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# Parental Duties Toward Severely Impaired Infants: An Ethical Analysis

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*This paper comes from a 1986 summer seminar on "Principles and Metaphors in Biomedical Ethics" at the University of Virginia.*

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Parents, ground down in some cases by the stresses of caring for their severely impaired child, may decide to turn their offspring over to a state agency or a private group. In doing so, do parents violate their moral responsibilities? These situations raise profound questions about the moral responsibilities of parents which, as the Carnegie Council on Children writes, "society has never solved."<sup>1</sup> The fact that parents are allowed to surrender their children under a variety of circumstances does not make this a moral practice. With the rise of child advocacy movements, the moral challenge placed upon parents by a medical technology that gives life to infants who in other eras would have died in accord with the balance of nature, and the growing recognition that seriously impaired children generally develop better in the atmosphere of love and security which a family provides, rather than in large institutions, the time for moral deliberation is upon us. What is the basis of parental responsibility in these cases, and what are the limits of responsibility, if any?

## **I - Parental Responsibility? A Historical Backdrop**

Before responding to this vexing question, it is helpful to place it in historical context. This is because major voices in the current debate, particularly those which emphasize children's rights and expanded correlative parental duties, are reacting to centuries of child neglect in the West. Just as the feminist voice in ethical debate is best appreciated in the light of historical inequalities, so also the movement for children's liberation can best be understood with history in mind.

Traditionally, children have had very little moral status; they have, by and large, been treated as personal property to be discarded for reasons of parental convenience. As William A. Silverman writes:

On the whole, parents have acted on the assumption that each baby is a personal possession and that they are the ones to decide whether to invest the economic and psychological resources needed for the transformation of their completely dependent biologic creation into an independent social being.<sup>2</sup>

Children, with few exceptions, have been treated with relative indifference, for most parents believed, like Montaigne, that they "have neither mental activities nor recognizable bodily shape."<sup>3</sup> Westerners who have, in this century, granted children the moral status of full persons, would do well to realize that the veneer of civility is only a thin one, under which lurks what some suggest is an innate tendency toward infanticide.<sup>4</sup> As Philippe Aries has shown in his history of Western childhood, "This feeling of indifference towards a too fragile childhood is not really very far removed from the callousness of the Roman or Chinese societies which practiced the exposure of newborn children."<sup>5</sup> Indeed, the history of infanticide in the West is a long and tragic one which reached, even as late as the 19th century, epidemic proportions.<sup>6</sup>

### Precarious Life

If life for healthy children was precarious, all the more so for those with impairments. These children were often understood as "changelings," i.e., creations of the devil rather than of God, who should be beaten to death in the hopes that the devil would return the real child.<sup>7</sup> Impaired children were viewed, as Robert F. Weir has written, to be "supernatural substitutes or 'demon-children' who had taken the place of 'real' children."<sup>8</sup> The only recourse for parents was to "beat the devil out" of the child, destroying it in the process. Even Martin Luther, who had some progressive notions of parental responsibility, counseled the parents of a retarded 12-year-old child to throw it off a bridge into the water below.<sup>9</sup> If parental destruction of healthy neonates and bastards was as rampant as the historians suggest, it was surely all the worse for infants born with impairments. Parents rid themselves of these subhuman beings as soon as possible.

How is it that the West has gradually affirmed moral status for children and enlarged its notion of parental obligations? Here the historians are in agreement that Christianity took the lead in gradually establishing "a social policy aimed at limiting parental autonomy with respect to offspring . . ."<sup>10</sup> There are several prominent aspects of Christian teaching which have, over the course of time and despite setbacks, brought children into the moral community.

