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The Nontreatment of Seriously Handicapped Newborns **Hans Tiefel**

[1] Reflections about moral obligations toward severely handicapped newborns will become more and more urgent, since advancing medical technology not only continues to surprise us with ever increasing possibilities but also with inevitable dilemmas. As medical science advances into unexplored territory in which it can now save those who would formerly have been lost, medical professionals and the families of seriously ill newborns find themselves without established signposts or maps. The task of Christian reflection is to explore what directions might be appropriate in this alien landscape for those who take their bearings from biblical traditions.

[2] Churches might welcome such reflections for a number of reasons. For one, attention to the afflicted bodies of ill newborns will keep believers from being too otherworldly, from speaking too readily of the next life and of their souls, from conceiving religious responsibilities too narrowly. Moreover, this topic has not been deadlocked and is not as emotionally burdened as our strife over the rights and wrongs of abortion. In the case of newborns we tend to agree that we are speaking of human beings and children of God, and therefore find our tradition more applicable. It is also especially fitting for congregations to reflect on these questions since neonatal diseases are often so horrendous and difficult that both physicians and pastors may fear to counsel and may simply leave the dilemmas to parents, who will have to live with whatever choice they make. Pastors may be reduced to offering the gospel's consolation and forgiveness without first offering insight into what the gospel might have us do. And finally, the burdens posed by care for handicapped newborns may be so heavy that it is almost impossible to bear them alone. Jesus' injunction to bear one another's burdens may have special urgency in this context.

[3] When we consider an actual case of a severely handicapped newborn, we may approach it in a totally misdirected way. Our children are the most vulnerable among us, deserving most our protection and care. How incredibly unfair that they should be born in pain, retarded, malformed, permanently harmed. The misery of such poor babies can so shock us that we want to know the reason why. And a biological reason will not do, for the Giver of all life seems answerable for this poor life's afflictions.

[4] We must resist such inclinations to ascribe cause and blame, whether in a religious or a secular mode. We know that it is not God's will that any of his little ones should suffer. The most fitting answer to the aggrieved why is that we do not know. And just

as we may not ascribe the cause for infant handicaps to God, so may we not blame parents. To be sure, since we are all sinners, a newborn's tragic affliction may be ascribed with some plausibility to the fault of parents. Behind such desperate accusations, however, may simply lie our fear that life does not make sense in a fair balance of suffering and merit. Yet our obligation is not to explain the unexplainable, to ascribe cause or guilt. It is to share the afflictions of those who suffer.

[5] We can get off to a false start in another way by avoiding the issues in the very way we talk about the problem. If we speak of "defective" or "damaged" infants, we imply an inferior product that can be "replaced" with something better, since parents "can always try again for a healthy child." Such dehumanizing ways of speaking dismiss the sick newborns as if they were production errors. Similarly our feelings of shock express themselves when we refer to one of "nature's mistakes" for which "nature should be allowed to take its course." We depersonalize sick newborns when we speak of "monstrous neonates," of the "fetus ex utero," of "merely potentially human life." With such words we cut the Gordian knot of deciding what to do by saying that these afflicted little ones do not count. If we say that "every child has a right to live free of suffering," we fool ourselves into thinking that anyone has such a right or could conceivably have it, and we abandon the infant in the name of its own good. Even "allowing such children to die" may be a pretense of indulging their wishes, of granting their requests, and of not actually taking human life. These are self-deceptive and misleading beginnings, refusals to walk in this alien land, disavowals of those whose miseries would bid us enter.

[6] By contrast, if we say "handicapped newborns" we use humane and inclusive language. Children, adults, veterans, victims of accidents can be handicapped. The newborn share a disability with the rest of us, and might therefore be offered similar chances for overcoming their handicaps with medical and community support. "Defective" invites us to discard; "handicapped" challenges us. Moreover, if discrimination against the handicapped be immoral and against the law, then medical neglect of seriously ill newborns or refusal to treat them because they will not be useful and productive may be wrong and illegal as well. How we speak, then, tends to direct us in how we act and how we think we should act.

[7] The fundamental problem with seriously handicapped newborns is that their disabilities and diseases most often cannot be cured. Their handicaps will be life-long; they will continue to burden the child, its family, and its community; Moreover, treating such children has implications beyond merely mitigating the disease; therapy itself may bring added pain and burdens.

