neglect is also wrong?

Marzano-Parisoli's final and most compelling argument against the concept of wrongful life is that it establishes being born disabled as a "bad" thing. If we establish that, she says, we must then ask *who* the birth is a bad thing *for*. She believes that the parents' desire not to bear a handicapped child is probably selfishly motivated because it would be bad for them as much as for the child. John Harris, a respected bioethics researcher and author, disagrees with her on this point.

Harris, a Professor of Bioethics at the University of Manchester Institute of Medicine, Law and Bioethics, argues that there can be far more altruistic motives for terminating a defective pregnancy. In his 1998 book, *Clones, Genes, and Immortality: Ethics and the Genetic Revolution*, Harris writes that parents are "blameworthy" if they "deliberately produce children with more than a slight disability" (5). Harris' basic position seems to be that to deliberately give birth to a child with a significant disability is to consciously allow that child to suffer. Further, Harris suggests that a fundamental difference exists between a developing child and a fully-formed child who exists outside the womb. He argues that since this difference exists, it is foolish to treat the developing child as we would treat an existing child: "[t]he fact that an entity can undergo changes that will make it significantly different does not constitute a reason for treating it as if it had already undergone those changes" (5). Following this logic, we are to understand that because a developing child is essentially different than an existing child, we should treat them differently. Since we can prevent suffering in the case of a developing child, it is our responsibility to do so. Harris' argument contradicts Marzano-Parisoli's conclusion that genetic testing and selective termination would necessarily lead to eugenics because the differences between an unborn child and a child outside the womb would lead to different treatment.

## **The Limits of Law in Determining Morality**

The conflicting, often strongly held legal and ethical views on this subject made my research challenging and intense. Every source I read affected my overall understanding of and opinion on the topic. Some sources made me angry; I could not understand how the authors could disconnect themselves so thoroughly from the emotional ravages of the subject and consider only technical issues. I found myself most drawn to those authors who showed a blend of scientific knowledge and emotional understanding. It is from this double viewpoint that I draw my own conclusion.

It is obviously folly to insist that there is no value to be had in a disabled life. Many disabled people have made great contributions to society: two obvious examples are the mathematical brilliance of John Nash, who suffered from severe schizophrenia, and the poetry and philosophy of Helen Keller, who was severely disabled from birth. However, I think it is also wrong to insist that there can *never* be a case where it might be better for a

child not to have been born. Wrongful life as a concept simply allows that there are some disabilities which can affect some people in such a severe, painful, debilitating way that it would be cruel to knowingly bring a child into such a life of suffering. While it would be morally wrong to universally deny the value of disabled life, it would also be morally wrong to cling selfishly, in a sense, to the lives of children who will be unable to enjoy those lives.

My research leads me to conclude that there can be no absolute, no single rule that applies to every situation. Every parent and each child is an individual: they have particular, personal considerations and intimate religious and ethical beliefs that must be respected. To create legislation around the concept of wrongful life which would deny this individuality is to ignore the complexity of each situation and of those involved in it. So far, the Curlender case rulings are our best guides: they allow the disabled child and her parents to argue for injury and compensation without, however, attempting to evaluate life according to physical ability or disability.

When the great playwright Henrik Ibsen approached this problem in his 1881 play *Ghosts*, he did a great service to every parent and child who would face this terrible situation. He did not tell us what Mrs. Alving decided to do when her child, suffering from an inherited, incurable disease, begged to be euthanized. Instead, he gave us a window into her soul: He let us watch and hear her as she struggled with this tragic request. What is she telling her son when she says that what "walks in us" is more than what we have inherited from our ancestors? Ibsen doesn't say, and this is a reflection of his own great humanity: He showed us that he understood the intensity of the situation and recognized that he did not know the "correct" answer. I now feel that no one knows that answer. We can only strive to make moral decisions and live in a manner that we and our families can be proud of. Sometimes, in order to do that, we must empower people to make their own decisions, rather than make those decisions for them.

*I would like to thank Professor John Cerullo for constantly challenging me to consider this subject, and many others, from every angle. I would also like to thank Cathy Overson, registered nurse and UNH-Manchester senior, for her sensitive and intelligent discussions on the subject. As always, I am grateful to my family for their willingness to listen to me "think out loud." All of these people were essential to this work, and without their support I could not have done this subject justice*

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## ***Author Bio***

*Devon Mercer, from Auburn, New Hampshire, is a student at UNH-Manchester. She intends to earn a B.A. in History and then go on to law school. Her article is drawn from the research she did for Professor John Cerullo's "Rights Revolution" course. She was surprised, she said, at how the sources she read were able to deal objectively with so emotional a subject. This research has helped her decide to concentrate on civil rights law, especially the role of the state in moral and ethical questions.*

## ***Mentor Bio***

*John Cerullo, Professor of European History, has been on the faculty at UNH-Manchester for twenty-six years. His research and teaching subjects, wide-ranging during these years, have been principally in the area of modern European intellectual history, especially the history of moral thought. A recent interest in legal theory led him to spend a sabbatical as visiting scholar at the Boston College School of Law. One result of this was a new course, "The 'Rights Revolution,'" which he developed and taught for the UNH Justice Studies Program. Professor Cerullo is an enthusiastic, effective supporter and mentor of students doing independent research.*