First and foremost, Christian consciousness includes children within the community of persons. Specifically, Christ declared that adults can enter the kingdom of heaven only by becoming as little children. It is evident that Christ had a high sense of the dignity of the child, and was displeased by those who followed Him for failing to value children as He did. Thus, the following words of Christ which have done as much as any others in the West to upgrade the status of the child:

And they brought young children to Him, that He should touch them: and His disciples rebuked those that brought them. But when Jesus saw it, He was much displeased, and said unto them, 'Suffer the little children to come unto Me, and forbid them not: for of such is the kingdom of God. Verily I say unto you, whosoever shall not receive the kingdom of God as a little child, he shall not enter therein.' And He took them up in His arms, put His hands upon them, and blessed them. (Mark, 10)<sup>11</sup>

Just as modern Christian feminists take note of the presence of women such as Mary Magdalene among the followers of Christ, and point out how the male disciples were deeply troubled by this affirmation of women, so also those who advocate children's rights can make use of the teachings of Christ.<sup>12</sup> Christ did not prescribe details of parental obligation, but He successfully inspired parents within the Christian community.

### Early Theologians' Reaction

The early Christian theologians, in continuity with the dignity Christ bestowed upon children with His blessing, reacted powerfully against the practices of their surrounding Roman culture. Every human being, they insisted, has a soul, and is therefore of inherent value—that was the vital argument. They asserted that children, having souls, were inviolable, to which religious doctrine probably more is due in the way of checking infanticide and encouraging parental responsibility than any other single idea. Earl E. Shelp, a philosopher rather than a theologian, in his analysis of the transition in Western culture from a child-denying to a child-affirming culture which begins with the 17th century, remarks: "The growing influence of Christianity contributed to these changing perceptions and practices. The social implications of Christian teaching that children had immortal souls, just like adults, seemed finally to affect family life and child-rearing practices."<sup>13</sup> Silverman makes the same point: "With the coming of Christianity, there was a specific theologic motivation for the importance of species membership: the belief that all born of human parents were immortal and destined for an eternity of bliss or everlasting torment."<sup>14</sup> As a result of Christian influence, Roman laws governing infanticide were gradually revised, though only partially. The Church did not accomplish as much as it wanted.

There are many passages from the early Christian theologians which are cited for their clear proscription against abortion and infanticide. There are also some interesting passages on parenthood which have, to my knowledge, been entirely overlooked in the contemporary literature. In the fourth century, for instance, Jerome wrote thus:

If then parents are responsible for their children when these are of ripe age and independent, how much more must they be responsible for them when, still unweaned and weak, they cannot, in the Lord's words, 'discern between their right hand and their left'.<sup>15</sup>

This heightened view of parenthood carries through the Christian theological tradition, and is echoed in Luther's prescription: "Then, if ever

our dear God and Father in heaven grants you children, nurture and care for them, raise them up in the discipline, fear, and admonition of the Lord."<sup>16</sup> Thomas Aquinas echoed the Christian call for parental responsibility as well when he argued that child-rearing is a part of the natural law to be discerned by the observation of animals. (Here he borrowed from the Stoic Ulpian).

In the light of this historical background, the views of contemporary Christian medical ethicists become understandable. Catholic ethicist Charles J. McFadden, basing his position on natural law theory, writes, "The primary purpose of marriage includes not only the procreation of children but also their proper rearing. In this respect, man can learn much even from the animals in lower creation. Natural instinct compels the beast to exhibit a tender care and self-sacrificing solicitude for its young."<sup>17</sup> McFadden lists attention to bodily needs, but also intellectual, religious, and moral nature, as included among parental duties. Protestant ethicist Paul Ramsey also has a lofty conception of parental responsibility which rests on a set of assumptions about divine love. God, argues Ramsey, creates nothing apart from a love which is steadfast. Creation is linked with nurturing love on this theological level. Then, Ramsey suggests that when parents procreate, "There is a trace of the original mystery by which God created the world because of His love."<sup>18</sup> That is, parents should link procreation with steadfast love for their children after the image of God. To procreate without assuming a relationship of love and loyalty with one's offspring is to fall short of Christian expectations.