[8] One response to this basic problem is to refuse treatment and to "let" the affected newborn die. Parents may refuse consent for life-saving interventions. Afflicted newborns may be heavily sedated so that they will not cry and demand nourishment. No one is sure how widespread such practices are, since infanticide would not be listed as a cause of death. But the media have repeatedly presented notorious cases, such as a baby with Down's syndrome being starved to death since

the disease causes mental retardation. Congress has recently been sufficiently alarmed to insist on a law to save handicapped infants.

[9] Most of what follows here addresses itself to that refusal to treat. But it does so in a roundabout way. For many the certainties of our faith do not seem relevant. That lack of relevance explains the following circuitous route.

[10] As modern Americans we tend to see ourselves as unique individuals, called to achieve our potential and to realize ourselves in the pursuit of happiness, individually conceived. The starting point in considering what it is to be human is to begin with the self and ultimately to return to it. To be sure, we require others to make our lives meaningful. But we do not like to depend on them and may consider it an imposition when others continuously depend on us. Our heroes tend to be the independent, self-reliant individuals portrayed by John Wayne, Clint Eastwood, Charles Bronson, and the Marlboro Man.

[11] Clearly, such an individualistic, self-sufficient ideal offers little hope for the seriously disabled or handicapped, to those whose handicaps remain insuperable. The sick Western hero must heal himself or die trying. He could not remain who he is if he really needed or depended on others. We do admire those who heroically surmount incapacitating dependence. The Helen Keller syndrome rates high in a society that honors the self-made person who survives the odds. But most seriously handicapped newborns will not achieve such feats. And even if they had a reasonable chance of achieving self-reliance when they mature, we cannot predict such improvement when they are still mere newborns. Thus the fateful choice of initiating, continuing, or stopping life-giving care occurs before we can predict the chances for a "meaningful life." If, then, we cannot be reasonably sure of a self-fulfilling life for the newborn, and if the child's dependence threatens the parents' right to an independent and happy future, our secular and individualistic ethos concludes that the newborn lacks the right to live.

[12] Our culture decrees that children, well or ill, cannot be exempted from the requirement for self-reliance. Parents support children during the years of their dependence, expecting them to make their parents proud and become what they were expected to be when they were brought into this world. A handicapped child, therefore, seems to be not only an imposition but an injustice against the parents. We are inclined to think that children have a right to exist only when they are wanted - and no one wants a handicapped child. So, it would be our wanting, our hoping and expecting that justifies parental dedication, sacrifice, and care. But all parental wishing must be fruitless when children can never be on their own. Such dependent lives would deprive us of the right to live our own lives, to dream our own dreams.

[13] Rights are keys to the world of ethics in this individualistic vision. Rights and liberties form the fences that protect the self from external interference. Thus the right to privacy safeguards individuals from being violated by the tyranny of the meddling public, an obtrusive government, and an unwanted offspring. Here the self insists on

protections to pursue its own good in its own way, for that is the promise of the American Way.

[14] Handicapped newborns, of course, can hardly be called selves. They do not yet know what they want and cannot insist on anything without an advocate. They are not equal partners in this world of independent individuals, and if they are unwanted or deficient will have little standing in this heroic world that seems not only American but Spartan. Their diseases so overshadow these children that we regard them, to use a biblical phrase, as unclean.

[15] The self in this prevailing American civic faith is analogous to a round hard sphere. It is self-contained, self-moving, self-directed. It may touch other selves, as in friendship, marriage, and partnerships, but there should be no burdensome bonds. For liberty is freedom from others. Dependence is weakness. And liberation calls for the strength and self-reliance not to depend on anyone. To be free means needing or being beholden to no one. Children, of course, do not yet play by these rules. And their dependence may well backfire on those who begot them in order to fulfill themselves and create happier marriages.

[16] If such a portrait of the American ideal be roughly drawn, the reader will nevertheless recognize the features, will correct some of the strokes, and will supply missing or neglected details. If the features be dear to us - and how can they fail to be? - we should nevertheless resist enhancing them with a halo. They do not form a picture that could reasonably be called Christian or biblical. They constitute, instead, our very own idol that we worship in our reflections and decisions.