The West has struggled perennially with the question of parental responsibility and the correlative moral rights of children. As Lloyd deMause has shown, Western attitudes toward children have shifted from infanticidal to ambivalent and only in this century, to "helpful."<sup>19</sup> Other cultures, despite the practice of infanticide, have had a much more child-centered worldview than the West, which issues in a more nurturing parental ethics.<sup>20</sup> The recent progress of the West can, in part, be attributed to the cultural impact of religious faith. Currently, the Christian attitude toward parental duties and the dignity of the child has spilled over into the discussion of seriously impaired infants. Stanley Hauerwas, for example, is right in suggesting that Christian parents try to view seriously impaired infants as "divine gifts" who teach the community to care.<sup>21</sup> This morally idealistic view of parental responsibilities may be a necessary one, in dialectic tension with the morally minimalist tendency of parents to discard impaired children for the sake of convenience.

### **Parental Response to Severely Impaired Infants**

One of the most important aspects of moral argument is strictly descriptive: "What is going on?" How we draw the picture of a set of circumstances is itself a moral act insofar as inaccurate and reductive images inevitably lead to mediocre ethical analysis.<sup>22</sup> Therefore, the first step in an examination of parental responsibilities for seriously impaired infants is an impartial consideration of parental attitudes.

On the one hand, there is a wealth of literature indicating that parents are relatively unstressed in caring for such infants. Surgeon General C. Everett Koop, M.D., known for his work in the surgical treatment of impaired newborns, writes the following: "I know what can be done with the child's family. I know that those children become loved and loving, that they are creative, and that their entrance into a family is frequently looked back upon in subsequent years as an extraordinarily positive experience."<sup>23</sup> Koop bases this thoroughly optimistic statement on a study he made of 53 parents of infants on whom he operated for correction of esophageal atresia. Eighteen parents said that the infants had no impact on the family; 14 responded "mild and positive," 10 "strong and positive," seven "mild and negative," and two "strong and negative."<sup>24</sup> Koop's conclusion is that having an impaired infant is, for most parents, a positive experience. This evidence, however, is not critically assessed by Koop. He does not, for example, question whether the parental responses might be defensive, for few parents are willing to reveal negative attitudes toward their children. In short, Koop's study is hardly full-blown.

I also have doubts about the conclusions drawn by Rosalyn Darling in her oft-quoted *Families Against Society* (1979). Darling describes the stages of parental adjustment to a seriously impaired child, the first of which is "anomie," i.e., a sense of helplessness in what appears to be an overwhelming tragedy. However, with support from family and friends, this stage can often be quite brief. Then parents are able to accept their child, especially as they learn that they are able to care for it adequately. Soon, parents learn that society—including pediatricians—does not share their attitude of acceptance. They therefore enter the "advocacy stage," in which they challenge social prejudices against the impaired. Darling argues that despite society and the problems which these infants pose for their parents, "in most cases the family seems to adjust to the difficulties."<sup>25</sup> The families which fail to adjust are ones "that had serious personal or financial problems in addition to their handicapped child."<sup>26</sup> For the most part, impaired infants have a positive effect on families, maintains Darling: "If anything, the presence of such a child seems to draw family members closer together as an ingroup facing the hostilities of the outside world."<sup>27</sup> Darling does acknowledge that the literature "cites families torn apart by the presence of a handicapped child," but such families were already weak.<sup>28</sup>

### Some are Impacted

There is absolutely no doubt that some parents and siblings are "positively" impacted in these cases. But literature which underlines the success stories and de-emphasizes the tragic realities of stress leading to "chronic sorrow" for parents ignores the complexity of reality. It is therefore ideological in the worst sense of the word.<sup>29</sup>

## Literature Highlights Impact

On the other hand, there is a wealth of literature which highlights the negative impact of a seriously impaired child and its family.<sup>30</sup> Sandra L. Harris, for instance, reports that parents face relentless problems of burnout, fatigue, loss of free time, financial burden, and so forth. "Having a developmentally disabled child," she writes, "triggers a multitude of different, and often unpleasant, emotions in parents. Along with tenderness, love, and nurturance and deep-felt caring that is elicited by their child, there is also likely to be anger, disappointment, guilt, and other uncomfortable feelings."<sup>31</sup> S.E. Waishren, to cite another example, compared the parents of young impaired children with those of normal babies and found that the former viewed themselves and their children more negatively than the latter control group.<sup>32</sup> Other researchers have pointed out that parents of seriously impaired children may live in a state of "chronic sorrow," and that their divorce rates are very high.<sup>33</sup>

In my view, an ethical analysis of parental responsibilities must take these realities into account. Otherwise, based on the rather excessively optimistic literature, it is difficult to take parents seriously when they claim that they simply cannot care for their child anymore. It is necessary that we be reminded that modern technology, in saving the lives of severely impaired infants, has also extended the caring these lives require far beyond what parents knew in past generations. The biological balance has been altered, and with it the moral balance of the family as we have known it. As Hauerwas comments, "Our technologically expanded care has placed choices before us which seem inconsistent with our original intentions of care."<sup>34</sup>

It must be kept in mind, then, that severely impaired infants disrupt the natural moral order, perhaps "extending a child's dependence beyond a parent's natural strength."<sup>35</sup> Under ordinary circumstances, even healthy children exact a heavy commitment from parents, but they eventually grow independent and the demands taper off. Parents regain some of the freedom they sacrificed to have children through this process. However, with the impaired child, such is no longer the case. As one mother puts it, as described by Helen Featherstone, "And when I project, all I see is a sleepy life of never-ending diaper changing for all of us."<sup>36</sup>

This is not to dispute the claim that some parents have a positive experience with their impaired child. As John A. Robertson has mentioned, one parent discovered altruistic emotions through caring for such a child: "In the last months I have come closer to people and can understand them more. I have met them more deeply."<sup>37</sup> These accounts are both genuine and moving, though the actual response of such parents may, I suspect, be more complex than the testimonies indicate. My point here is simply to note that the picture of the parental situation that we draw must be a balanced one, for otherwise it makes no sense to consider the possible limits to parental obligation, nor to seriously envision the support

services such parents may require, given the limits to altruism. To ignore this complexity is a moral mistake.

### III - Relinquishing Care: The Problem of Child Placement

There remains one final picture to be drawn before ethical analysis can begin. When parents decide to relinquish care of their severely impaired child, are there alternative settings available in which such a child can develop as well as he or she would in the context of a loving family? If satisfactory settings are unavailable, or if there really is no substitute setting which approximates the love and security a child receives in the family, then whatever limits to parental responsibility we can discern philosophically will surely be tempered.

In fact, there is a clear consensus among social service professionals and developmental psychologists that children with disabilities are better off in a family or family-like setting. The Department of Health and Human Services has recently reported that impaired children "are more likely to achieve their maximum potential residing in small facilities which provide them with the opportunity to participate more fully in the normal life of the community rather than in institutions."<sup>38</sup> There is a clear trend in the direction of deinstitutionalization, i.e., "the integration of handicapped persons into the community, as opposed to their placement in institutional residences."<sup>39</sup> Thus, most current literature indicates that the institution-versus-family-and-community-debate has been convincingly settled in favor of the latter.<sup>40</sup>

As a result of this trend away from institutionalization, most states emphasize, at least on paper, a commitment to expanding family support services. New York State, for instance, has issued a recent report which begins thus: "Families are clearly the primary providers of care. An intact family offers stability, consistency, and close relationships which cannot be duplicated, as well as provides basic support, shelter, food, and attention to health care. Like other people, the quality of life for developmentally disabled people is at its best when they can live in their home."<sup>41</sup> The goal of the New York State Office of Mental Retardation and Developmental Disabilities, then, is to reduce family stress, i.e., "to strengthen the family's ability to care for a developmentally disabled family member in the family's home."<sup>42</sup> As a result, New York is concentrating on providing respite care as a means of temporary relief for families, caregiver training, sibling services such as education and counseling, community recreation for the disabled, and so forth. It is difficult to imagine a more thorough reversal of past policies, when impaired children were typically institutionalized.