[17] A contrasting image that may bear some resemblance to biblical traditions begins not with selves but with community. Not "I think (want, decide, choose, seek), therefore I am," but "We are created and loved and therefore we are." Our biblical traditions offer us "the people of God" and "the body of Christ," communal terms that find the meaning of life not in atomistic self-realization but in communal service to God and of one another. Not contract but covenant binds us to one another. A sphere of privacy that would isolate us from one another, and perhaps even from God, expresses alienation and loneliness, not independence. For we know ourselves dependent to our very roots on the grace of God, of our loved ones, of our community.

[18] Indeed, the term "roots" may serve as the key metaphor of a Christian self-understanding. As believers we are not analogous to self-contained spheres but to interpenetrating roots. We live, are supported and nourished, receive strength from being intermeshed with and interpenetrated by the lives of others and the presence of God. The Christian who in the context of the worshiping community kneels before the altar at communion must be the very antithesis of the Marlboro Man.

[19] The shift of focus from self to community may also affect our perspective toward handicapped newborns in a drastic way. To speak of handicapped newborns tends

normally to elicit thoughts of their condition, of their status, and of what is appropriate for them. A communal perspective can no longer do that without also reflecting on who we are, as we think and decide about these newborns. We are deciding not only about them but, in doing that, about ourselves as well. Who are we as we respond to their plight? We should not only see the image of God in them, but consider whether that image is also recognizable in us as we decide and formulate social-medical policy. We are judged in our very judgment. And we may well ask who at that point stands most in need of prayer.

[20] Rights are not here drawn in the prominent lines that they enjoy in the American ideal. For rights tend to focus on ourselves, on what we may claim, rather than on what we owe others. When it comes to talk of rights, love may already be lost - as in the appeal to rights between marriage partners or family members. Love must be a more important concept and obligation. Love preempts rights, as it were, by meeting needs before they can be rightfully demanded. The place of rights must then be subsidiary in Christian reflection, a fall-back position, an emergency ethics that protects us against each other when we have failed one another. It would then be amiss to ask about the rights of handicapped newborns as if that were the content of our responsibilities. We owe them more than their rights, whatever those be.

[21] Of course these reflections only indicate the wrong approach rather than offering helpful directions for how to resolve moral dilemmas. But knowing what to leave behind is no small advantage in entering this unknown medical- ethical territory. Also, we already know what to take along since church people always carry with them the living stories of their faith. Wherever we go we bring our biblical traditions, for without them we could not know who we are and where we have come from, and would therefore be totally lost. If the almost redundant question should be asked, what then are our bearings?

[22] The church has always known that we are called to save, to heal, and literally to redeem human lives wherever and whenever possible. We always value each child as God's creature and image. We know ourselves to be called to care for the afflicted as we might care for our Lord. If our Lord treats us as precious regardless of abilities and merit, and even shows a clear bias for the sick and useless, we are called to walk in such ways ourselves. If dependence, the persistent inability to help ourselves, is an occasion for divine concern and intervention, how can believers use the great needs of handicapped newborns against them?

[23] Perhaps that is enough to jog our memory as we enter this fearsome land. But we must remember not only once but continuously. If we speak for saving such lives at their start, we must also advocate help for them as long as they need it. We cannot intercede initially and then abandon them to an everyone- for-himself ethics when it comes to the less dramatic matters of teaching them how to live, of providing therapy, of supporting hard-pressed families, and of securing private and public assistance.

[24] A certain Lutheran pietism restricts the love commandment to individuals and to private charity, refusing to invoke the political and governmental support essential to create and finance continuing care. Such religious individualism takes offense when love compels action to support higher taxes, enabling the handicapped to count on more tangible and public support than our compassion. We should ask whether our individualistic qualms arise from our dedication to the American way, to ways of Lutherans in their pietistic past, or to the ways of our Lord.

[25] Enough has been said to point ourselves into the right general direction. We will not have gone far, however, when we run against hard cases that make wonder if we are not fundamentally misdirected. For there are cruel situations in which we should not treat and "allow" the child to die - in apparent contradiction to what has been said here.

[26] The very preciousness of these children may compel us to cease treating when our intervening will no longer do them any good, when our therapies become fruitless and therefore harmful. We must cease when life and continued treatment become so burdensome for these infants that our best efforts will not help to make them better. We must stop when continued treatment is fruitless and becomes overtreatment, and thereby mistreatment.