Most states, in addition to offering family support systems, also provide alternative family-like settings. Group homes have come into existence, though more are needed. Located in residential neighborhoods and professionally or paraprofessionally staffed, these homes may house from several to a dozen or more disabled children in an atmosphere which only



imperfectly approximates the homelike. In addition, there has been a trend toward individualized foster care. In 1982, for example, the Chimes Program was initiated in Baltimore to train foster parents to care for seriously impaired infants and young children. The Family Care Program of California began a foster care program for such children in 1968, and it has been remarkably successful. Ann Coyne has documented the successes of the Lancaster Office of Mental Retardation in Nebraska with regard to recruiting foster care. Each week, an impaired child needing foster care was introduced to the community through the local newspaper, and the community responded with volunteers.<sup>43</sup> Finally, there has been some progress in the area of adoption. At the forefront has been Spaulding for Children. The Child Welfare League of America has also been active in finding adoptive parents for children with impairments.<sup>44</sup>

### Parents' Choices

Nevertheless, parents often are faced with the choice of keeping their child or giving it up for institutionalization. This is because the alternative services listed above are not readily available. As Madeline H. Kimmish has reported in her *America's Children, Who Cares?*, since 1981 the federal role in children's services has been reduced. The 1985 budget "included significant cuts in children's programs, specifically education for the handicapped . . . ."<sup>45</sup> While donations from the private sector have increased, the provision of human services to needy children and their families has been seriously hampered. Due to reduced economic commitment, many states have not been able to develop satisfactory alternative family-like settings. Indeed, many family support services are forced to charge rather heavy fees now. We may do well to remind ourselves of the words of Daniel Patrick Moynihan: "A commonplace of political rhetoric is that the quality of a civilization may be measured by how it cares for its elderly. Just as surely, the future of a society may be forecast by how it cares for its young."<sup>46</sup> The movement to establish alternatives to institutionalization is succeeding gradually, but these options mentioned are available only for a restricted number of children. More can and should be done.

Parents, then, even in "chronic sorrow," are often forced to continue caring for their child because they know that the only sure alternative is the large state institution. Realizing that this is hardly fair to their child, they may retain custody and do their best, despite their sense of having reached their limits. Parents may want to relinquish care, and they may have moral reasons for doing so, but because the options are few they are willing to endure greater stress than should be expected of them.

### IV - An Ethical Analysis

"How are we to understand and live our lives," asks Daniel Callahan, "when the moral demands made upon us seem to require more than we can give, more than we can make sense of, and—in our society at least—more

than commands much respect and admiration?" Callahan raises this question in response to the trend "to return to families and the home the long-term care of the chronically ill and those in need of rehabilitation."<sup>48</sup> In particular, Callahan doubts the assumption that with "some modest degree of social support", families will have the moral and psychological strength to be caregivers. He acknowledges that some families may find provision of care to be a rewarding experience, but notes that families also experience feelings of oppression and guilt, for "the caregiver is often trapped in a way of life not chosen and a future direction not of his or her own." Technology keeps people alive for ever-longer periods of time, and these people need to be cared for. What is to be done? Is the answer to widen the scope of family care? Just how much caring can we expect parents to do?

For all that I have written about the dignity of the child, the correlative duties of parents, and the family or family-like setting children require, I do not accept the notion that parental responsibilities for severely impaired newborns are unlimited. Indeed, I think the policy of returning persons in need of long-term care, especially infants, to the family must be examined most carefully. Parents and families are not morally inexhaustible, though some policy-makers assume the contrary. Technology has upset the natural moral balance and imposed burdens fit for a society of saints; but we are not all saints, even in the parental role. It is high time medical ethicists began to consider the problem of the technological expansion of care in systematic terms, for it may be the crucial problem of our times. Indeed, if this trend continues, it may be that only a religious ethic with a strong sense of unconditional care and radical self-denial as moral vocations can sustain us. But there is little likelihood of such an ethic being generally accepted. Thus, we are at something of an impasse.

On the one hand, we as a society can aim at improved social support systems for the family, as the State of New York is attempting to do. But on the other hand, the moral claim of others puts us, to use a metaphor, on a leash of imperative duties which are simply beyond the forms of morality that we as a society know of. Here I am in agreement with Daniel Callahan's rather pessimistic conclusions:

At one level, what I am saying points in the direction of improved systems of social support for those who care for family members. They need financial and psychological support of state and federal agencies, and they need responsive, sensitive people to give them help and to give them respite. But that is hardly enough. At another level, we need another kind of society and another kind of morality.<sup>49</sup>

Callahan suggests that only religious cultures embody the visions of sacrifice and community of which I write, and those who are not believers are left "with a severe problem." As he concludes, "I am not certain, but until we do [create a secular version of a way of life that fully shares

burdens] I think we should be wary of asking families to undertake heroic sacrifices."<sup>50</sup>

### Crucial Question for Ethical Analysis

The crucial question, given this framework, for ethical analysis is the following: Are there limits to the duty of beneficence on the part of parents toward their needy impaired children? To resolve this dilemma, it is necessary to consider the basis of parental duties, and whether the distinction between obligatory acts of beneficence and supererogation holds in the family as it does in the wider society. If the latter distinction does hold, then there are some actions which we cannot expect parents to perform other than voluntarily, for these actions lie beyond the call of duty.

My contention is that, in fact, the distinction between the morally obligatory and the supererogatory does hold in the family, although the line of demarcation between the two is raised higher than is the case outside of "special relations," i.e., in the wider public sphere of morality between strangers. This contention is not one which will be accepted by those who consider the family a community of absolutely steadfast love that satisfies all needs. I grant that family members must be ready to care for one another at considerable inconvenience, and that breaches of faithfulness in the family should be viewed with disdain under anything like ordinary circumstances. But there are limits even in the family. Thus, I disagree with Alan Donagan's comment that, "Except for special institutional duties, for example, those of a parent, to promote the well-being of others at the cost of one's life or fundamental well-being would be supererogatory."<sup>51</sup> If theologian James M. Gustafson means, with his statement that "In family life self-denial is not a supererogatory norm; it is a moral necessity for common life", that sacrifice in the family is unlimited, then I disagree with him as well, though I suspect that Gustafson does have some limits in mind.<sup>52</sup> We can expect morally inspiring forms of self-denial in the family, but self-denial must be distinguished from self-immolation.

In order to substantiate my proposition, I will first examine the distinction between obligatory acts and supererogation, placing special emphasis on the association of the latter with freedom. Most philosophers grant that there are duties of beneficence. Common morality teaches us that if a pedestrian sees a child about to walk out in front of a school bus, the pedestrian ought to lay a hand on the child's arm and prevent the tragedy. This act is done without any danger to the pedestrian, and the benefit to the child is enormous. It fulfills all the conditions for the duty of beneficence which are spelled out by James Childress and Tom Beauchamp: the child is at risk of significant loss or damage; the pedestrian's action is needed to prevent this loss; the pedestrian's action will prevent the loss; the pedestrian's action would not present significant risk to the pedestrian, and finally, the benefit that the child will probably gain far outweighs any harm the pedestrian is likely to suffer.<sup>53</sup>

However, if the child is already out in the middle of the street and the school bus is closing in fast, there is no duty for the pedestrian to leap out and push the child to the side when he or she knows that the result will be his or her own death. Such an act is beyond the call of duty, and though morally praiseworthy, it cannot be required of the pedestrian. This act is thus supererogatory, i.e., the act is morally good, done for the sake of another, and places the moral agent at grave risk.<sup>54</sup>