[27] Certain diseases may make any treatment senseless from the start. Anencephalic infants (congenital absence of the brain) are never alive in a sense, because they are already brain-dead. Babies with Lesch-Nyhan syndrome (physical and mental retardation, compulsive self-mutilation of fingers and lips, spastic cerebral palsy) are always past cure and soon beyond our help. Even where treatment has begun, as in very low birth weight babies, complications and continuing deterioration will make it necessary and morally right to stop at some point when to continue treating would be uncaring.

[28] Our reasons for stopping treatment of handicapped newborns must hold across the lifespan and must be compatible with reasons for treating. No one should be treated actively when treatment no longer does any good. That reason, however, does not single out unwanted infants as nonpersons; it does not regard early human life as dispensable or replaceable; and it does not prefer the rights or values of adults to the lives and needs of these patients.

[29] If these are our bearings in this unexplored, fierce land, they are not sufficient to tell us how to turn when we come to the really hard cases. There we need to study and weigh the facts of the case, knowing that at best we can only choose the lesser evil and will inevitably stand in need of forgiveness. Luther's "Sin bravely!" would be sound advice here, as long as we remember his counsel to believe more bravely still.

[30] However we resolve these dilemmas, they compel us to ask whether we cannot forestall such painful choices about sick newborns by preventive abortion or genetic counseling. Here one moral controversy spills over into others no less difficult. Yet the

kinds of considerations that prove relevant to handicapped newborns - to those who have just arrived - would probably also hold for those still on the way: That prevents abortion from becoming an easy solution to the hard choices about handicapped infants. On the other hand, genetic counseling appears to be more promising. For here we may still ask whether or not to set anyone upon the way to joining the human community. The very reasons that urge us to sustain the life and share the sufferings of newborns constitute compelling arguments for not begetting children at risk of serious genetic harm in the first place. The same care that sustains and nurtures even when it cannot cure or heal argues against carelessness in engendering new life. We cannot consistently love a child that might be conceived while doing it serious harm by conceiving it. Prevention of genetically caused handicaps to newborns will become increasingly obligatory as the science of genetics matures. Of course that will never be a sufficient answer since we cannot always predict the future, and since for actual handicapped newborns that would always be too late.

[31] The question of the nontreatment of seriously handicapped newborns thus expands into unexpected dimensions. Since we are being pulled in diverging directions not only in regard to what we shall do but also to who we shall be, our very identities are at stake in such life and death issues. We cannot resolve such questions without also asking who we are as communities of faith, as parents, as citizens. This ethical dilemma, therefore, turns into a question of faith. We cannot resolve it without deciding and confessing who we are and who we are to be.

[32] **Discussion Questions**

1. What do we expect of ourselves as parents?
2. What should we expect of ourselves as parents? How should the Christian faith influence such expectations?
3. Why do we have children?
4. What do and what should we expect of our children? How should the Christian faith influence such expectations?
5. How do our expectations of ourselves as parents and of our children reflect cultural beliefs?
6. How do we treat the handicapped in our congregation? The mentally retarded?
7. In what ways is the issue of handicapped newborns the business of the church? In what ways is it not the business of the church?
8. How is our thinking about seriously handicapped newborns affected by the availability of prenatal screening (amniocentesis) and by abortion?
9. What do we expect of children with serious physical or mental handicaps?
10. What are essential features of a meaningful life? What does it take to have one?
11. What might be political implications of caring for handicapped newborns and children?

12. Should sermons focus on political questions that affect our treatment of seriously handicapped newborns, mixing the word of God with such externals as advocacy and legislation?
13. What could possibly be misleading in the statement that "our handicapped child has brought so much happiness and closeness to our family"?
14. Should church people endorse the recommendations about handicapped newborns in the 1983 President's Commission for the Study of Ethical Problems in Medicine report "Deciding to Forego Life-Sustaining Treatment"?
15. Should church people support federal law P.L. 98-457, the child abuse amendments of 1984?
16. Evaluate the claim "We should not make the unfit survive."
17. Should church people endorse the court decisions of the Phillip Becker case? The case of Brian West? Baby Doe? The 1982 Bloomington Baby case?