### **Distinctions Between Duty/Supererogation**

The distinction we make between duty and supererogation on the level of common morality means, as J.O. Urmson has put it, that we are not required to be "saints and heroes."<sup>55</sup> It would be a moral outrage, insists Urmson, "to apply pressure" on anyone to do such a deed as sacrificing his or her life for others.<sup>56</sup> While we can expect persons to fulfill their duties and penalize themselves if they fail, heroic acts of self-sacrifice are strictly a matter of personal choice. Millard Schumaker establishes the same point: acts of supererogation are, like charity or grace, "free gifts" or favors which cannot be compelled.<sup>57</sup> Supererogatory acts are done voluntarily and freely chosen. It makes no sense to coerce someone to give a gift, for gifts are by definition left up to the agent to give or withhold. It can thus be said that freedom is the mother of supererogatory virtue, as it is for all acts of altruistic love.

One of the most famous cases of supererogation in recent American history is that of a man whose plane crashed into the wintry Potomac River. He, a mere passenger with no special duties or stations, helped dozens of people out of the icy waters without the slightest thought for himself. Finally, he was overcome by the cold and died. The nation was inspired by this heroism, largely because it was undertaken freely and lies far beyond what we would ordinarily think required.

Granted, there are occasions when, because a particular individual has taken a specific role in life, we can expect heroism. A lifeguard, for example, is expected to risk his or her life by swimming off into the sea after hearing cries for help. A fireman is, by virtue of his station in life, expected to take risky actions to save others. In these cases, the distinction between moral duty and supererogation breaks down. Can the same be said for parenthood?

### **Distinction Holds Up**

It is clear from ordinary language that, in fact, the distinction between duty and supererogation does hold up within the family. We do speak of "saintly" parents who endure tremendous stress without complaint. Parents are understood to have inclinations or interests other than caring for their children such that when they refuse to make certain sacrifices they are not morally blamed. Parents bring children into the world knowing that their responsibilities are substantial. However, they do not bring children into the world with radical forms of self-denial in mind. If they did

so, then the birth of a severely impaired child would be cause for celebration. Parents do not opt for a future in which all of their central interests will be displaced. Few of us would want to suggest that our children hold a blank check, though they do hold a large one.

Permit me to make use of a metaphor to underscore this argument. Children have obvious rights based on their needs, for example, rights to food, shelter, education, and psychological nurturance. But for every right, there is a correlative parental obligation. Therefore, the metaphor of a leash has been suggested by William Aiken and Hugh LaFollette as an appropriate way to view this correlation.<sup>58</sup> The right holder has the other—in this case the parent—on a leash. Under relatively normal circumstances, parents willingly and without serious threat to themselves hang onto this leash until the child reaches adulthood. However, sometimes the pull of the leash is so strong and burdensome that the holder must simply let go. Some holders will hang on, come what may, for they are willing to endure possibly great damage to themselves. Surely, though, we do not fault a person for, as a matter of last resort, releasing the leash.

The distinction between duty and supererogation is also borne out by our response to parents who are unexpectedly faced with caring for a severely impaired infant. Certain Christians might view such circumstances in highly positive terms, given their theological notion that suffering and unconditional love are the most lofty ethical ideals. And no doubt parents, who themselves have adjusted to such a life of care, might view these circumstances with relative delight. However, most of us feel uneasy when we see parents asked to sacrifice their “selfhood” and future for the sake of another. Displays of moral idealism are inspiring, of course, but generally we feel grateful that we ourselves have been spared such demands. We wonder what we would do in a similar situation, and often think that such care would be understandably beyond us.

Even as parents, our common morality is rooted in some sense of the transcendence of the individual over the community—in this case, the community of the family. The autonomy of the self is viewed as a good, and even a supreme good. When we are faced with difficulties that require long-term radical self-sacrifice, our ethic of moral autonomy does not suffice. Our image of human fulfillment is independent selfhood, and our sense of demanding care is quite limited. When forced to endure suffering, even in the family, we often turn against each other. Included within our ethics of autonomy is a proscription against involuntary self-denial.

### **Blustein's Comments**

In one of the few contemporary works on the ethics of the family, Jeffrey Blustein makes several comments which are in accord with the view suggested here. Blustein writes: “To be acceptable, a childrearing practice should not force parents to choose between duty and interest but should accommodate both the needs of children and the legitimate non-parental interests of parents.”<sup>59</sup> He also remarks that “Parents whose own interests

must always be sacrificed to those of their children are likely to end up not satisfied but miserable and resentful."<sup>60</sup> The fact that parents are inevitably on a leash does not mean that the pull upon them can or should be total.

If what I have suggested is true, then it would be seemingly useful to develop some moral calculus to balance the interests of parents against severely impaired children. But this is an exceedingly difficult task, and one which may be all but impossible. The most I can do is offer some rules of thumb. For instance, if a mother refuses the option of sustained self-denial in radical form on the basis of her appeal to self-identity, such refusal should not be dismissed. After all, countless psychologists have argued that if a person has no proper love of self, that person cannot satisfactorily love others. My major thrust, however, is not to develop a calculus, but only to establish the moral credibility of parents who, despite a certain amount of social support, simply refuse to live a life of supererogation. It must be recognized that circumstances do arise in which caring for a severely impaired child presents a significant risk to parents, and it is not clear that the probable gain for the child outweighs the harm done to the parents.

At this point, a case study will help to clarify some of the ideas highlighted in the above:

Mrs. Anderson is suffering from serious depression, with suicidal ideation. Her year-old infant daughter, Betsy, is severely impaired. Though the family has received some financial relief, Betsy remains a major physical and economic drain. Mrs. Anderson is worried about her husband, who is working two full-time jobs and says that he has had it. The two teenage daughters are concerned about their own futures. Despite the help of a support group, Mrs. Anderson cries much of the time. She is too tired to enjoy anything, and feels isolated. She has told a social worker at the hospital, where Betsy is receiving yet another operation, that the Andersons will never take Betsy home again.

Here is a case in which the parents of Betsy have been asked to sacrifice too much by any ordinary standards. Even if they once had determined to care for Betsy as a matter of duty, they have been unable to sustain that commitment emotionally. In this case, because of the seriousness of the Andersons' plight, Betsy does not possess a moral trump card that mandates a preference for her interests at the expense of others.

### **V - Concluding Remarks**

In arguing that parents can morally refuse to continue caring for a seriously impaired child, I by no means want to suggest that the parents have a right to end their child's life. If history has taught us anything, it is that children and childhood have for centuries been in need of liberation. That in recent years a children's rights movement has emerged can only be applauded, for it represents progress. Once children were afforded no moral status, and impaired infants were quickly killed. Fortunately, and with the help of Christianity's impact on the West, children are now highly

valued and the subject of many a learned volume. It is, I will assert, unfortunate that some medical ethicists look back on our tragic history and then argue that because parents have always rather easily engaged in infanticide, they should be allowed to do so now with impaired infants. Perhaps the worst offender here is Earl E. Shelp, who suggests that in the light of the historical record, infanticide is "regrettable but acceptable."<sup>61</sup> Moreover, I accept the moral principle that children have special claims on the basis of their unfulfilled needs. It is better to heed the United Nations Declaration of the Rights of the Child than the latest bit of pro-infanticide philosophy. That declaration reads as follows: "Principle 5. The child who is physically, mentally, or socially handicapped shall be given the special treatment, education, and care required by his particular condition."<sup>62</sup>

The severely impaired child should, whenever possible, grow up under the care of loving parents. But there are many instances when parents, for good reason, want to relinquish care. It is a moral mistake for society to impose upon parents in this area, even though this is evidently a good way to save money. The family is simply not an endless source of moral heroism. The solution to the grave problem of the technological expansion of care will be a complex one which will require more imagination than is possessed by those who would place the burden and stress on parents who may well long for a previous era.

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